It Takes Two to Tango: Rethinking Resistiveness to Care

Elisabeth Drance MD FRCP(C) Geriatric Psychiatry
Clinical Associate Professor – Dept Psychiatry UBC
Psychiatrist – Parkview Tertiary Behavior Support Unit
Regional Medical Lead – Older Adult Mental Health Services VCHA

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Learning Objectives

By the end of the workshop, the learner will be able to:

- Explain how the terminology we use can influence the outcomes of care
- List care-recipient risk factors that predict responsive behaviors during care
- Describe caregiver contributions to responsive behaviors
- Use a “hand model” of the brain to understand the role of fight-flight reactions in responsive behaviors during care
- Use techniques drawn from the “Mindfulness” literature to improve the outcomes of challenging care interactions

Acknowledgements

- Thanks to my team-mates at Parkview for their passion and creativity in providing person-centered hands-on care to elders living with dementia and for their willingness to share their ideas and experiences with me.

- Thanks to Kimberley Smith – our Clinical Coordinator at Parkview and my partner in crime in putting these thoughts together

Disclaimers and Disclosures

- The descriptions of theoretical neurobiological contributions to responsive behaviors during care in this presentation are:
  - Gross oversimplifications of a complex issue
  - Drawn from **interpersonal neurobiology and mindfulness** literature which has had very little exploration in this population
  - Designed to move forward our conversations & research regarding complex care interactions.

- No financial conflicts to report.

Language and Care

Why does it matter?

Meet Brenda “the terrible...”

- What do you hear most clearly in the language?
- How do you think this may influence the care she receives where she is, and in any new place she moves to?

Meet Brenda the person….

- What do you hear differently?
- How might that make a difference to meeting Barbara when she arrives?

Why I don’t like the term “resistiveness to care”….

- Implies the problem lies with the person living with dementia
- Implies they need to change and that they can.
- Does little to create empathy for the individual
- Creates fear and derision amongst staff
- Does very little to create understanding of the unmet needs of the situation
- The term itself can have some powerfully negative cumulative effects…

Why terminology matters

From interpersonal neurobiology -

- Words influence my thoughts
- Thoughts influence feelings
- Together –
  - These influence my brain
  - These influence my behaviour.

- *Our brains are wired to physically change based on what and how we think about things.*

- “Neurons that fire together wire together”
  - Donald Hebb

…So the more negatively we think about something, the more negatively our brain becomes programmed to think…it ***hardwires*** more negatively.

Why terminology matters

- Recurrent negative thoughts :
  - Reinforce and grow my negative thought patterns
  - Reinforce my negative feelings
  - Reinforce my negative associations with the term “Resistiveness-to-Care” and the people associated with it
  - Reinforce my sense of learned helplessness

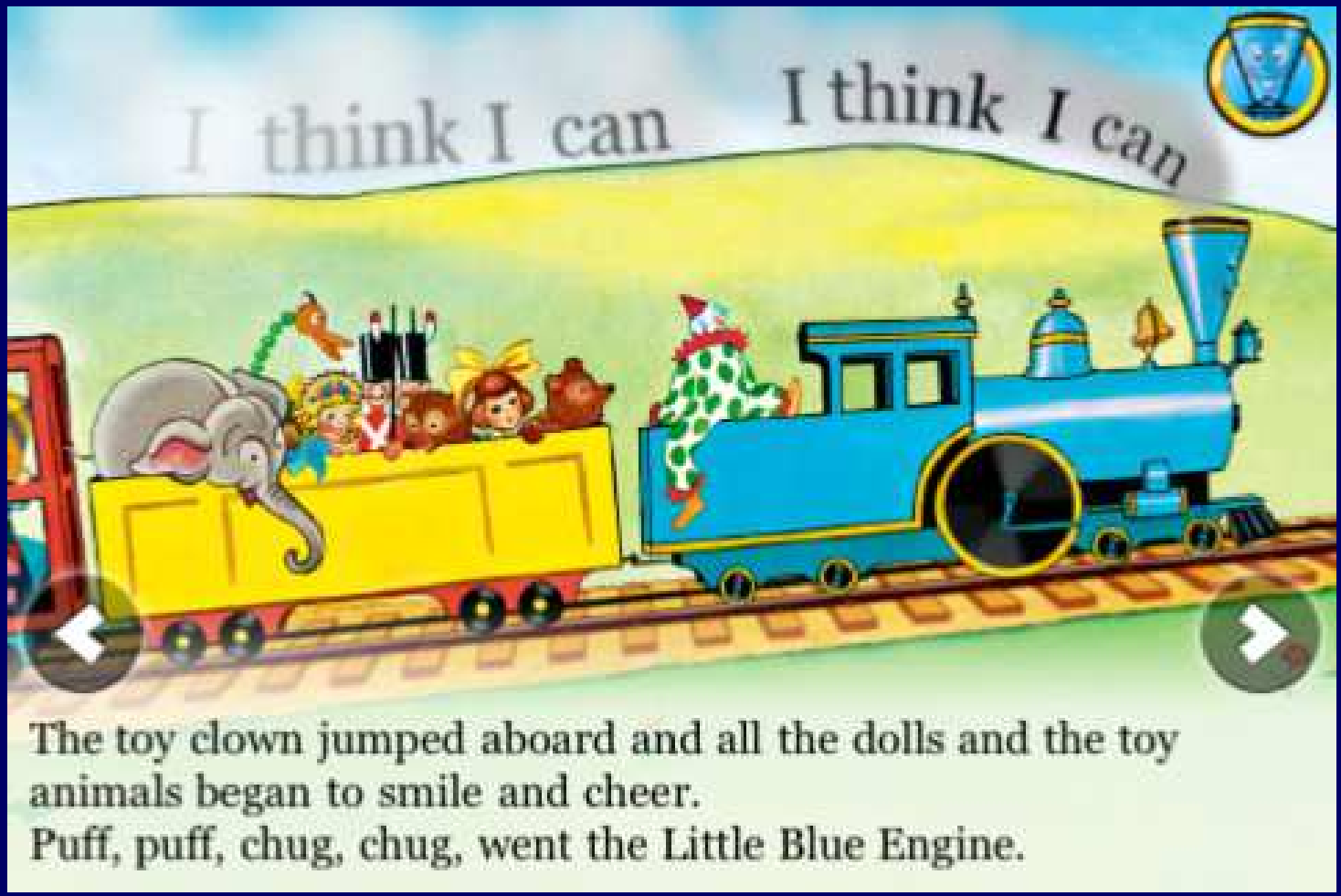
- Your brain is like velcro for negative experiences and teflon for positive ones.
  - Rick Hanson PHD
    Buddha's Brain

…Misery loves company….

- Negative team conversations reinforce negative connotations to terms and lead to care that is often less successful –
  - Losing the person in the task
  - Adding more and more staff to make it safe
  - Doing care quickly to get it over with
  - Recurrent negative thought patterns and conversations in teams contribute to *negative cultures of care….*

How can terminology be helpful?

- We need terminology that
  - fosters **curiosity**
  - helps us to have **compassion** for the person who is overwhelmed by care interactions
  - **encourages us** that we ***can*** get to safe comfortable care.


I think I can
I think I can
The toy clown jumped aboard and all the dolls and the toy animals began to smile and cheer.
Puff, puff, chug, chug, went the Little Blue Engine.

- Whether you think you can or think you can’t, you’re right.
  - Henry Ford

Alternatives to the term “Resistiveness-to-Care?

- Overwhelmed by care interactions
- Self-protective behaviour
- Challenging care interactions
- Objective descriptions of the behaviours that are seen during care.
- Responsive behaviour
- Others?

Reminder - Behaviour is communication…

- “Every message, regardless of form or content, is an expression of a need.”
  - Marshall Rosenberg NVC
- “All behaviour communicates unmet need”.
  - Need-Driven Dementia Compromised Behaviour Model
    - Whall & Kolanowski 2004

Being overwhelmed by care interactions:

- Is the result of a complex set of unmet needs.

- These needs can range from the most biological (pain, infection, meds etc) to the most psychological (safety, security, attachment).

Assessment - PIECES

P = Physical Issues, Pharmacological Issues

I = Intellectual (Dementia/Delirium)

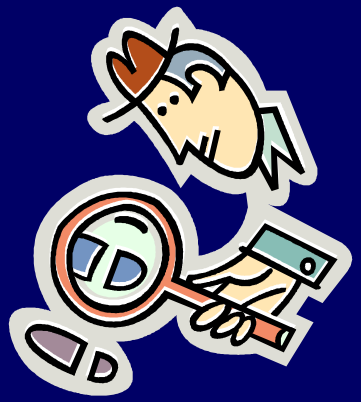
E = Emotional & Psychiatric Issues

C = Capabilities – ADL/IADL

E = Environment (Physical and Interpersonal)

S = Social – Life Story, Personality, Social Network

- “*We need to be a good detective rather than a good judge*”
  - Teepa Snow



- For today's discussion, we will focus on what's going on in:
  - I – Intellectual function
  - E – Emotional realm
  - E – Environment – Interpersonal
  - S – Social Factors – Life experiences

…..for the person living with dementia & the caregiver in the moments of care

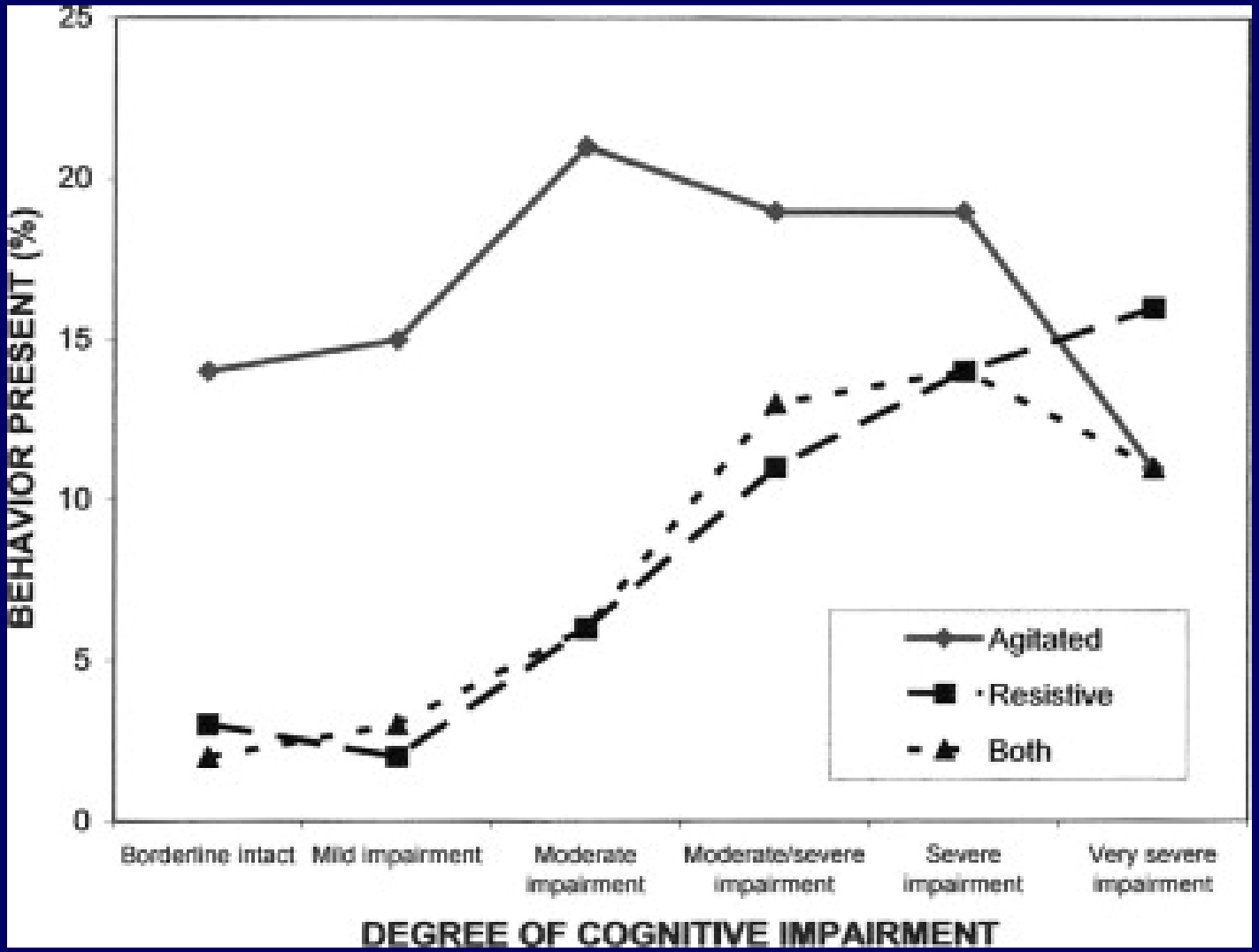
Breaking down the Tango of Care into its component steps

- What's going on for the person with dementia?

- What's going on for the caregiver?

Identifying the Risks in Care Interactions: Person Living with Dementia

- Form of Dementia – FTD highest risk
- Stage of Dementia*
- Communication abilities
  - Expressive aphasia
  - Receptive aphasia
- Premorbid personality style
  - Irritability, negativism
  - Need for independence
  - Narcissism
  - Antisocial Personality style
  - Racism
- Traumatic Life Experiences – sexual or physical, or emotional abuse
- Premorbid interest in contact sports – eg. Boxing



Volicer et al; JAMDA 2007 8:527-532

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Identifying the Risk Factors in Care Interactions: Caregiver

- Inadequate Training
- Work-related issues
  - Lack of experience and confidence
  - Lack of collegial/organizational support
  - Organizational Philosophy of care – Task Focused Care
  - Staffing issues
- Physical Illness – Pain issues
- Depression, Anxiety Disorder, PTSD
- Attitudinal/Personality
  - Negativity, irritability, anger management issues
  - Dislike for work or feeling trapped in work setting
  - Tendency toward use of Elder Speak
  - Energy mismatch

Caregiver Risk Factors

- …..Anything that prevents the caregiver from being truly present during the interaction…….

The “Brains” Behind the Operation

Turning to the brain…..

- Hand-Model of the Triune Brain
  - Primitive to Recent Development
  - **The Lizard Brain** – Brainstem & Midbrain
    - Messages in and out from the body, states of arousal, **fight-flight-freeze**
  - **The Mouse Brain** – Limbic Area
    - Emotion, memory, **evaluation – good/bad, safe/unsafe, stress responses, fear response (ALARM BELL)**
  - **The Monkey Brain** – Cortex
    - Planning, Perceptions of Outer world, Tracking/planning location & movement
    - **Prefrontal Cortex – Attention, Pause before acting, Insight, Empathy, Moral Behavior – the great integrator**

Mindsight 2012 – Daniel Siegel MD
Just One Thing – Rick Hanson PhD

In the healthy brain -

- The intact cortex – particularly the **prefrontal cortex (L>R)**, modulates the alarms of the lower parts of the brain.

- The intact cortex can ***evaluate*** safety & use language to alter the course of another's behaviour.

What happens in the brain with dementia?

- In people with degenerative dementias affecting the cortex or subcortical pathways, **the controls over the amygdalae and the brain stem are impaired.**
- The **amygdalae** firing “unsafe” messages goes unmodulated by the cortex
- The unmodulated amygdalae firing activates the fight-flight response….

….and the person with dementia can react self-protectively/aggressively with what appears to be little provocation.

So – from a ***neurobiological perspective***, what does the person with dementia need during care?

- He or she needs to receive messages that will reassure the amygdalae that he or she is safe and secure

- Messages that there is no need to activate a fight-flight response

Yes….it's on us

- The person with dementia's brain is broken
- Expecting them to change volitionally is unrealistic
- It's on us to
  - Learn to read the PLWD's communications to us
  - Shift our language and our approach,

thereby enabling the elder to feel safe and secure, and to work with us.

Neurobiology of the Caregiver's Brain

- Amygdalae constantly assessing – SAFE/NOT SAFE, good/not good

- Engaging the Left prefrontal cortex
  - Setting the intention - planning
  - Attention & Awareness
    - To the Person's needs
    - To their own needs
  - Attending to the Amygdalae firing
  - Acting on the messaging of the other – STOP and GO

So….what are the rules of engagement for care…

- If you insist…..they will resist!
- If you keep insisting….they will resist more!
- If you repeatedly insist….they will resist earlier and earlier in the interaction.
  - Teepa Snow

So what is the goal of each care interaction?

- To prevent firing of the fight-flight response of the person living with dementia (and the caregiver)

How is that achieved?

- **Activating as much positive emotion as possible for the PLWD**
  - Connect on a social level before care
  - Compassionate connections
- **Keeping the PLWD's amygdala from sensing danger***
- **Preventing amygdalae from needing to activate fight or flight response**
  - Learning and reading the signs of early signs of fear in the PLWD
  - Responding to the early signs of fear

What triggers the amygdalae that a care interaction is unsafe or not good?

- Verbal miscommunication
  - Too little explanation
  - Too much explanation
  - Missing receptive aphasia
  - Elderspeak words
- Affective Tone
  - Power differential
- CG body language that says “I don’t want to be here”.

What triggers the amygdalae that a care interaction is unsafe or not good?

- Outpacing
- The “crowd” factor – “less is usually more”
- Situations reactivating traumatic memories
- Other

How is that achieved?

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How does responsive behaviour get worse over time if we continually push through the fear response?

- Recall:
  - “Neurons that fire together, wire together”
  - The brain is velcro for the negative…

Recall: The brain is like velcro for the negative…

- Negative interactions: more powerful than positive
- Negative stimuli get more attention and processing.
- We generally learn faster from pain than pleasure.
- Easy to create learned helplessness, hard to undo
- Negative experiences sift into implicit memory (which remains intact longer than explicit memory in cortical dementia).

  - Rick Hanson PhD

How does it get worse?

- If caregivers push through care repeatedly in a triggering way – this increases amygdalae alarm bells ringing, strengthening that wiring (***emotional conditioning***)

- Amygdala and ‘fight-flight-freeze” fire with less and less trigger
  - Fear becomes more generalized
  - Fear of caregivers entering personal space for other reasons
  - Fear of entering room where care is given (bathroom, bedroom)

So What Are the Answers?

- Our work is to –
  - enter caregiving interactions in a mindful way
  - read the early signs that the interaction is becoming stressful and respond early
  - avoid strengthening/conditioning the negative stressful response
  - gradually extinguish the fear response where it has become conditioned

Preparing for a successful care interaction

- Learning from the “Mindfulness” literature
  - Mindfulness is:
    - Paying attention
    - In the present moment
    - Without judgment

Jon Kabat-Zinn

Preparing for the interaction

- Before entering a person's space
  - STOP, take a deep breath, form a positive intention for the interaction, and ask yourself:
    - Who am I going to meet?
    - Am I aware of the person's care plan?
    - Is this a good time for me?
    - Is this a good time for the person?
    - Do I have who and what I need to provide care?

In the room…

- Activate your pre-frontal cortex (attention & pausing)
- Connect relationally before any care.
- Avoid elderspeak
- Take the emotional temperature as you go.
- Slow the care down
- Language – a helper or a harmer?
- Time out! (S.T.O.P when you need to…)
- I’m sorry….

S.T.O.P – Sue Bauer-Wu

- S Stop
- T Take 3 deep breaths
- O Observe and noticing what is going on for you right now (thoughts, body sensations)
- P Proceed with kindness for yourself and others

5 types of “I’m sorry”

- I’m sorry I made you feel _____.
- I’m sorry – I was just trying to help.
- I’m sorry – I didn’t mean to treat you like a child.
- I’m sorry – this is hard.
- I’m sorry – you’re right.
  - Teepa Snow

Following the care interaction…

- Catch the learnings
- Record the learnings
- Communicate the learnings
- Model the learnings

Assessing the Role of Medication

- Look for the Obvious
  - Depression
  - Psychosis
- Nothing obvious to ‘treat’?
  - **Caught early and no major distress/danger:**
    - Revise plan and hold off on medications
  - **If behaviour dangerous or distressing – look at short term intervention:**
    - Identify primary affect of care
      - Anxiety – Benzodiazepine pre care (short term), Trazodone+/- SSRI
      - Anger – Antipsychotic
      - Disinhibition – SSRI + antipsychotic
- Pre-care medication may be helpful until deconditioning of fear response achieved.
- Short term use only….and NOT done instead of shifting the approach to care.

Summary Slide….

- Language matters to the outcome
- Recognize the red flags
- The “handy” brain model – goes everywhere you do ☺
- The brain’s subcortical warning systems are less modulated in the person living with dementia
- Assess & revise your approach early
- We cause emotional conditioning when we trigger self-protective responses over and over
- A mindful approach to caregiving makes a difference to both care partners.

NEVER GIVE UP

"Obstacles don't have to stop you. If you run into a wall, don't turn around and give up. Figure out how to climb it, go through it, or work around it."

- Michael Jordan