

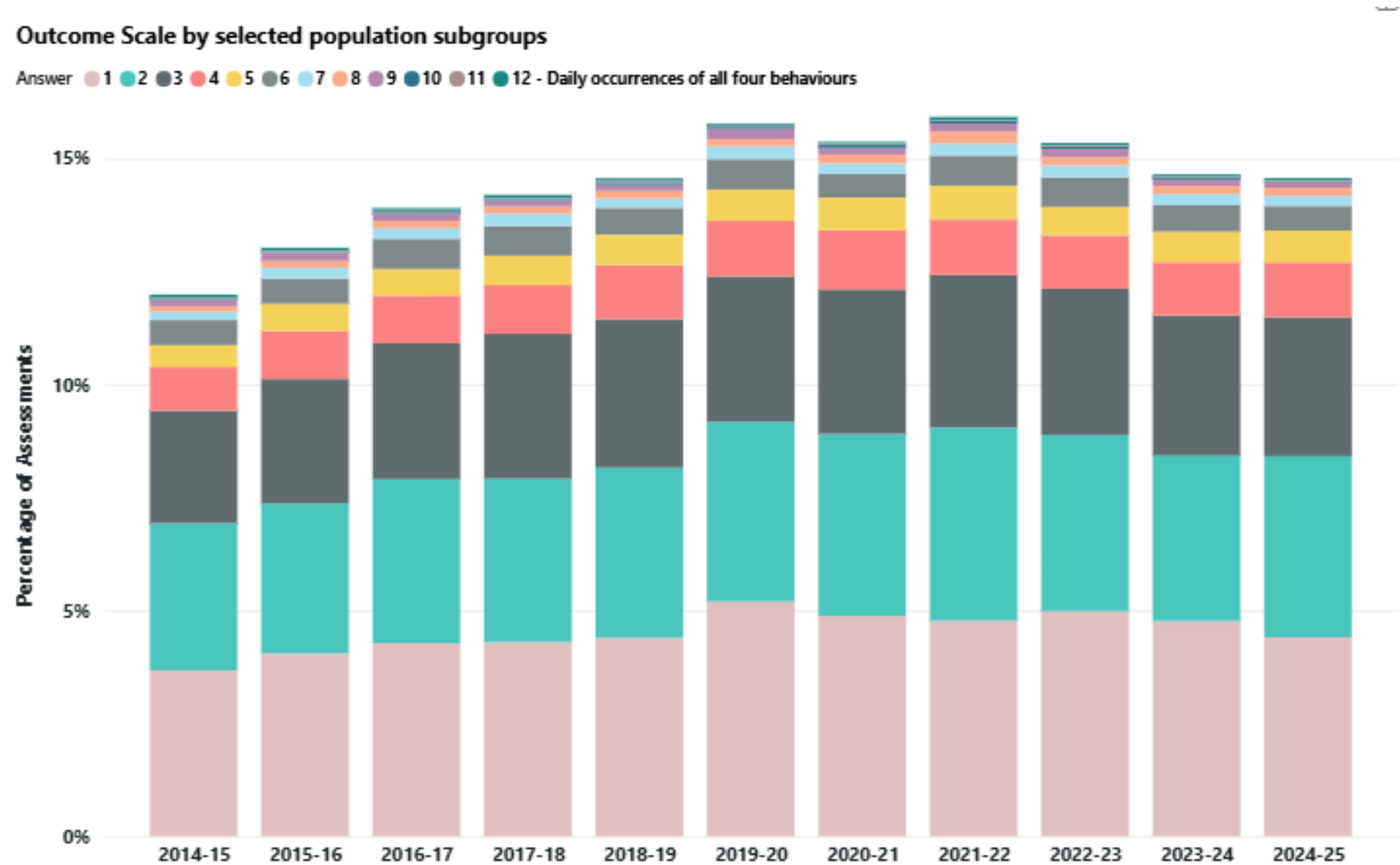
Supporting people who experience distress



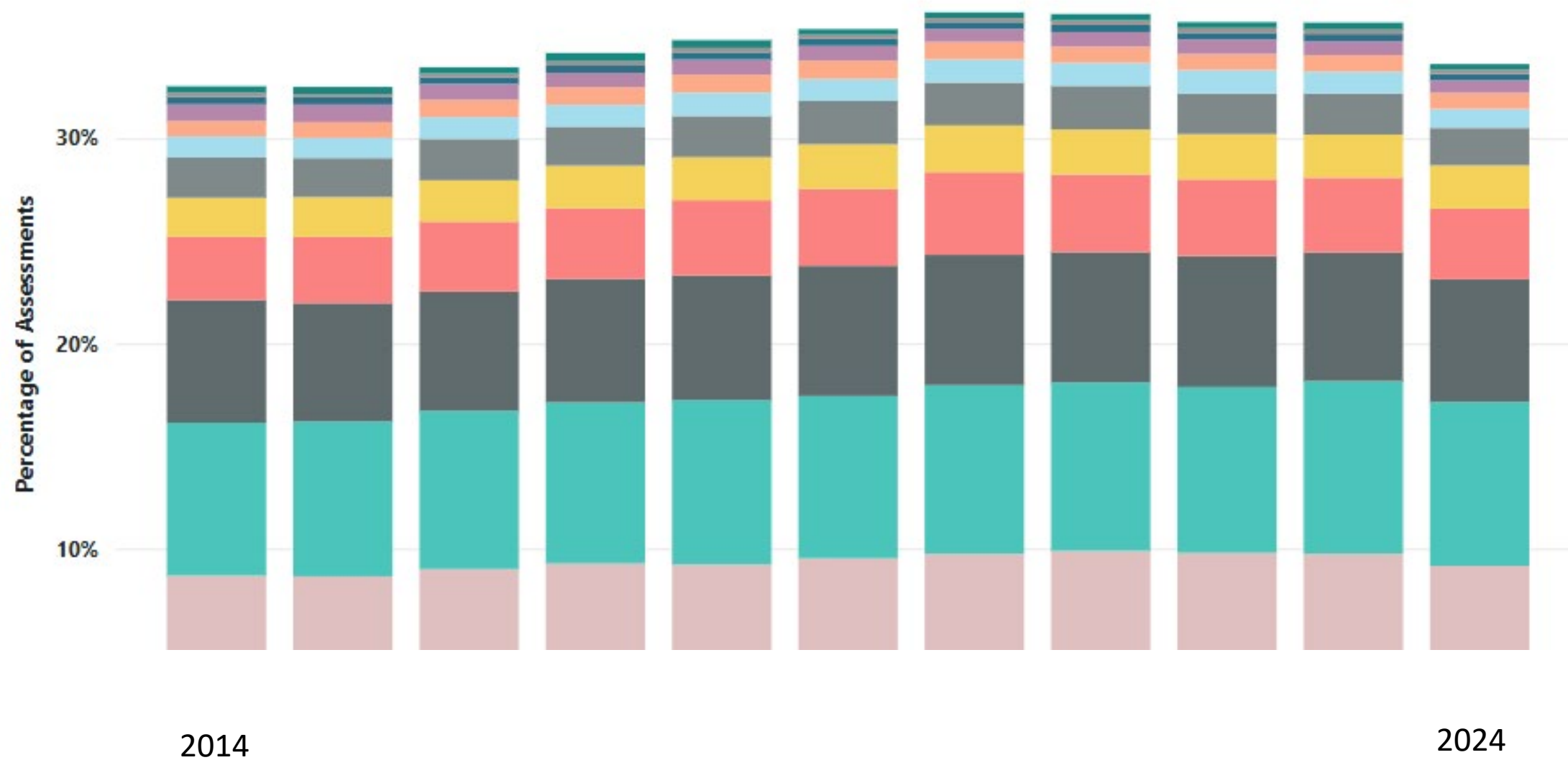
Learning Outcomes

1. Describe the human impact of unmanaged distress on people living with dementia and their whānau
2. Identify the financial and workforce impact for organisations (e.g., staff burnout, turnover, compliance risk)
3. Articulate the impact of language on practice, stigma, and learning in dementia care
4. List a range of approaches / models to supporting people experiencing distress
5. Explore strategic leadership actions for addressing distress using a systems lens
6. Recognise the role of lived experience in shaping compassionate and effective responses to distress
7. Evaluate how learning systems can be strengthened to enable change in distress-related practice

InterRai HC (outcome measure aggressive behaviour 65+)



InterRai LTC (outcome measure aggressive behaviour 65+)



Context



HDC complaints (gaps in planning, training, escalation, communication).



Antipsychotic prescribing patterns



Cochrane 2021: little benefit, big risks.



Cochrane 2023: psychosocial interventions mixed but promising.



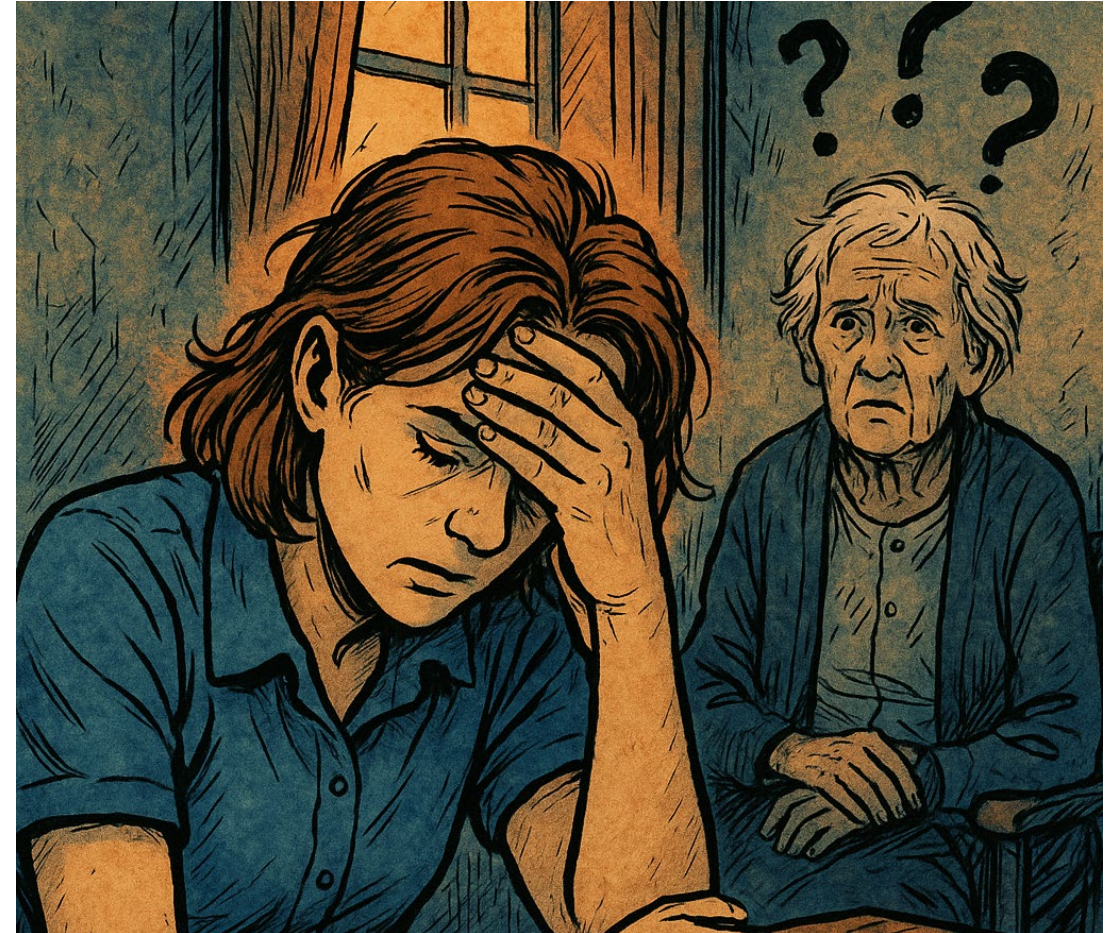
Systematic Review 2025: non-drug therapies (music, digital, sensory) show benefit.



The words we use shape practice

What it costs us

- linked to carer mental health (Black & Almeida, 2004).
- increases the risk of elder abuse in the community (Steinsheim et al 2022. Cooper et al 2009)
- leading cause of breakdown in home care packages & admission to residential care (Banerjee 2003, Gaugler 2009, Livingston 2017).



What it costs us

- Repeated exposure to distress and suffering takes a profound psychological toll on staff.
- Unmanaged distress fuels a cycle of burnout especially when staff lack effective support (Appleton & Pereira, 2019; Moniz-Cook et al., 2017; Costello et al., 2019; Edberg et al., 2008; Zimmerman et al., 2005).
- Conventional “training” often fails to prepare staff to manage these realities (Ballard et al., 2018; Livingston et al., 2019; Panca et al., 2019; Keenan et al., 2020).



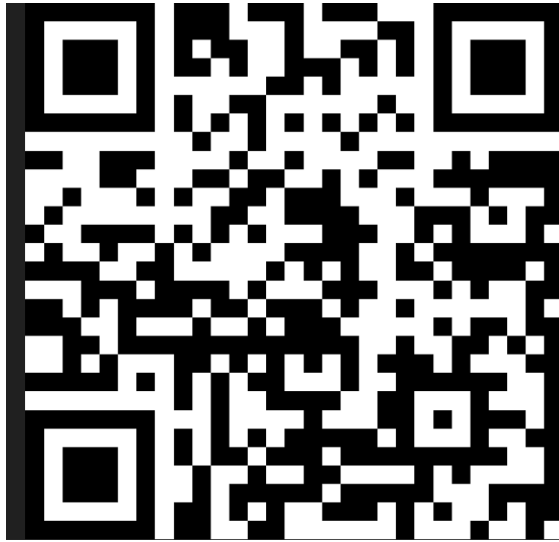
Words of staff

“You reach a point where you’ve got nothing left to give. We’re stuck in survival mode, and there’s no support to fall back on”

“I believe I have tried everything, and the behaviour remains. Then you feel like your back is up against the wall”

“I was hurt by a resident. My shoulder hasn’t been the same since. I am worried that I can continue to work as a carer, but I don’t know any other job”

Language – What is in a word?



Same country speaking a different language..

The evolution of language:

**“Demented / dementia-related” → “Challenging behaviour” → “Behaviours that challenge”
→ “Behaviours of concern” → “Responsive behaviours” → “Changed behaviour” →
“Distress”**

- * sometimes many of these just shortened to “behaviours”
- BPAC refers to BPSD and managing symptoms
- ARRC agreement refers to how challenging behaviours are managed and how to minimize challenging behaviour
- Careerforce refer to ‘unintentional behaviour’ new skills standards are exploring term ‘behaviours of concern’
- Alzheimers NZ speak about distress as communication / changed behaviour

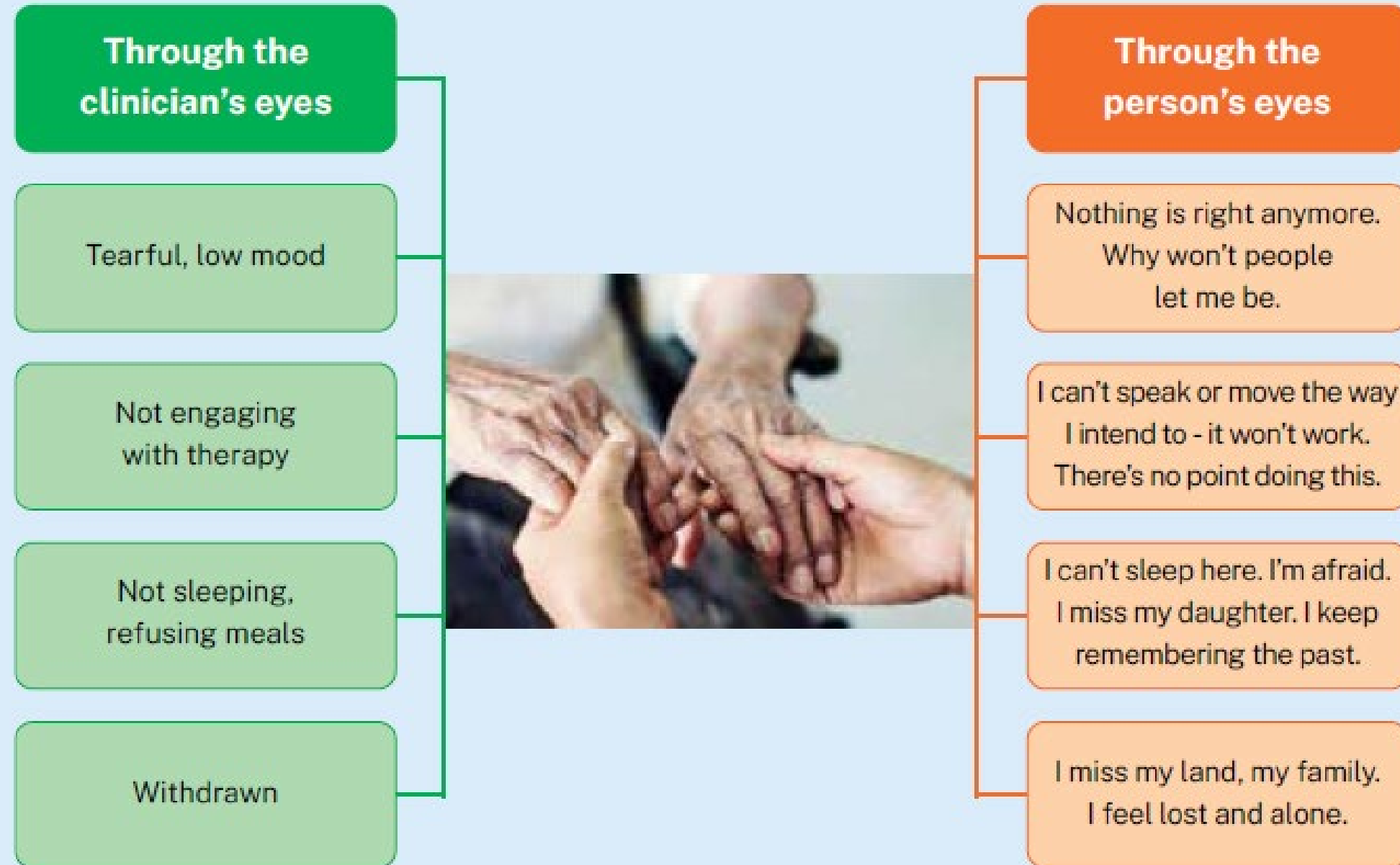
So why are we not speaking the same language?

And what impact does that have?

Figure 3.1. Relating to the person experiencing BPSD: through the clinician's eyes

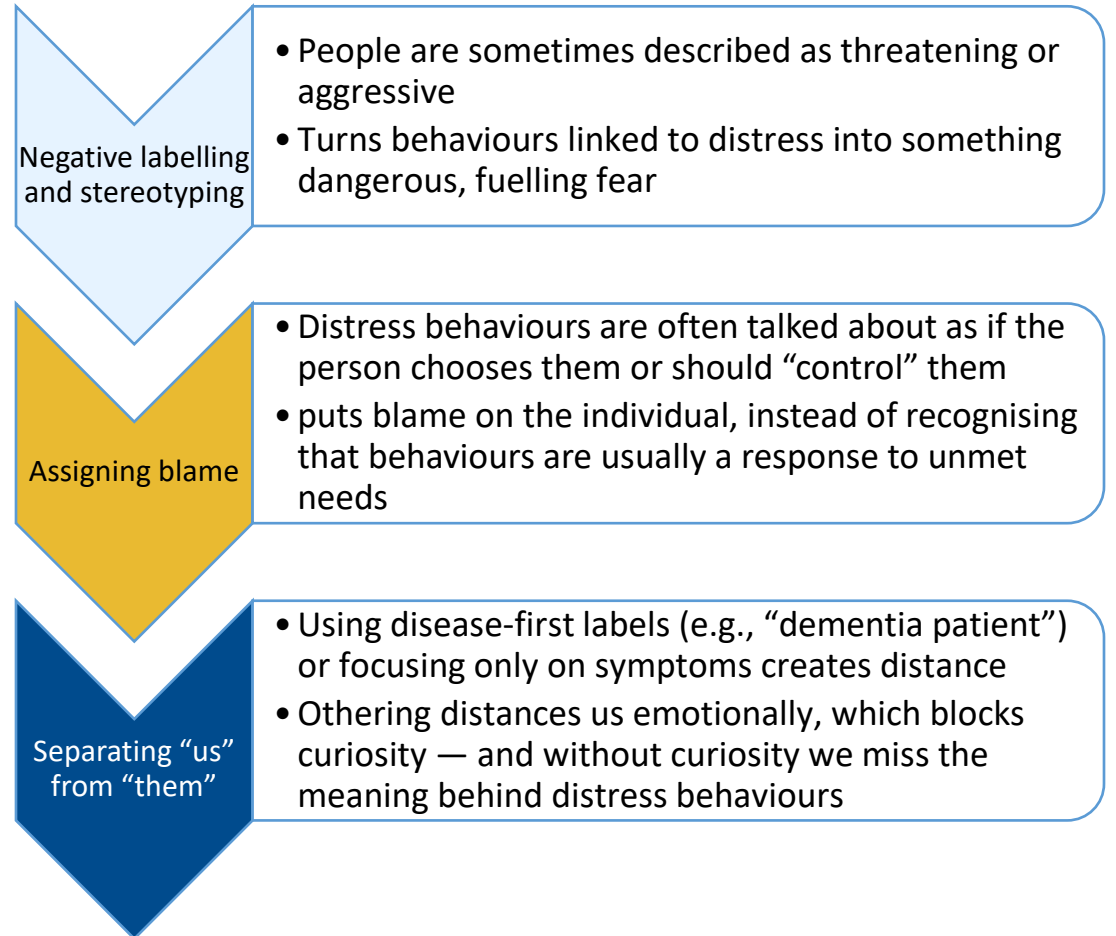
– through the person's eyes

A Handbook for NSW Health Clinicians providing services for people experiencing BPSD
2022

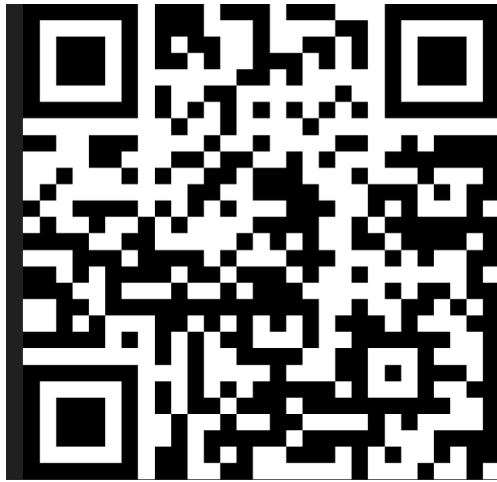


Language and dementia stories from research

- **BanBPSD campaign** - Dropping medical terms completely could hide the seriousness of some illness-related behaviours, but also cautioned against using such labels inappropriately ([Cunningham et al 2019](#))
- **What do families/whanau want?** Preferred 'Behavioural and Emotional Expressions of Need' rather than 'Challenging Behaviour' ([Wolverson et al 2022](#)) 'changed behaviours' ([Burley et al 2023](#))
- **What do individuals with dementia say about it?** Preferred 'unmet need' felt language affected how people were viewed and treated and how people feel about themselves ([Wolverson et al 2021](#))
- **What impact does it have on organisations?** [Putland and Brookes \(2024\)](#) review identified several recurrent language patterns that can fuel stigma



What do you do that works well



Enriched Model of Care (Tom Kitwood)

- Kitwood's work led to his formulation of the **experience of dementia** having five key components:
 - **NI** represents the persons neurological impairment
 - **H** their physical health
 - **B** their biography
 - **P** the person's personality or resources for action
 - **SP** the social psychology that surrounds the person from day to day
- **D (dementia) = NI+H+B+P+SP**
- *(Kitwood 1997)*

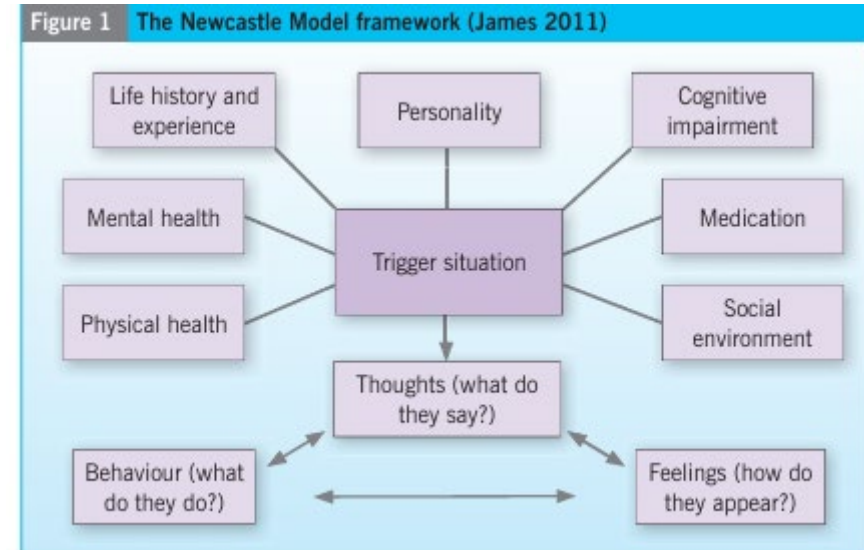
NEWCASTLE MODEL (Jackman & Beatty, 2015)

Assessment model – ‘formulations’

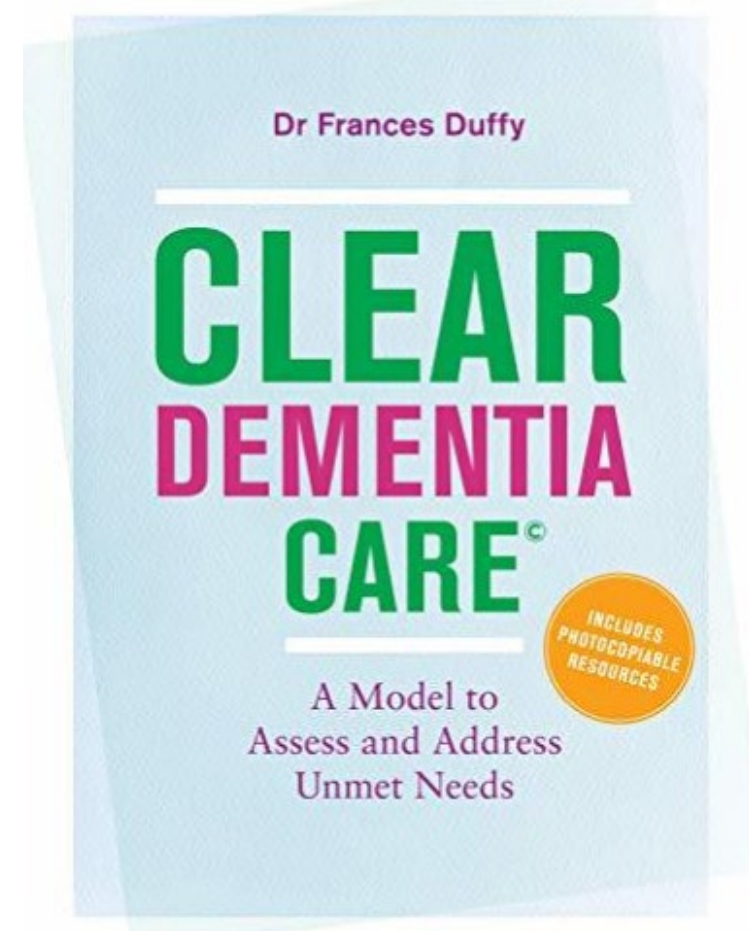
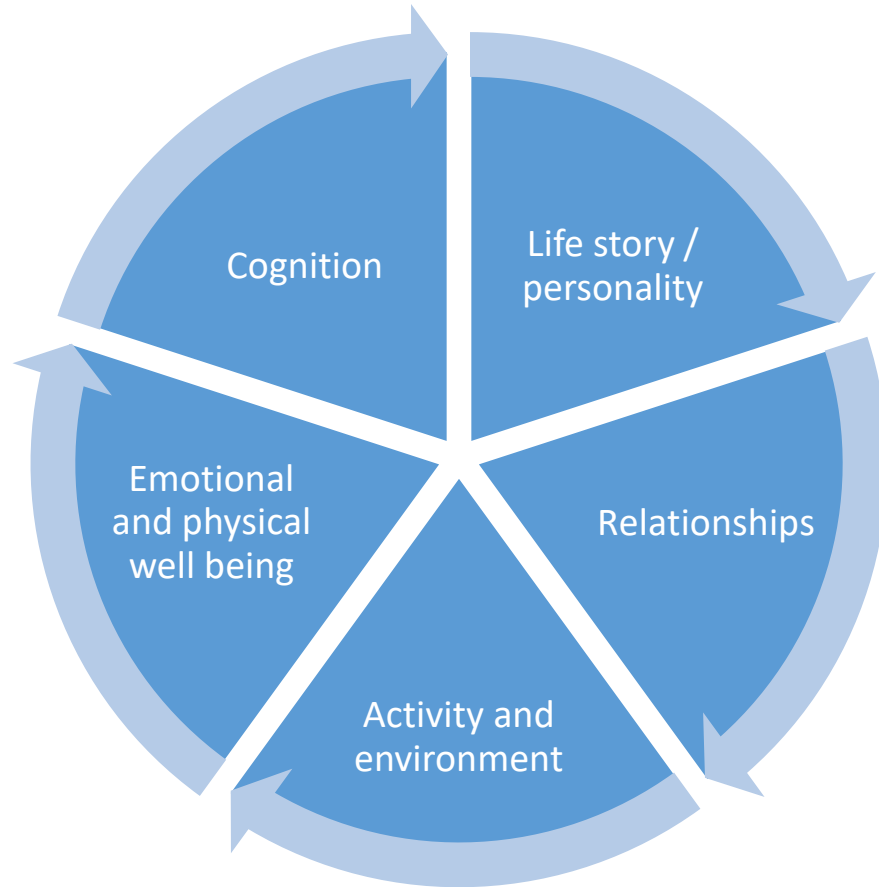
- formulation turns “behaviour that challenges” into behaviour that *communicates*

Psychosocial framework

- Emphasises understanding the individual’s life history, personality, health, environment and current situation to explain behaviour
- links between triggers, thoughts/feelings, behaviours, and unmet needs



CLEAR Model – Francis Duffy (2019)



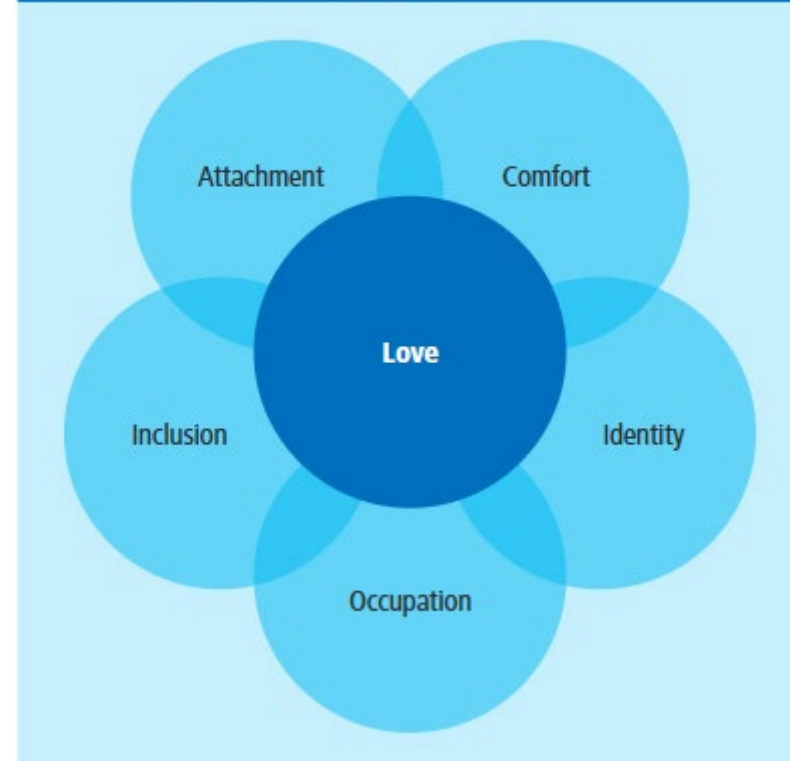
Trauma Informed

- Distress arises from trauma or delayed expression post-traumatic stress disorder (PTSD)
- Trauma is inextricably linked with PTSD
- High risk areas – personal care
- Good knowledge of environmental triggers
- Use of therapeutic lies

Four key elements

1. Realises the impact of trauma
2. Recognises the signs and symptoms of trauma
3. Responds by integrating knowledge about trauma into policies, procedures and practices
4. Resists re-traumatisation

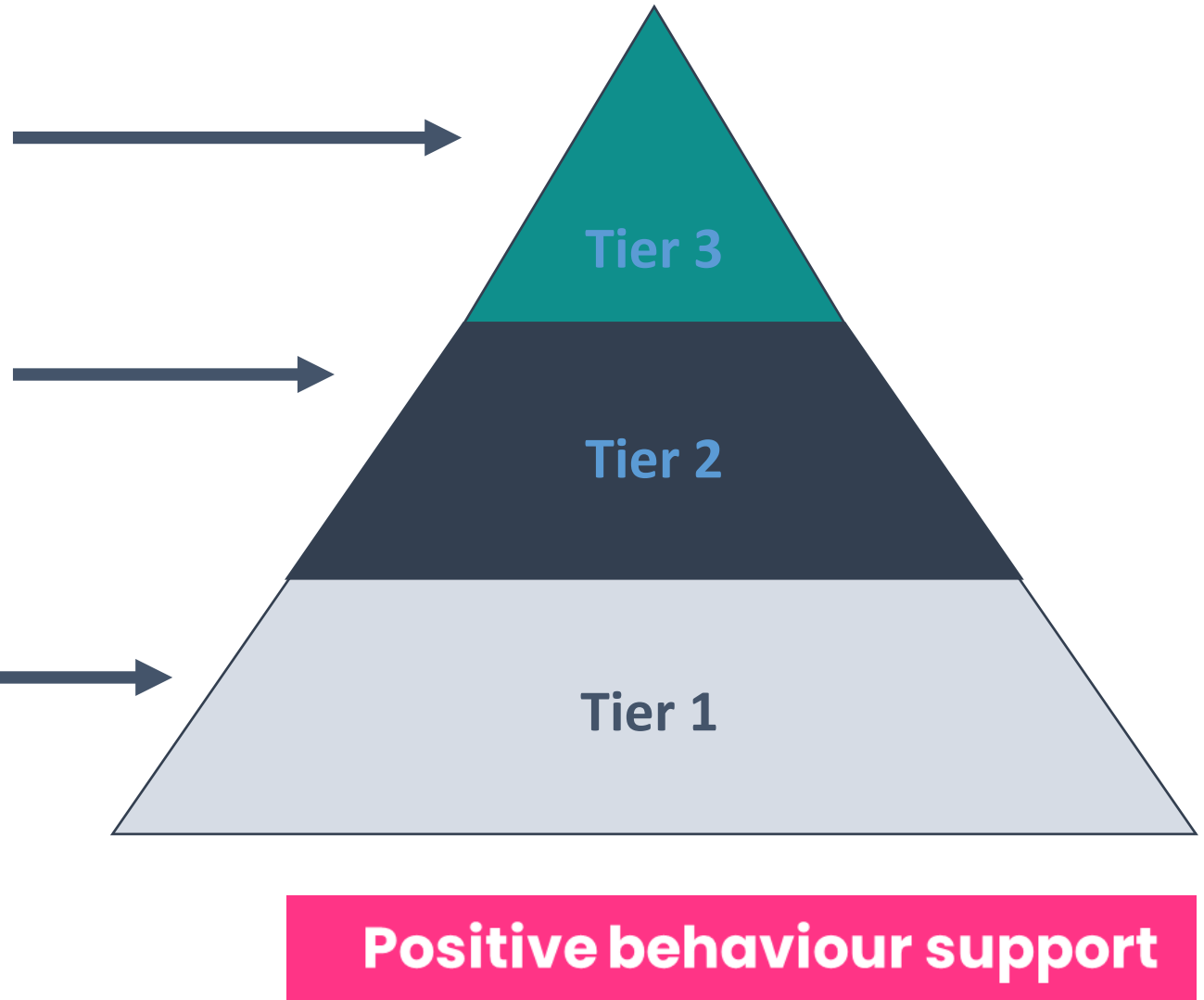
Figure 1. Kitwood's flower of emotional needs that evolved into person-centred care



Highly individualised interventions, including those that are “last resort”.

Targeted interventions based on function (e.g., gradually increasing difficulty, teaching alternative behaviour).

Preventative interventions help regardless of function of behaviour (e.g., free and regular attention, environmental enrichment).

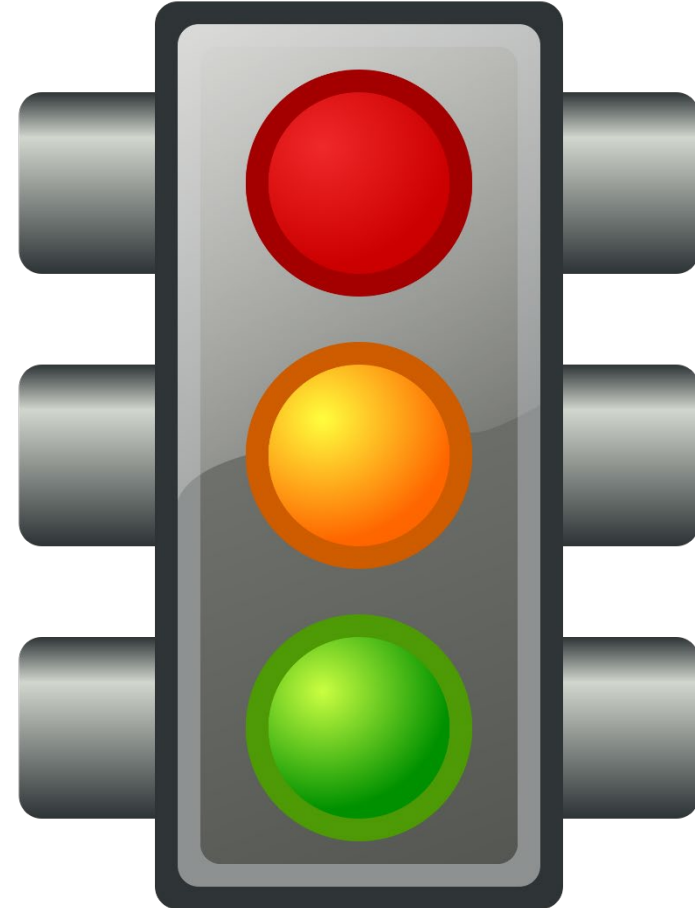


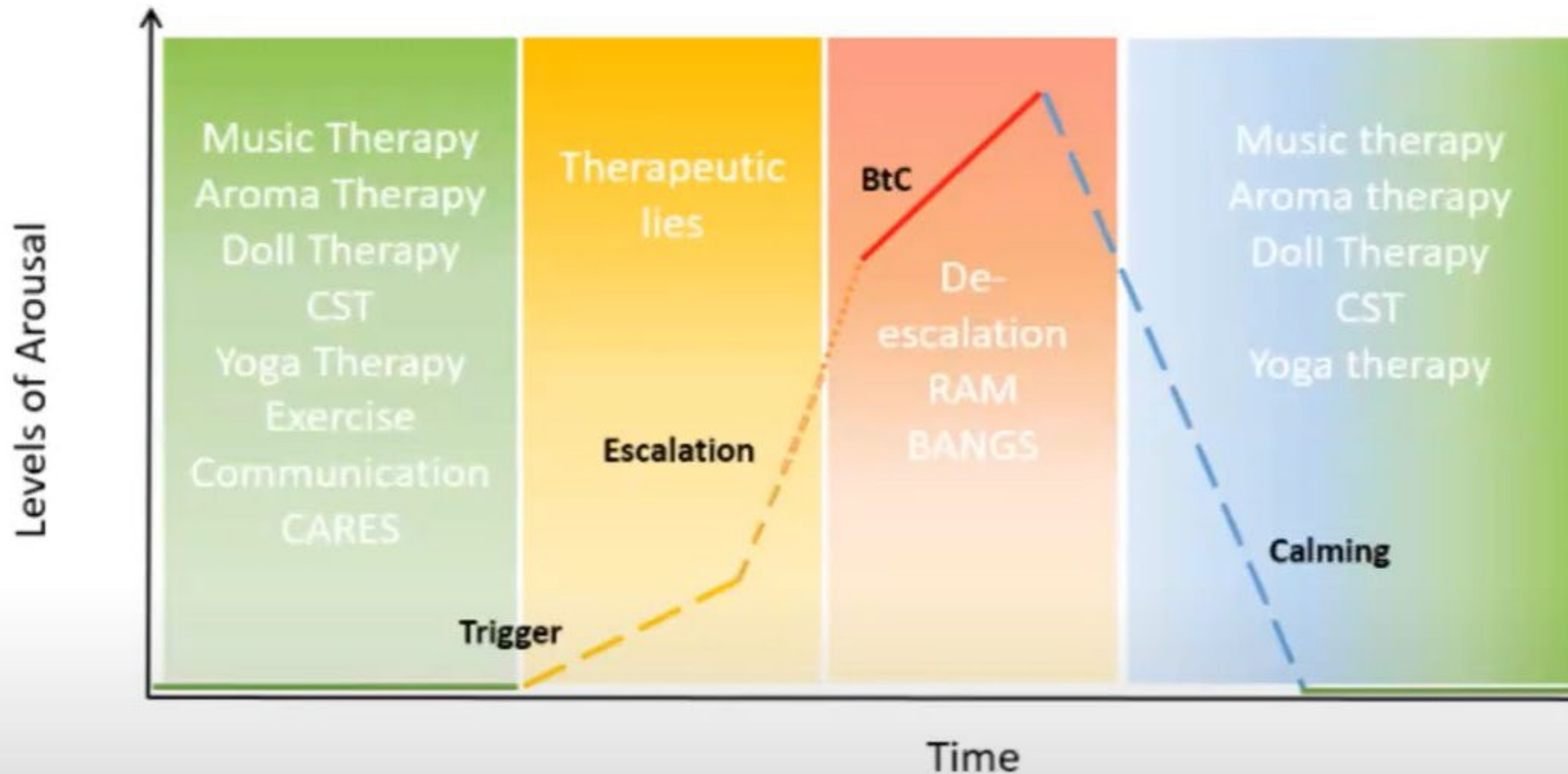
Traffic Light Approach & Positive Behaviour Support (PBS)

Traffic Light system (originally in intellectual disability services, adapted by Ian James for dementia):

- **Green** → Preventative strategies (proactive support, routines, environmental enrichment, meaningful activity).
- **Amber** → Early intervention when behaviour begins to escalate (adjust environment, identify triggers, use de-escalation).
- **Red** → Crisis management (safety, calming, last-resort strategies).

[Challenging behaviour in dementia care: a novel framework for translating knowledge to practice](#) | [the Cognitive Behaviour Therapist](#) | [Cambridge Core](#)





LET US ADD TO OUR KETE

SENSORY MODULATION IN PRACTICE

Presented by Carole Kerr Dementia Nurse Specialist



Sensory Diet

- We all utilise our personal history and sensory diet we have developed individually to try and reduce our levels of distress when placed in a situation of fight, flight or freeze
- We are going to complete our own sensory diet sheet
- Consider what you use to reduce your distress, whether you need activity ie do you go for a long walk

Or

- Do you like to sit or lie down calmly, listen to music, read a book
- Are you a mixture of both? How would I know which one to use for you

Sensory Diet Form

Taste

Sight

Smell

Sound

Touch

Discuss your Needs with your Group



Are there similar ways that we use to reduce distress



Is there other people in the group that need to be active or people that like to do something less active



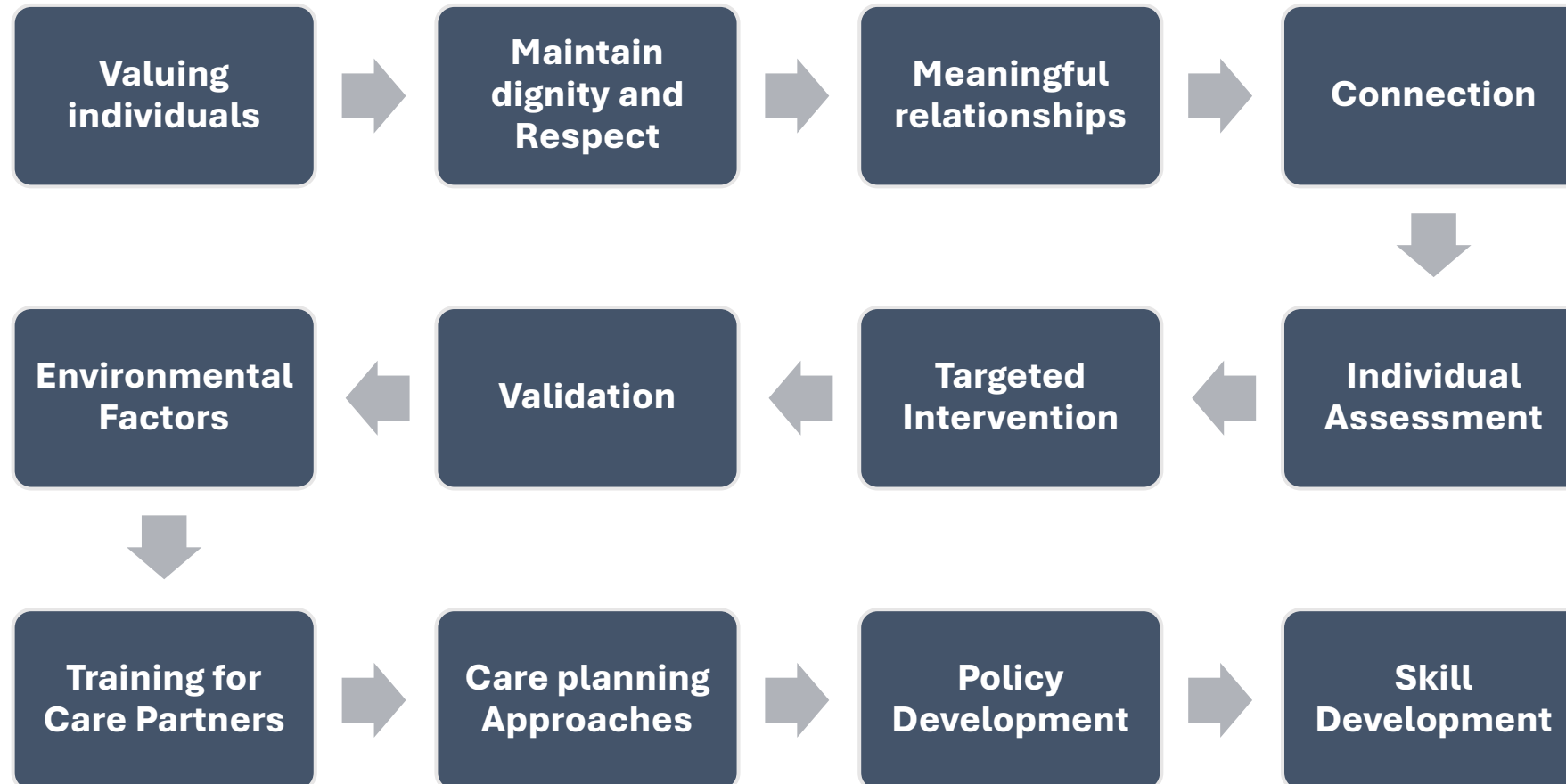
If you had dementia what else may be important for your family whanau support staff to know about you

First steps

The way of being with another person which is termed empathetic...means temporarily living in their life, moving about in it delicately without making judgement...

Carl Rogers

Outcomes from Models of Care



How do I know what I need?



Use Of Sensory Modulation to Support Care



Originally developed by Tina Champagne 2018 for mental health and then specifically for dementia care

Utilises the history of a person along with their sensory diet and the "powerhouses of senses" our internal senses which we use daily

Develop alternatives that can provide support and understanding of what maybe happening for the person living with dementia

Sensory Modulation: Tools and Techniques

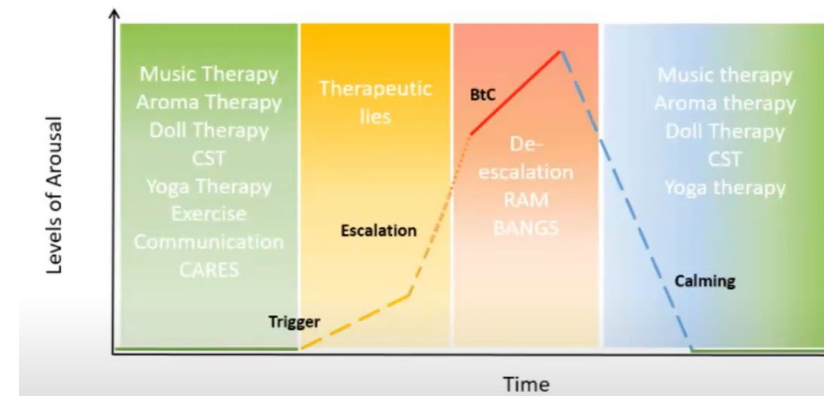


Music Playlists: Soothes and reduces stress. Must be personal to trigger positive memories.

Lighting: Adjust brightness/colour so objects are visible and not shadowed.

Textures: Provide comfort through familiar tactile items (e.g., fiddle mats, keys).

Aromatherapy: Scents can influence mood; avoid those linked to past trauma.



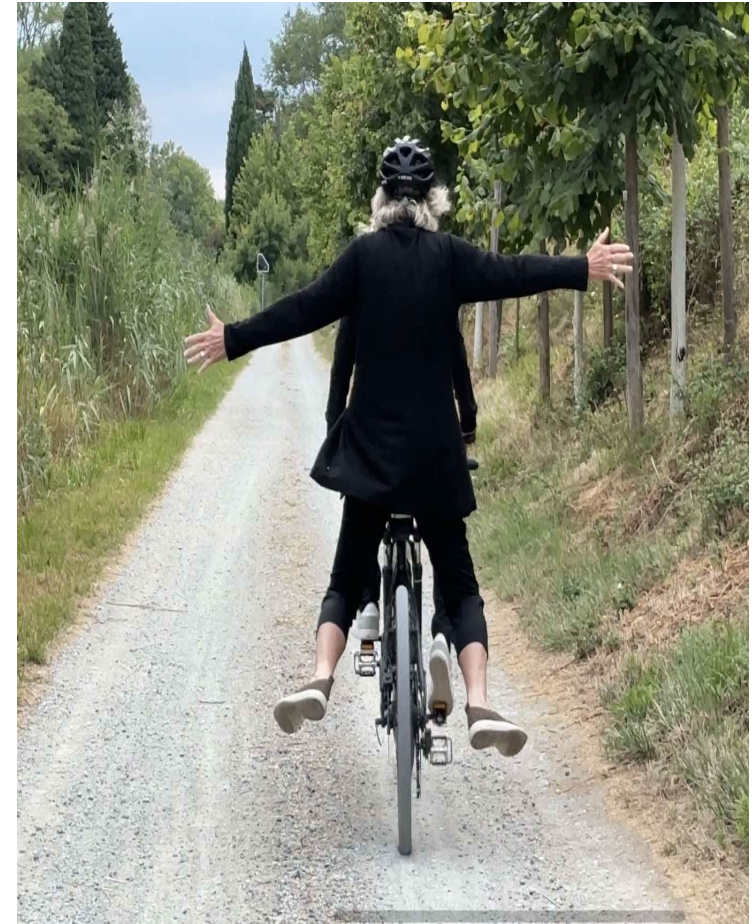
Options for Sensory Input

Utilise our individual sensory diet to support activities and sensory options for daily use

These options may not last for long and are usually used for primary prevention needs

When a person is very distressed we need to utilise the “powerhouses” our internal senses to support the person to calm

Replicate what is part of the person's life



Powerhouses” Our Internal Senses



Internal Senses

Proprioception

Awareness of the body in relation to surroundings

Interoception

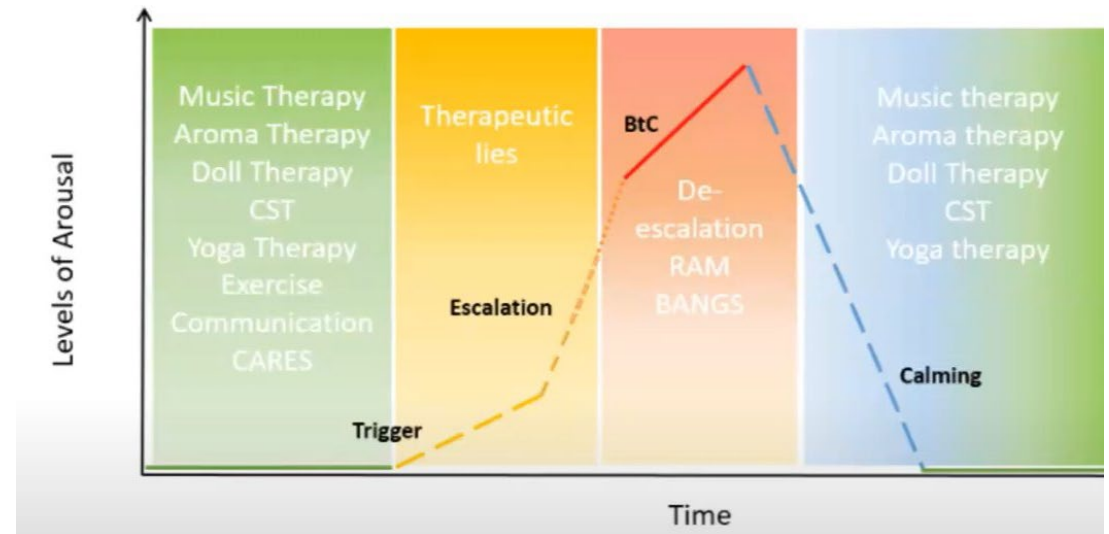
Ability to perceive and understanding what's happening in our body

Vestibular

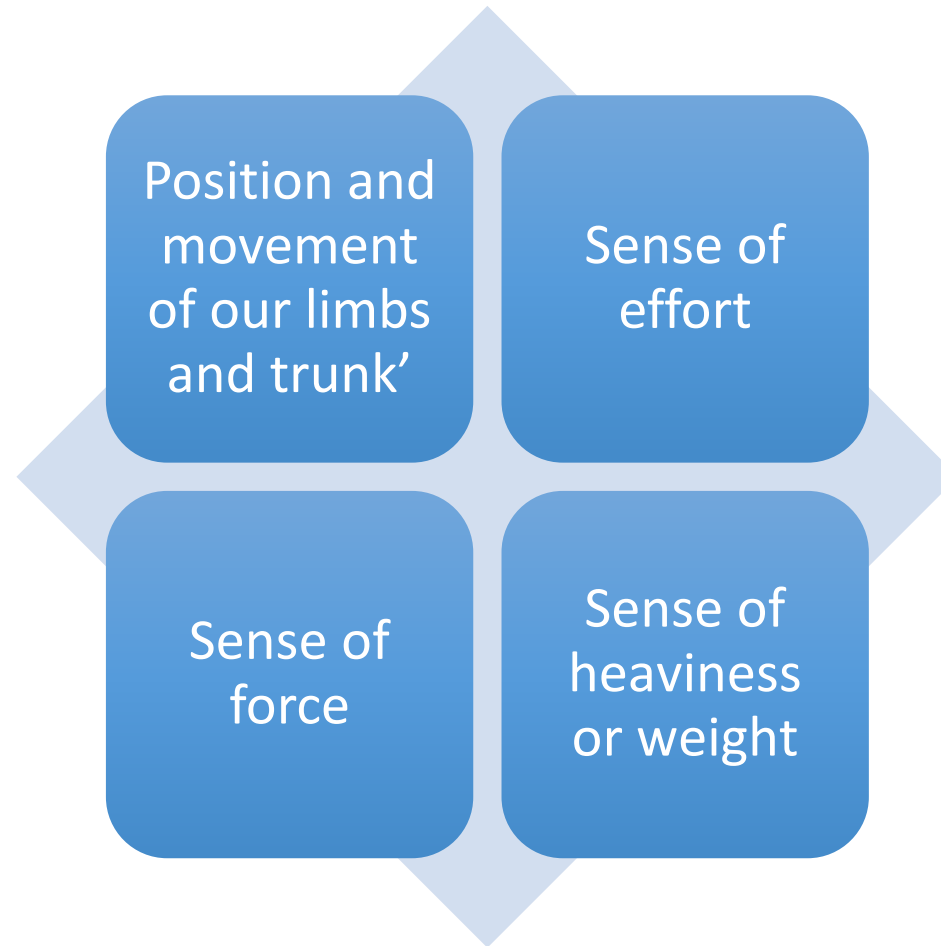
Responsive to movement and balance

Oral Motor

Use of oral facial muscles



PROPRIOCEPTION



Dancing activity

Options



- **Sweeping, wiping tables**
- **Weighted, animals, babies, blankets**
- **Moving furniture**
- **Lifting**
- **Stretch bands**



Interoception



Lets us know what our body needs ie Thirst, hunger, cold or too warm.



What our emotions are telling us

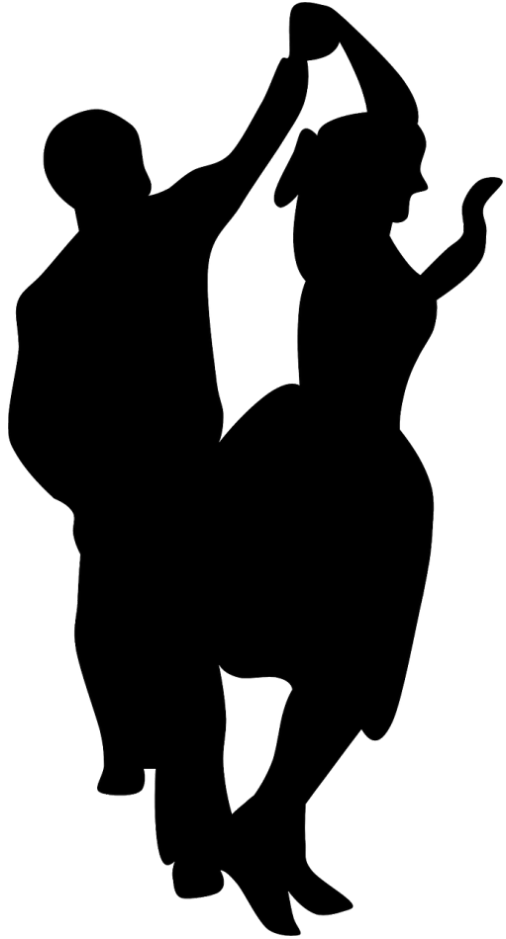


Where we might be feeling pain



Needing to rest

Vestibular



- Responding to movement and balance
- Utilise dancing, rocking or glider chairs, exercising
- Walking

Oral Motor



- Includes sucking, blowing ,licking chewing
- Utilise licking ice-creams, sucking smoothies through large straws, sucking lollies if the person is able to do this

Practical Applications for Reducing Distress

Individualised Care Plans: Tailor care to each person's needs to reduce distress and support wellbeing. Draw on insights from family, whānau, and staff about what has been observed and what helps.

Supportive Environments: Design safe, calming spaces that reduce anxiety. Pay attention to lighting, noise, and comfort to foster a sense of security.

Meaningful Activities: Engage people in purposeful activities that affirm identity and promote wellbeing.

Education: Equip family, whānau, and staff with knowledge and options to better support care.



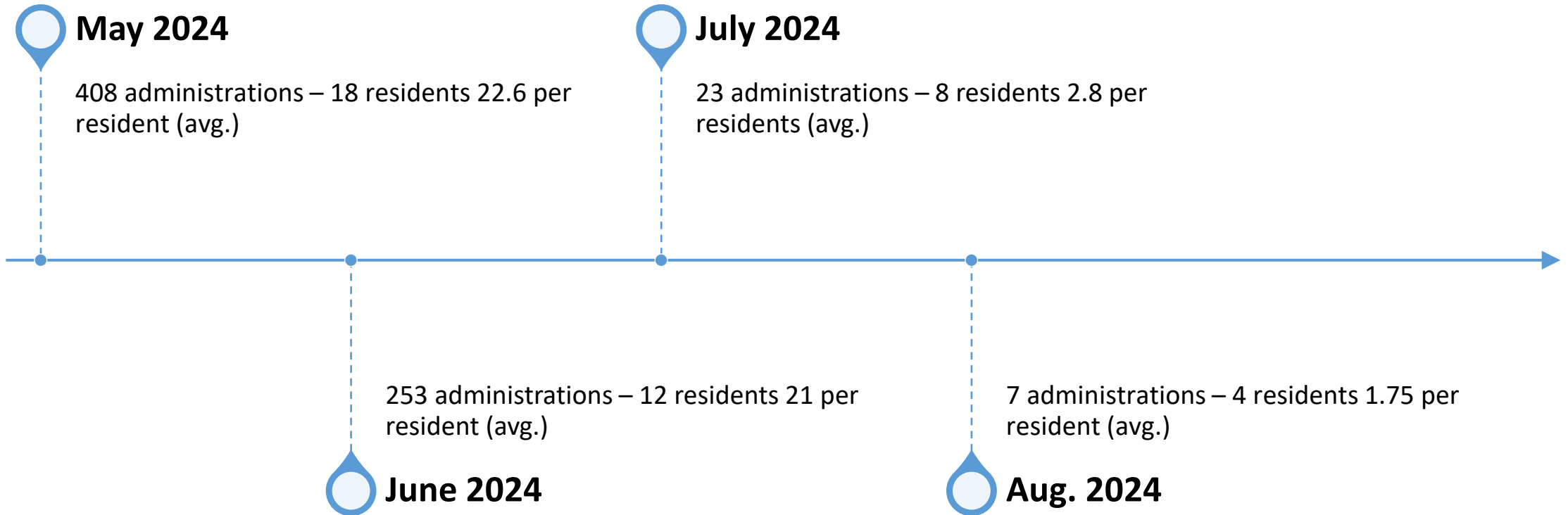


KUMEU VILLAGE

LUXURY REST HOME HOSPITAL DEMENTIA CARE
WELLNESS CENTRE AND  THE VINEYARD VILLA

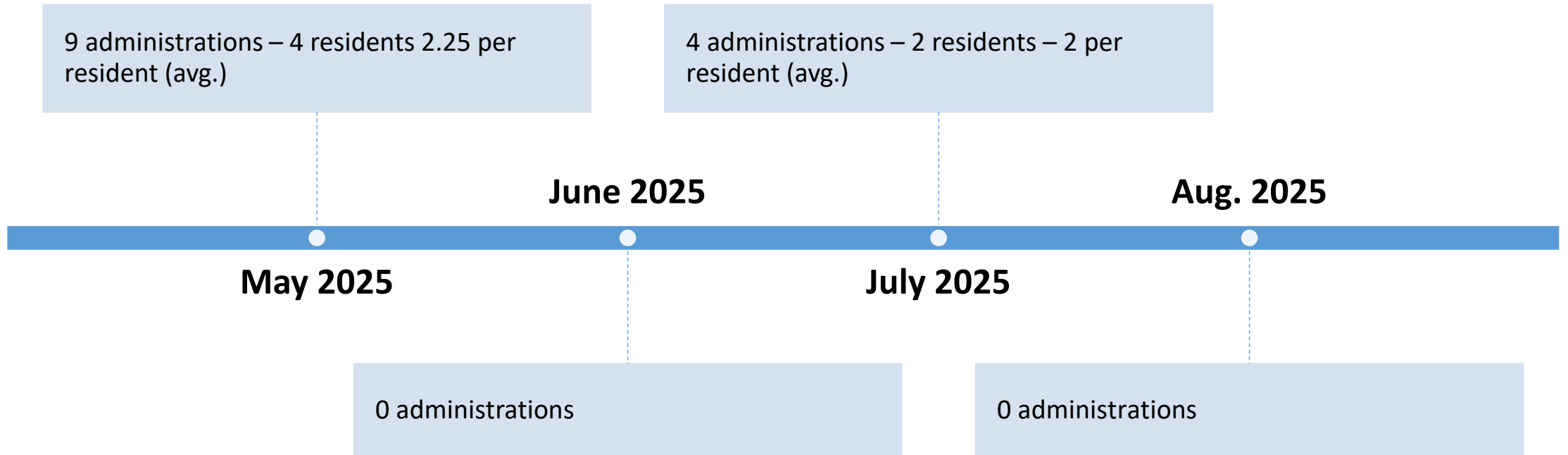
Reducing PRN
Antipsychotic Usage
For Distressed
Behaviours

2024 Baseline data



Very High Reliance On PRN
Antipsychotic Usage In
Mid-2024

2025 Progress



Sustained Reduction
Over A Twelve Month
Period, With Some
Months At Zero.

Comparison 2024 vs. 2025

May - 406 – 9 (98%)



June - 253 – 0 (100%)



July – 23 – 4 (83%)



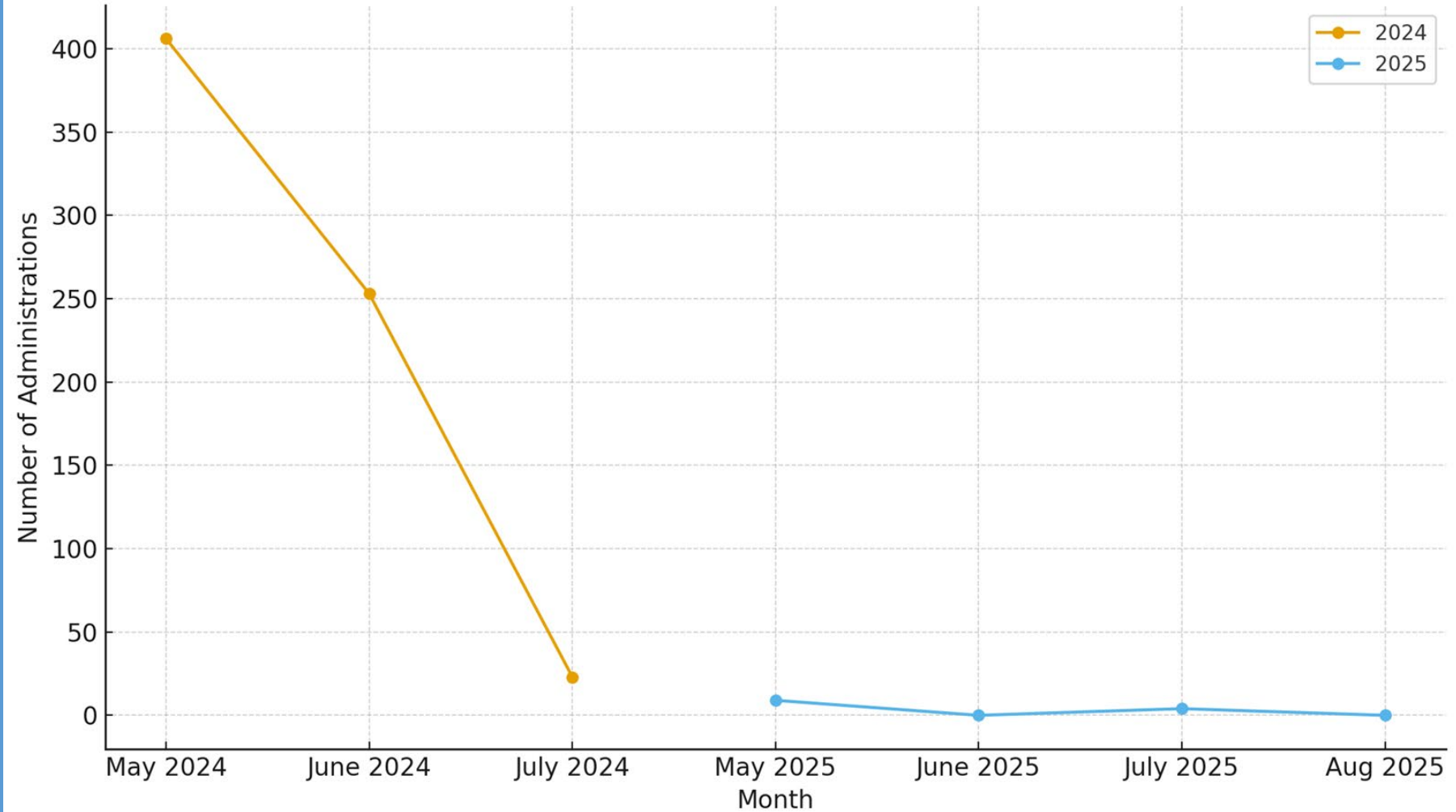
August – 7 – 0 (100%)

Major Reduction In PRN Antipsychotic
Usage Within One Year.

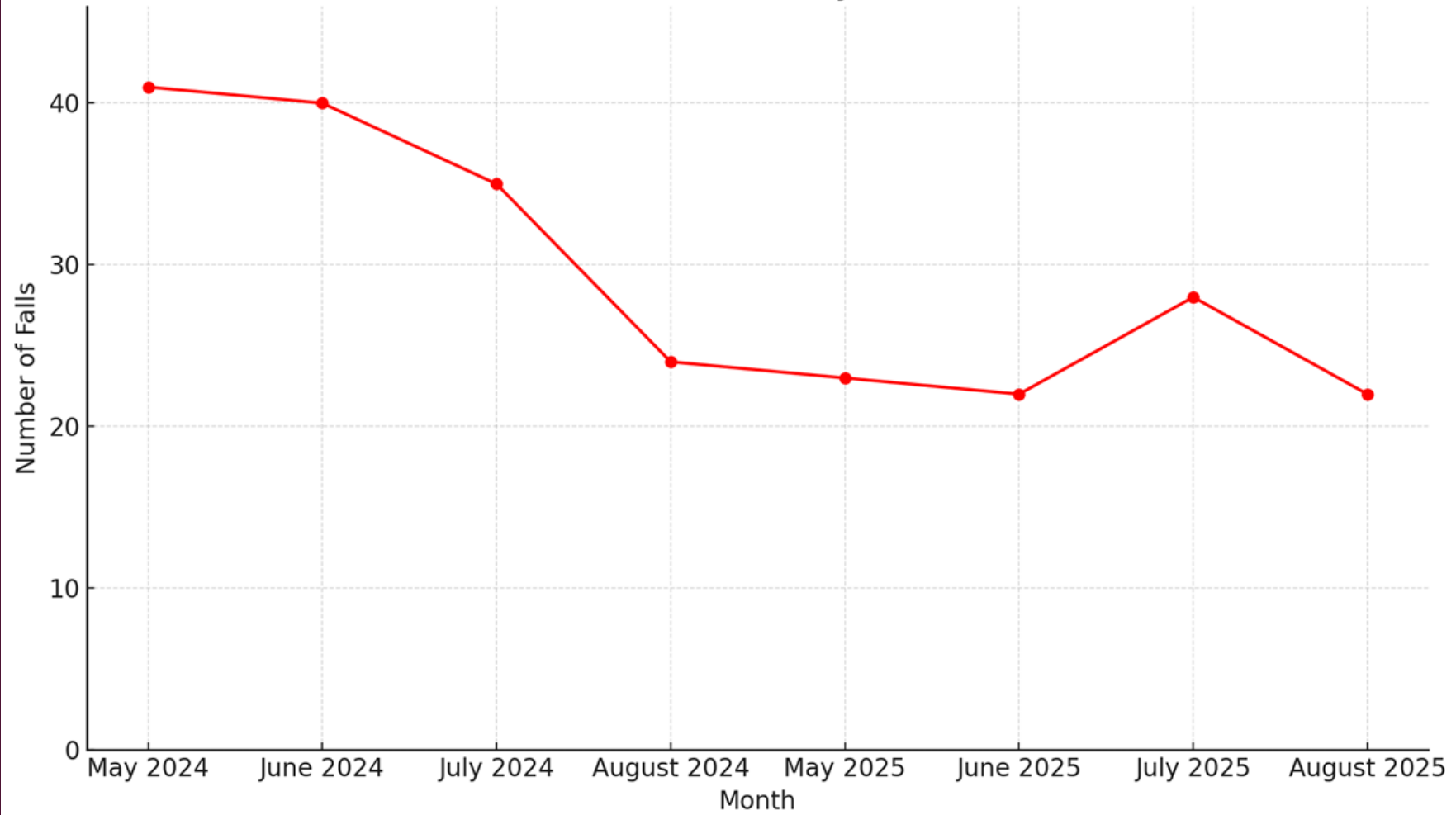
The Average Per Resident Has Dropped
From **19-21** (2024) To
2 Or Less In 2025

This Indicates Improved Behavioural
Support Strategies And Reduced Reliance
On Medication.

Antipsychotic Administrations for Distress Behaviours (2024 vs 2025)



Number of Falls by Month

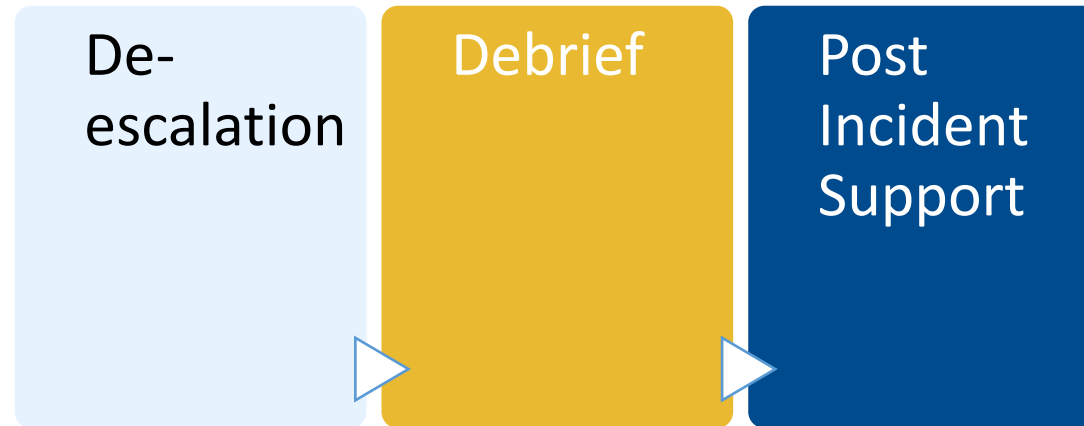








Leadership Approaches – Whole Systems Thinking



Leadership Approaches – Whole Systems Thinking



Prevention

- Nutrition, hydration, and sleep.
- Dementia-friendly environments.
- Meaningful engagement and occupation.
- Working with families to identify and prevent triggers.
- Early identification of health issues (pain, UTI, delirium).
- Staff noticing early warning signs of agitation

Capability & Support

- Staff training in communication, de-escalation, and person-centred practice.
- Staff wellbeing initiatives that reduce burnout and moral distress.
- Embedded practice leadership coaching and modelling good practice in real time.

Leadership Approaches – Whole Systems Thinking



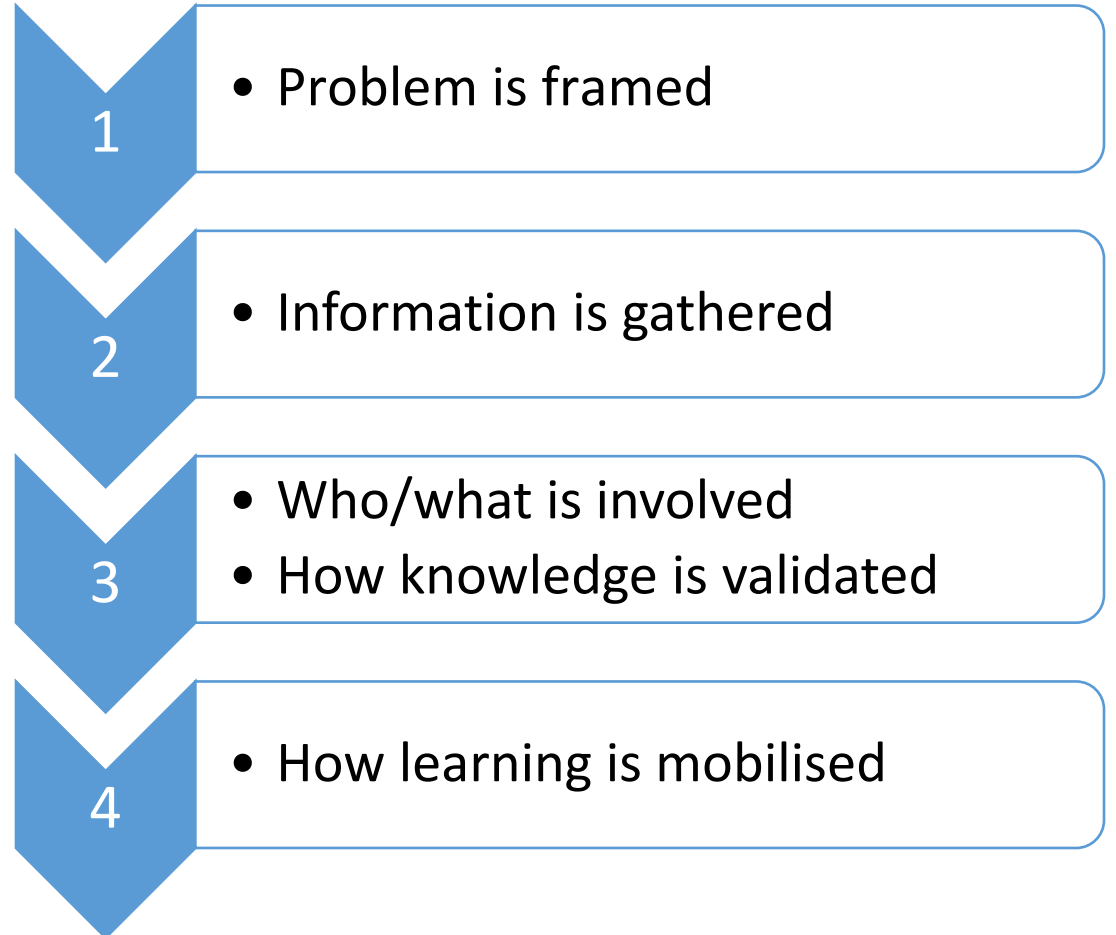
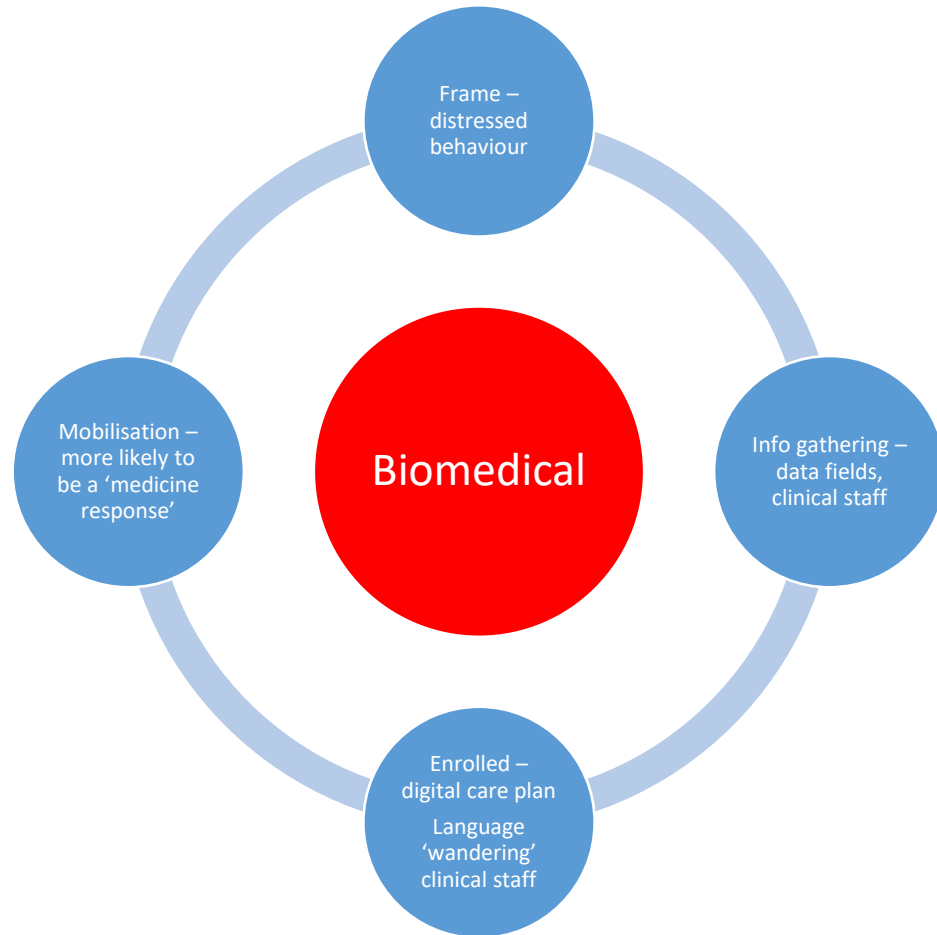
Continuous Improvement

- Evidence-based approaches
- Interdisciplinary working
- Data and learning systems.

Frameworks & Rights

- Supported decision-making
- Risk enablement to balance safety with autonomy.
- Language and system design that frame behaviour as communication, not pathology.

Organisational Learning



Beyond the Band-Aid: Shifting the Focus to Prevention with Therapeutic Re-creation

Orquidea Tamayo Mortera (She/Her/hers) – MNZM
Alzheimers New Zealand Summit, Solving the
Dementia Challenge with People, Partnerships and
Innovation, 23 – 24 September 2025. Grand
Millenium, Auckland, NZ



Gemini Generated Image, 2025



Alzheimers New Zealand



United Nations, n.d.

Leisure and recreation is a recognized human right under international law, most notably in Article 24 of the 1948 Universal Declaration of Human Rights (UDHR), which states everyone has the right to rest and **leisure**.

- 1) What Recreational Activities do you enjoy doing alone? Swimming
- 2) What Recreational Activities do you enjoy doing with other people? Movies
- 3) What Recreational Activities would you like to try? Scuba diving
- 4) What Recreational Activities would you like to get back into? Roller-skating

A Proactive and human centred approach to Dementia care

Diversional and Recreational Therapy (DRT), also known as Therapeutic Recreation (TR), is a holistic healthcare field that uses purposeful leisure and recreational activities to improve a person's health, wellbeing, and quality of life.

A New Zealand Therapeutic Recreation Specialist (NZTRS) is a qualified and registered professional who designs and leads individual or group recreational activities. These activities are tailored to each person's preferences, motivations, strengths, abilities, and needs.

Happy DRT Week!



The Science behind Therapeutic Recreation

TR is closely related to positive psychology, a field that studies human flourishing. Engaging in enjoyable and meaningful activities can stimulate the brain's reward system by releasing chemicals like dopamine and serotonin.

TR helps people lead fulfilling lives by focusing on three key pillars of positive psychology:

- Life of Engagement: Being fully immersed in an activity (a state known as "flow").
- Life of Meaning: Reconnecting with what is meaningful to you.
- Life of Purpose: The process of setting and achieving goals.



TR Approaches Transforming Health & Wellbeing



Building Healthy Habits

It encourages people to incorporate physical activity and proper nutrition into their daily lives, which lowers the risk of chronic diseases like obesity and T2 diabetes*

Stress Management

It provides tools such as mindfulness (emotional approach), creative expression (cognitive approach), and nature-based activities (spiritual approach) to help people cope with stress*

Fostering Community

It creates meaningful group social activities like cultural or spiritual programs that combat loneliness and social isolation*

*Risk Factor for Dementia

Improving / Maintaining Function: Adapted sports, hobbies, household tasks or games to help a person regain motor skills, maintain cognitive skills delaying further cognitive changes

Meeting Needs: Using recreational activities like music or pet therapy (emotional approach) to reduce pain and the need for unnecessary medication or distress.

Enhancing Quality of Life: Helping people find meaning and joy in their lives, which can prevent secondary complications (behaviour approach) like depression and social withdrawal.

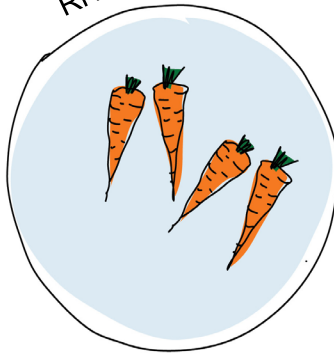


Gemini Generated Image, 2025

TR in teams

- ☐ Physical Wellbeing
- ☐ Cognitive Wellbeing
- ☐ Spiritual Wellbeing
- ☐ Cultural Wellbeing
- ☐ Social Wellbeing
- ☐ Intellectual Wellbeing
- ☐ Vocational Wellbeing

discipline
boundaries not
challenged
RN – RN, GP, PT – RN, GP, PT, OT, CG – RN, GP, PT, OT, CG, RT – RN, GP, PH, PT, OT, CG, RT, Family



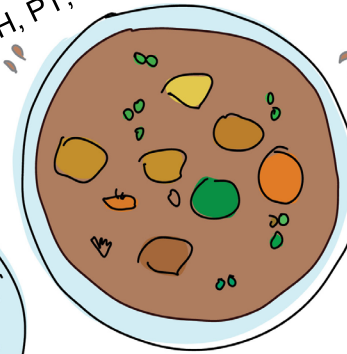
Intradisciplinary



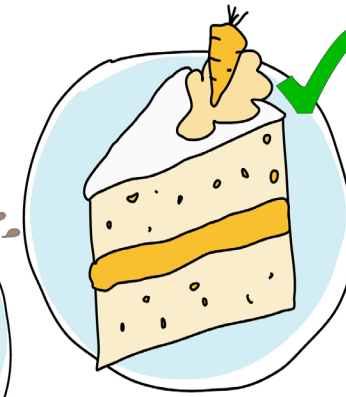
Cross disciplinary



Multidisciplinary



Interdisciplinarity



Transdisciplinary

discipline
boundaries transcended

- ✓ Holistic Assessment
- ✓ Integrated Approaches
- ✓ Shared responsibility



TR activities are design to uphold the mana of the person:

- Te Whare Tapa Whā
- Meihana model
- Te Wheke
- Te Pae Mahutonga
- Fonofale
- Te Vaka Model
- Kalsy-Lillico framework
- Leisure Ability Model
- Health Promotion Model
- Leisure and Wellbeing Model

BENEFITS OF THERAPEUTIC RECREATION

- Great activities
- Alternative to medication
- Alleviates the emotional (anxiety/depression) and physical (pain) aspects of illness
- Improves mood and self-esteem
- Teaches the importance of social interaction and communication
- Develops the ability to cope with stress
- Develops the ability to cope with stress

- A person who has recently had a heart attack becomes overwhelmed when faced with a rehab structure physical exercise he has been given.
- A person who has been diagnose with Alzheimer's becomes distress during mealtimes.



Loteria Club: A transdisciplinary approach of Game, Culture and Connection

An 89-year-old female resident with frontotemporal dementia was encouraged to participate in numerical bingo. However, during the sessions, she began calling for help, which was seen as a distraction by other residents and staff. As a result, she was no longer invited to the activity. Key stakeholders met to understand the reason behind the resident's calls for help. They identified that numerical bingo was a passive and unfamiliar activity for her because she was born in Mexico and moved to New Zealand in her 30's. The game lacked personal meaning and engagement for her. Instead, they created a "Loteria Club". This change allowed her to engage in a culturally familiar and meaningful activity, either with another caregiver or with other residents, transforming her experience from distress to purposeful participation.



Gemini Generated Image, 2025

Conclusions



If the Why is powerful, the How is easy – John Rohn

TR is a proactive, compassionate and preventative healthcare choice, shifting the focus from a reactive model of 'care' to one that actively promotes wellbeing, and genuine inclusion.

Far from being a “nice to have” or a non-essential treatment, TR is a lifeline. It is a human rights practice that upholds person lead care and support, honoring the individual as a whole. It ensures that services are tailored to a person's unique needs and preferences, rather than a one-size-fits-all approach.

TR enables a person to find moments of joy, connection, meaning, purpose and belonging. Experiences that are invaluable for the person, their family/whanāu and the wider community.





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