Delivering safe and accessible care for survivors of psychologically traumatic events: An introduction to trauma-informed dementia care

Dr Monica Cations
MRFF/NHMRC Emerging Leadership Fellow

Flinders University

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Before we start, meet Stephen

- 72 years old
- Divorced, no children
- Placed in institutional care at 4 years old, sexual abuse
- Limited education
- Left the home 18 years old, sporadic employment as a labourer
- ‘Home body’, rarely leaves home and two cats
- Moderate stage dementia (unspecified), GORD, spinal stenosis, hypertension, high cholesterol, type 2 diabetes
- Drinks ~4-6 beers/day, pack a day smoker

Psychological trauma

"Results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual wellbeing."

- Neurobiological and psychological impacts
- 20-40% of cases result in Post-Traumatic Stress Disorder
- Impact of event can persist even without PTSD
- Can (and often does) trigger a cascade of subsequent experiences

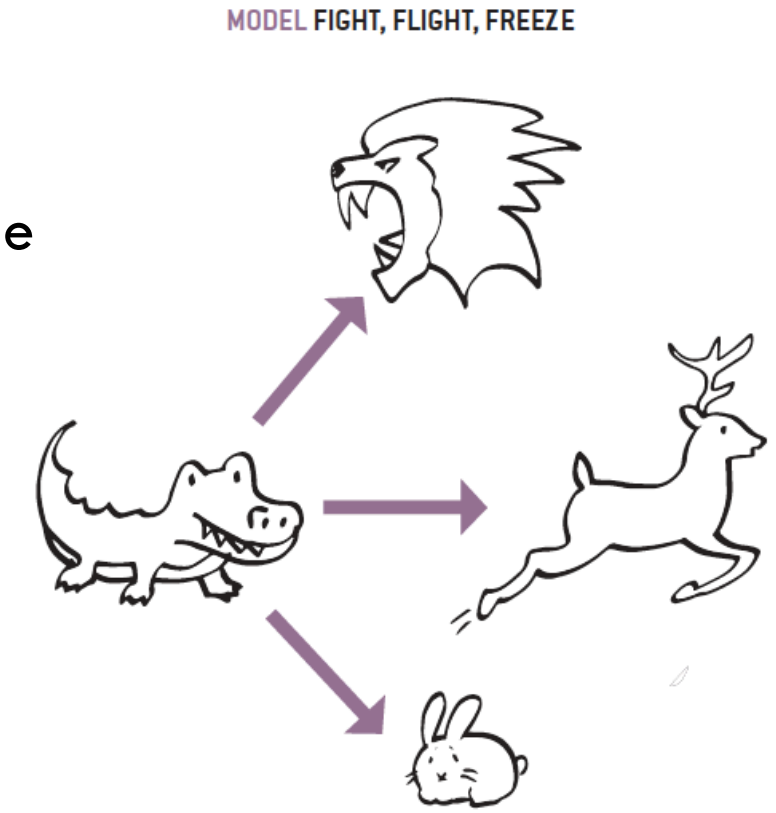
Substance Abuse and Mental Health Services Administration. *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach*. 2014.

Psychological trauma

<u>Psychological trauma can permanently alter our *stress response*</u>

- Hyper-alert to threat
- Misreading cues as dangerous
- Difficulty attending to information to make sense of cue

"Survival mode" kicks in even where it's not needed



Psychological trauma

<u>Psychological trauma can permanently alter our ability to *regulate our emotions*</u>

"The ability to exert control over one's emotional state"

Calm ourselves down
Think through our options
Assess the true risk for harm
Communicate our needs
Think rationally

Common reactions to stress / re-traumatisation / triggers:

- Anger
- Fear
- Aggression
- Hoarding
- Withdrawal
- Hopelessness
- Dissociation
- Anxiety
- Yelling
- Silence
- Resistance

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Psychological trauma

<u>Psychological trauma can permanently alter our *memory*</u>

- Intrusive memories of the events
- Skewed memory of event (e.g. self-blame) → self-worth, self-esteem
- Skewed memory of later events
- Emotional memory can be triggered without context
- Poor episodic memory

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Psychological trauma in later life

- More than 70% of older people have experienced one or more psychologically traumatic event
- Events that happen in late life can themselves be traumatic: falls, fractures, serious illness, hospitalisation, transition to residential aged care

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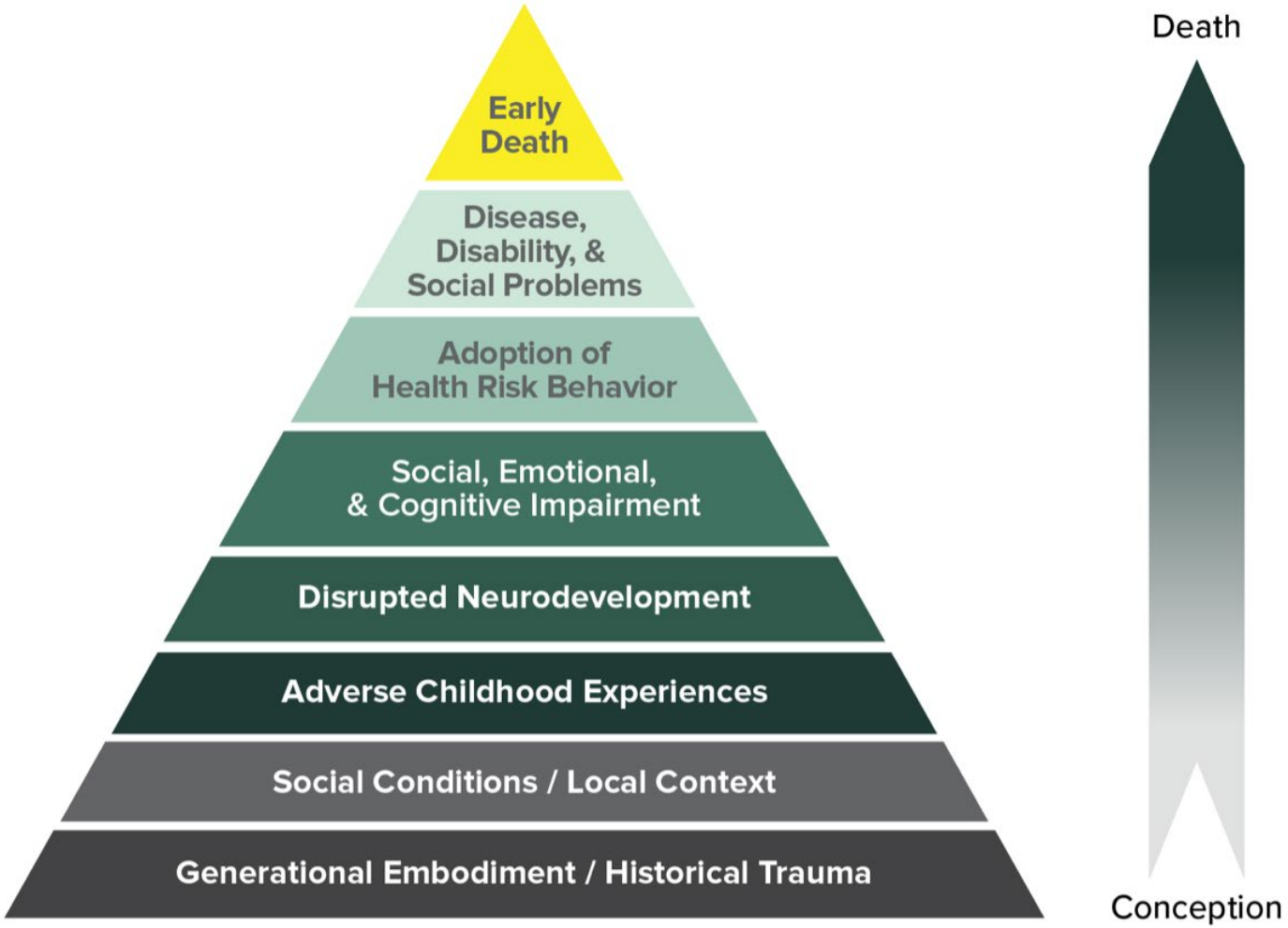
Psychological trauma in late life

Psychological trauma can have a longitudinal course



Mechanism by which Adverse Childhood Experiences Influence Health and Well-being Throughout the Lifespan

Psychological trauma in late life

Psychological trauma can have a longitudinal course: Stephen

Psychological trauma and aged care

- At presentation to aged care services you might see…
  - Mistrust
  - Isolation
  - Lifelong (perhaps unusual) coping strategies
  - ‘Safe spaces’
  - Withdrawal / ‘cagey’
  - Explosive behaviour
  - Responses that are difficult to understand
  - Depression
  - ‘Prickly’
  - Reactive
  - Lovely, chatty
  - Nothing at all

Psychological trauma and aged care

- Receiving aged care services introduces a **power imbalance**
- Trust for **the person** doing the caring, **the organisation** delivering the care, **the system** that funds the care
- Inherent limitations to **choice** and **control**
- Home care → disruption of a '**safe space**'
- Entry to residential aged care → **loss of possessions**

Psychological trauma and dementia

- Trauma → oxidative stress, hippocampal atrophy, other neurodegeneration
- Trauma survivors are at increased risk for dementia (Desmarais et al., 2019)
- Re-emergence of symptoms of post-traumatic stress disorder (e.g. Mota et al., 2016; Desmarias et al., 2020)

Orientation

Memory

Communication

Understanding the environment

Decision making

Expressing needs

Psychological trauma and dementia

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Psychological trauma and aged care

Mr Smith was placed in a 'boys home' when he was a child, and experienced physical and sexual abuse during that time	*Mr Smith becomes very distressed if his door is not locked and during personal care*
Mrs Clark experienced a traumatic childbirth that resulted in a stillbirth	*Mrs Clark cries all day, and calls out for her baby*
Mr Loi was a prisoner of war and held in confinement for an extended period of time; red light on ceiling	*Mr Loi demands that the smoke alarm on the ceiling is removed*

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Psychological trauma and aged care

What we learned from Care Leavers

- 500,000+ Australian children placed in institutional care: abuse, neglect, human rights violations
- Lifelong cascade of disadvantage
- Now in or approaching late life
- Profound aversion to ‘re-institutionalisation’ in aged care
- Autonomy, choice are essential

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Psychological trauma and aged care

What we learned from Care Leavers

- Narrow view of aged care as residential care only
- Counselling / psychological supports are a lifeline – difficult to access in residential aged care
- Willingness to disclose varies
- Assumptions about family cause pressure
- Strongest relationships with care workers, cleaners etc – similar class
- Very specific, varied preferences

Stephen

- Highly averse to accessing aged care, fear of being re-institutionalised
- Low digital literacy – no access to MyAgedCare
- Diabetic crisis – hospitalised
- Very distressed by the ward environment, several attempts to escape, aggressive behaviour
- Now bouncing between services, sedated

Trauma-informed care

- A model of care embedded into mental health services, homelessness services, and other services
- Recognises the central role of psychological trauma in shaping our experiences, perceptions, relationships, and care

> *"Trauma-informed organisations have processes and staff capable of identifying and anticipating the ongoing impacts of trauma, amending procedures to account for potential triggers, and creating an environment that maximises control and comfort for the trauma survivor."*

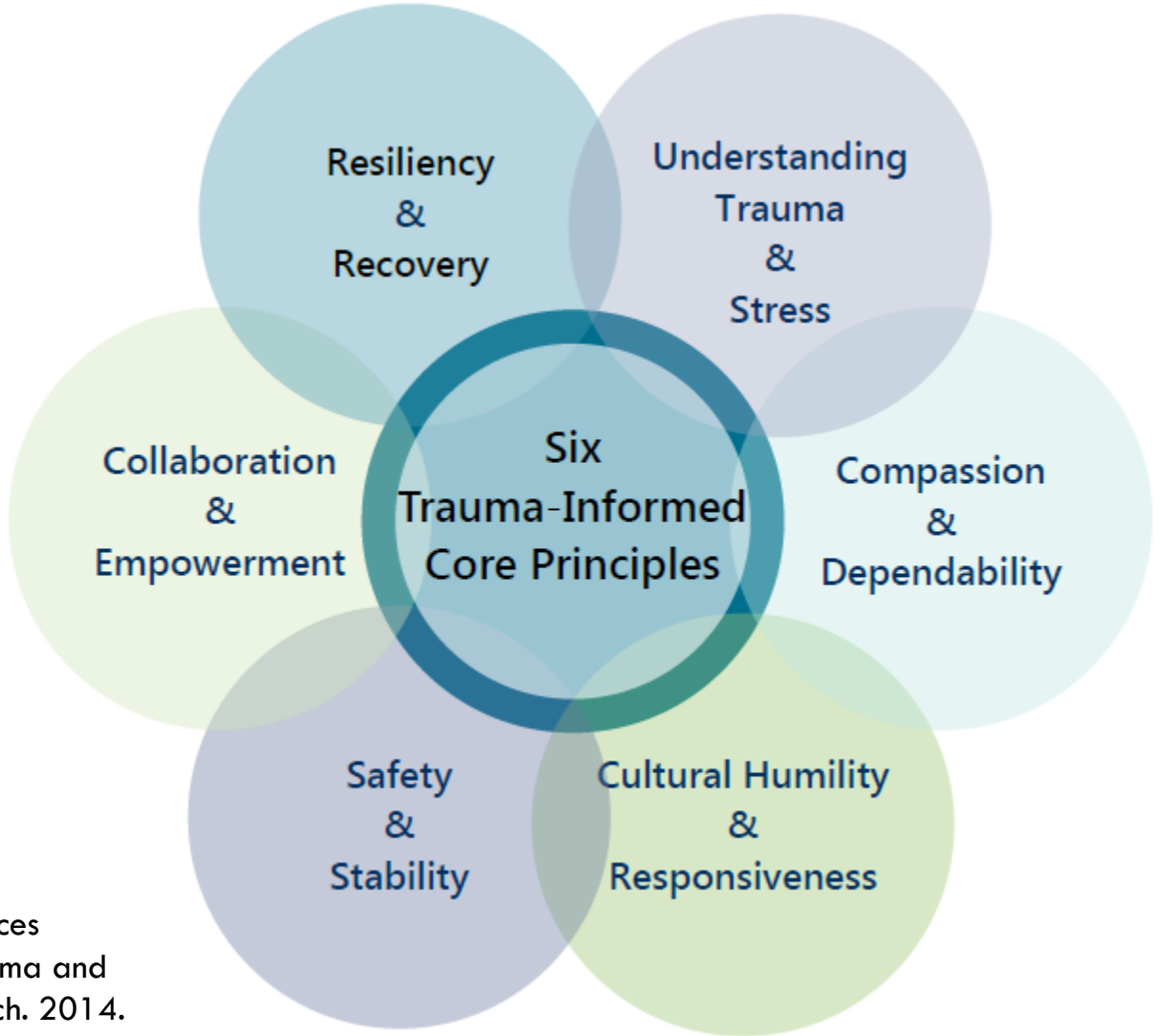
- Safe care for trauma survivors is person-centred AND trauma-informed

Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. 2014.

Trauma-informed care is NOT...

...a care setting where everyone can treat trauma symptoms

Trauma-informed care



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Trauma-informed care

Key to reducing risk for distress

As far as possible, provide care that:

Restores power	Creates safety	Builds self-worth
Choice	Physical safety	Care relationships
Empowerment, autonomy	Trustworthiness	Respect
Focus on strengths	Transparency	Compassion / empathy
Build skills	Predictability	Mutuality
Flexibility	Clear and consistent boundaries	Collaboration
		Acceptance and non-judgement

Yatchmenoff et al. Implementing trauma-informed care: Recommendations on the process. *Advances in Social Work*; 2017.

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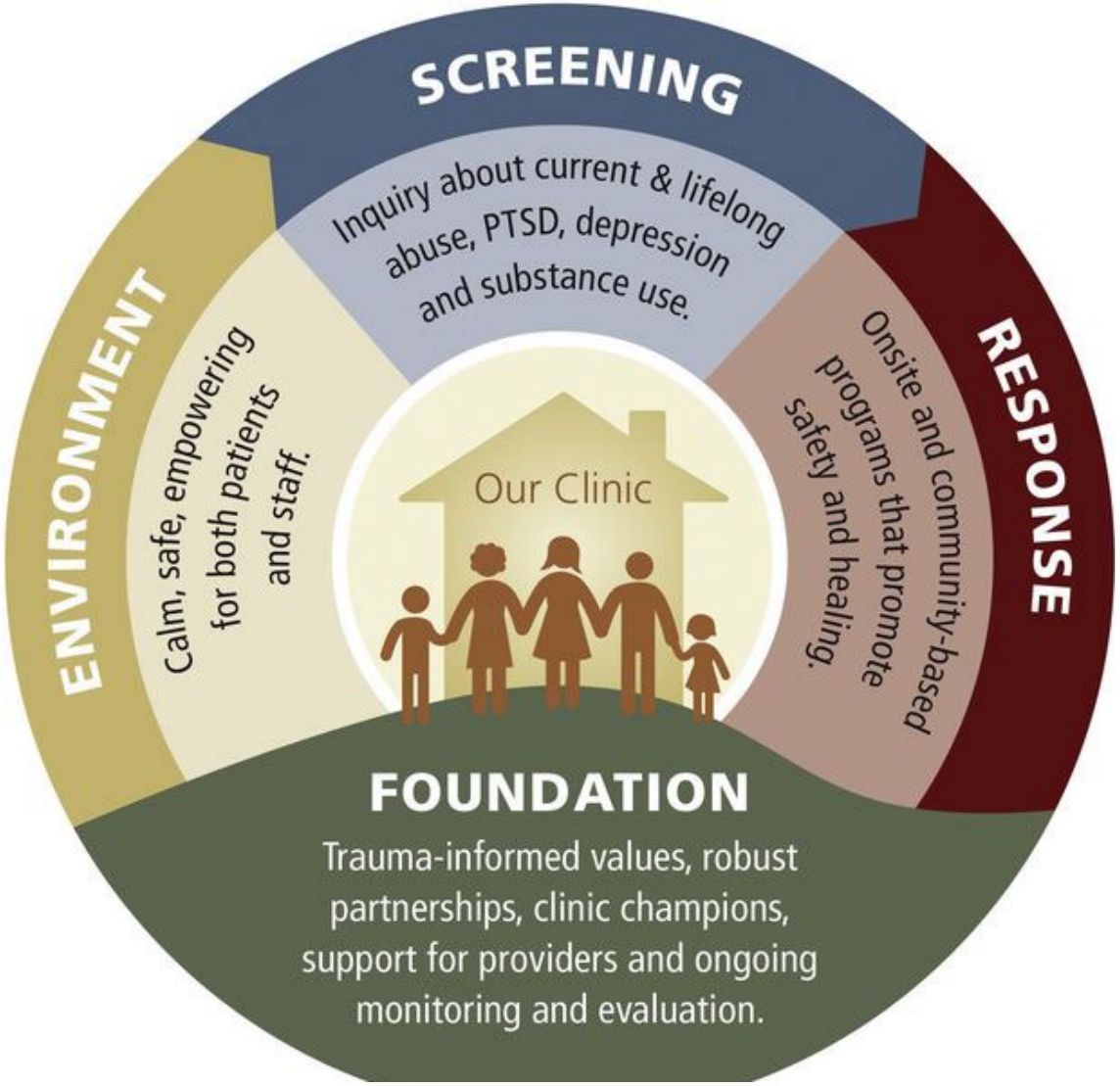
Trauma-informed *dementia* care

- Aged care (especially hospitals and residential aged care) has a **heavily biomedical focus**
- Psychological literacy of the sector is low
- Not enough psychologists, social workers, other mental health providers
- Trauma-informed care is a ***top-down*** approach



Trauma-informed dementia care

What gets in the way?

Restore power	Create safety	Build self-worth
Low psychological literacy	Inadequate crisis protocols	"Doing for"
Limited or no choice	Restraints	Limited or no choice
Not asked for feedback	Environmental triggers	Disrespect, lack of empathy
Staff not afforded flexibility	Staff not sure how to de-escalate	Staff self-care is not normalised, routinised
Not asked about needs / preferences (or not asked in the right way)	Assessment processes that are 'activating'	No time, skills to understand behaviour
	Staff not adequately supported	

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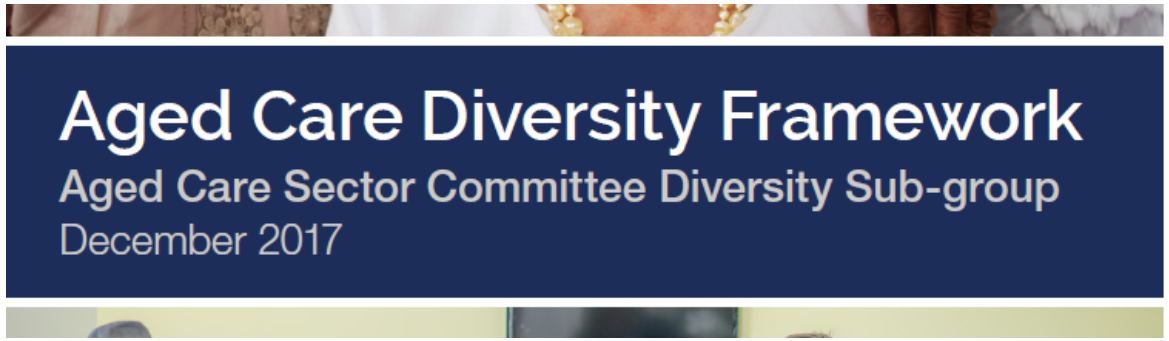
Policy imperative



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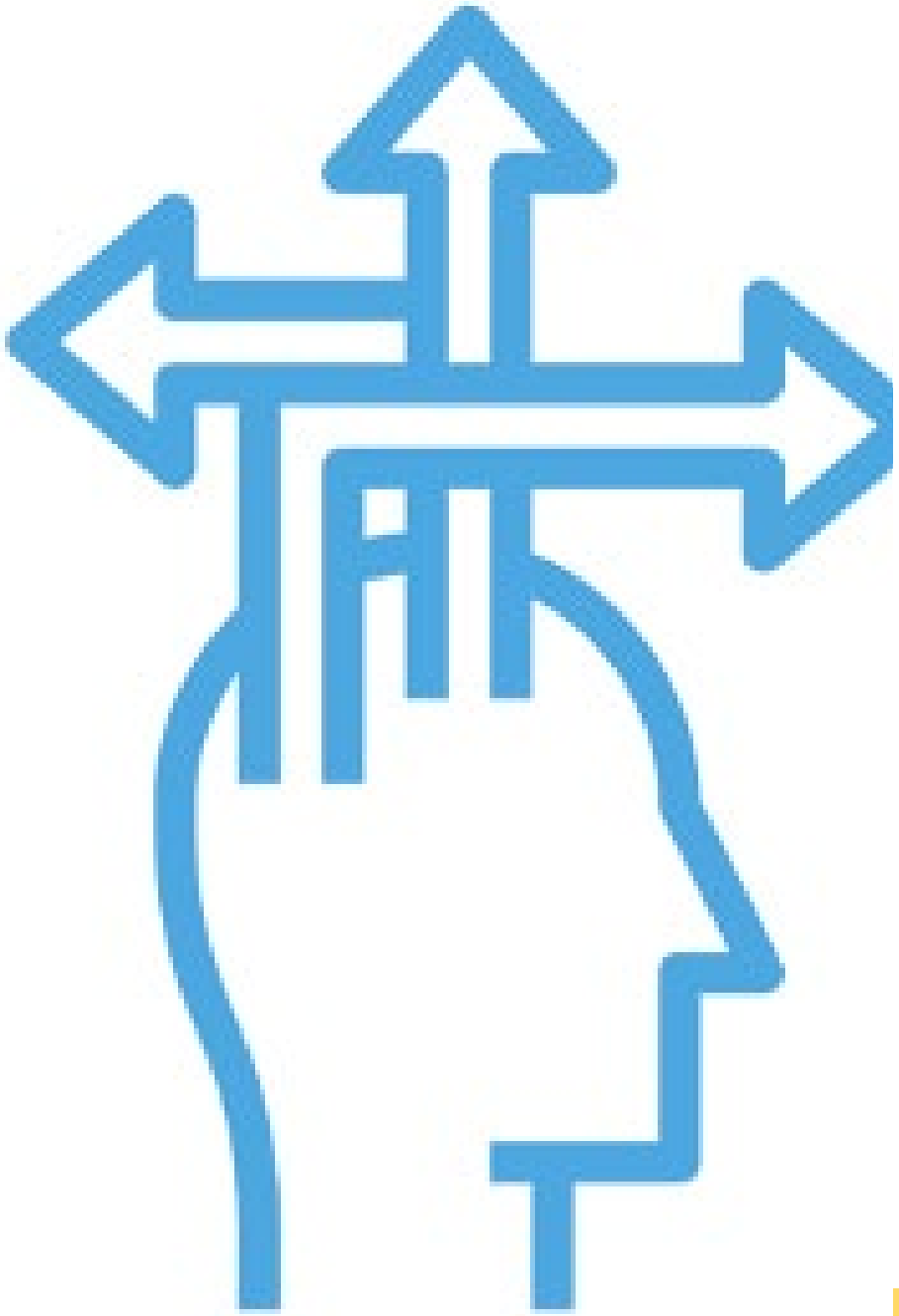

Trauma-informed dementia care services

- Organisational policies, procedures that clearly describe what to do where a trauma survivor presents
- Baseline training for *all staff* (including administrators)
- Opportunities for tailored care, choice, control
- Psychological/counselling/social work support OR clear referral pathways

Trauma-informed dementia care services

Maintain access to psychological or counselling supports

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Trauma-informed dementia care services

Consider the environment

- Quiet, spacious environment with opportunities for privacy
- Preferences for locks, meals, celebrations, room configuration will vary
- Flexible environments are most successful
- If therapist involved, discuss avoidance

Trauma-informed dementia care professionals

Finding out what you need to know: stick to the CURRENT impacts.
What are the **trauma-related needs**?

"Is there anything about your past that might affect your care, that you would like us to know?"

"Do you have any important preferences or requests that would ensure you feel safe while we provide care?"

Trauma-informed dementia care professionals

Finding out what you need to know: don't be afraid

If distress occurs:

1. Grounding

Trauma-informed dementia care professionals

Finding out what you need to know: don't be afraid

If distress occurs:

1. Grounding

2. Reassure that details **will not be shared** without their permission

3. Do they have a **therapist**?

4. Who can support them **right now**?

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Trauma-informed dementia care professionals

Finding out what you need to know when they can't tell you

- Ask family, support people
- Have traumatic experiences on your mental checklist
- Pay attention to patterns of behaviour, triggers – what do they tell you?
- Team debriefing after an incident – what came earlier that day?

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Trauma-informed dementia care professionals

Maximise choice, control, autonomy

- Choice in all things
- Accommodate preferences wherever possible (be creative)
- Consider the long term effects of trauma: lower schooling opportunities, literacy, digital literacy, wealth, avoidance
- The person is the driver, decision maker in all things

Trauma-informed dementia care professionals

Build trust

Ask for permission before touching belongings, entering rooms

Work in reliable ways – be consistent, on time, transparent

Respect preferences as far as possible

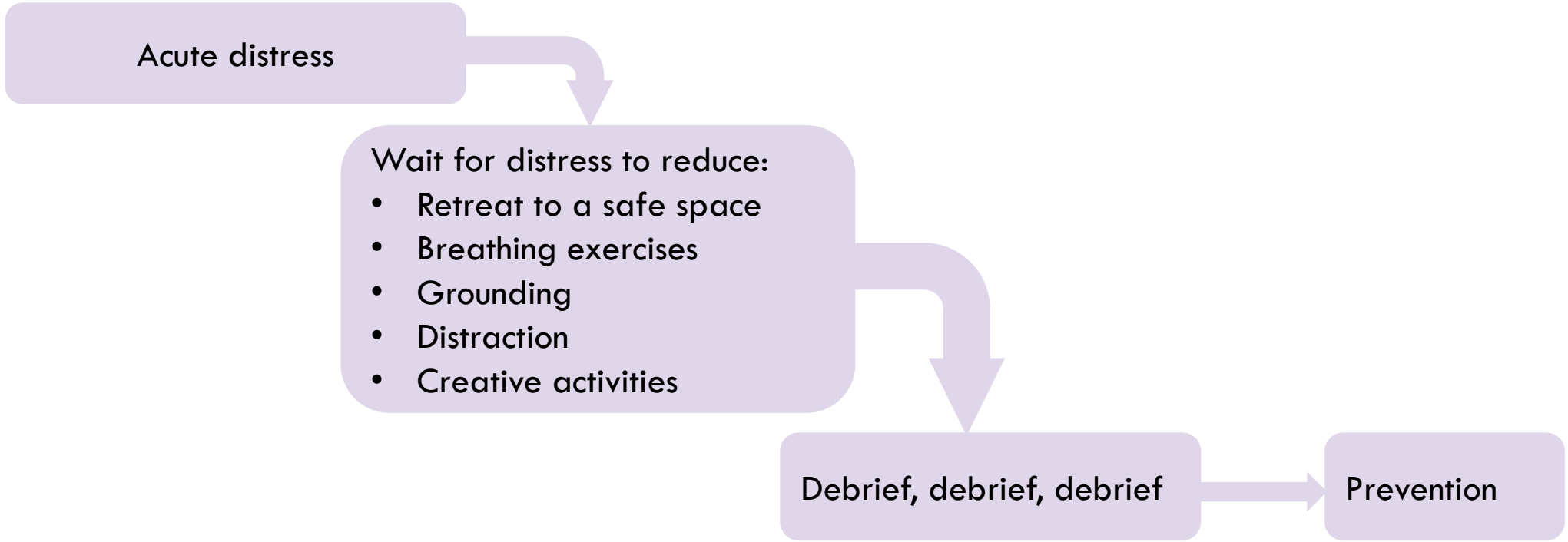
Always explain what will happen before it happens

Present security clearances when asked

Use the person's name

Trauma-informed dementia care professionals

Reducing distress



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Trauma-informed dementia care professionals

Share what you learn

- Many care settings lack ‘vertical’ information sharing
- Direct care staff often learn the most

- Care plans should be dynamic, forever updating
- Share with permission, where relevant

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Trauma-informed dementia care professionals

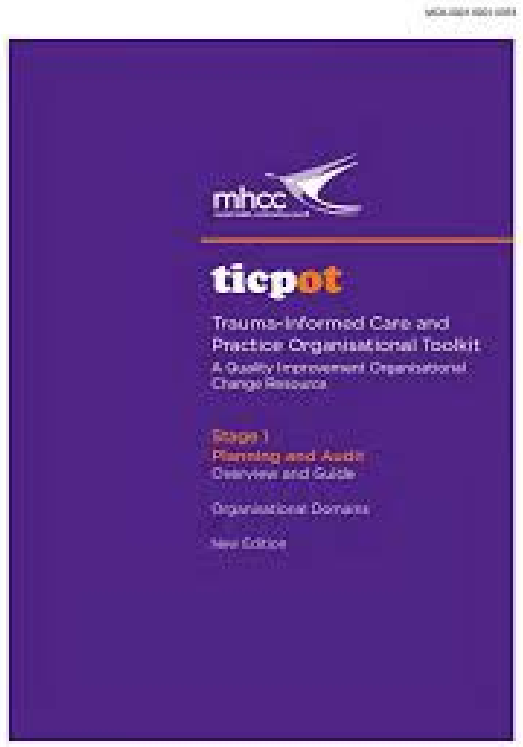
Self-care

- Caring for trauma survivors can be tough
- Being ‘rejected’ hurts, affects how you care
- Self-care is central to trauma-informed care

Stephen

- Earlier access to diabetic care – prevention
- Care provision in ways that meet Stephen halfway
- Seeking information in safe ways
- Debriefing after incidents to piece together what is learned
- Access to counselling and/or psychological support
- What else?

More reading



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https://www.phoenixaustralia.org/aged-care/aged-care-workforce/

https://www.flinders.edu.au/college-education-psychology-social-work/our-research/safe-inclusive-aged-care-forgotten-australians

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Thank you! Questions?

Contact:
08 8201 3058
monica.cations@flinders.edu.au

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"Excuse me, is this the Society for Asking Stupid Questions?"

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