Unspoken Histories:
Providing PCTI Care to Older Adults with Dementia

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Presenters



Gigi Amateau



Andrea Korsunsky



Alana Knoppow

Objectives

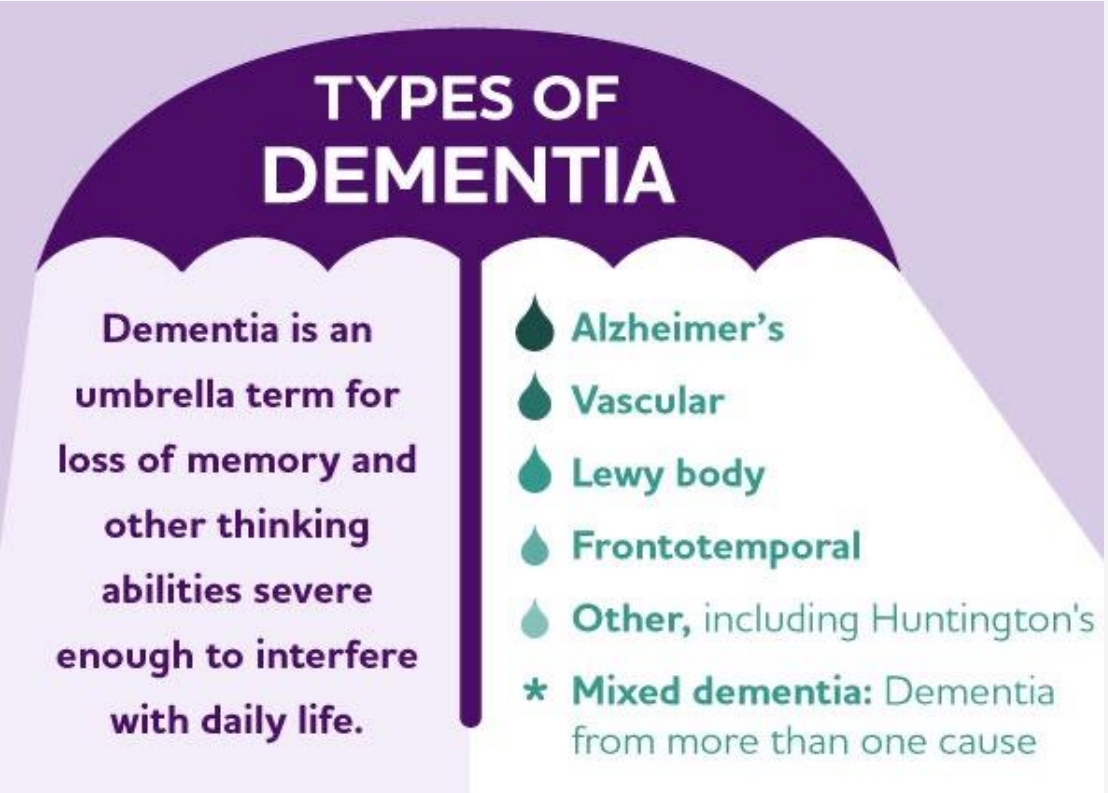
1. Identify areas to improve your organization's care environments and minimize re-traumatization.

2. Recognize an individual's triggers regardless of knowing their history of trauma.

3. Apply the PCTI strategies to provide care to support autonomy and agency for people we care with.

What is Dementia?

- An umbrella term to refer to a group of diseases
- Alzheimer's disease is the most common form of dementia
- NOT a "normal" part of aging



Alzheimer's Association, 2025

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Narrative Care: A Person-Centered, Trauma-Informed Framework

Gigi Amateau, PhD

Thinking narratively is another tool for communicating and caring with people with dementia.

- Storytelling is fundamental to being human.
- Our life stories are composed of facticity and possibility.
- We each exist in time: past, present, future.

"We age biographically as much as we age biologically, psychologically, and socially."

Kenyon, Clark, & de Vries, 2004

Narrative Concepts to Inform Our PCTI Caring with People with Dementia:

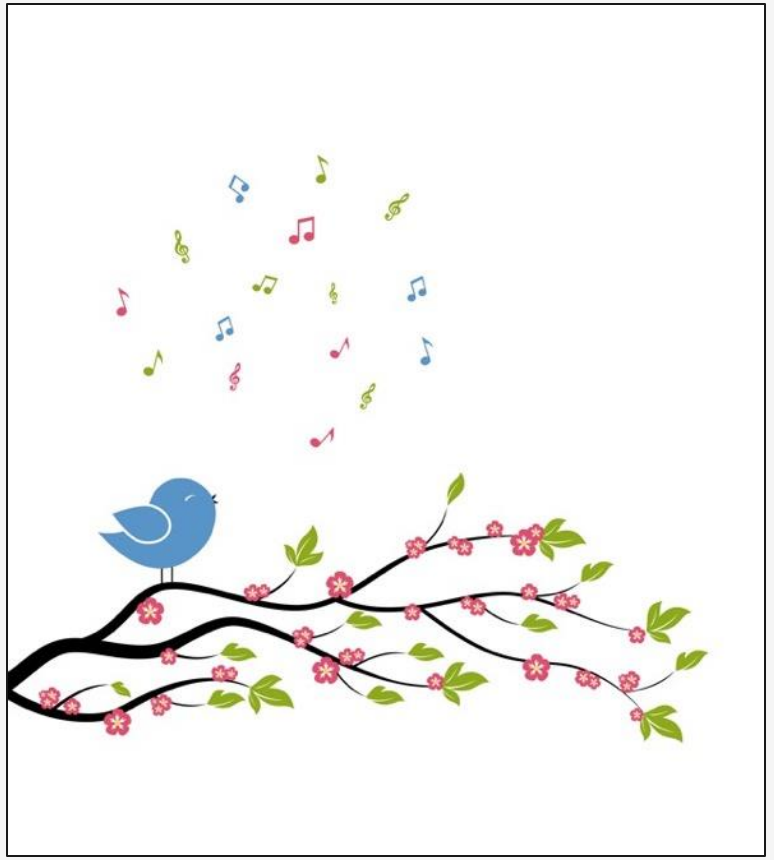
1. Narrative / Story
2. Narrative agency
3. Embodied narrative
4. Big Stories / Small Stories
5. Narrative Environments
6. Narrative care

"We are all narrative beings."

Berendonk et al.; Randall and Kenyon; Blix

1. What is Narrative?

- An expression of life experiences, memories, and reflections that shape identity and bring meaning to a lived life
- Often a collaborative, interactive process of recalling, recounting, and co-construction of stories
- A way of experiencing, relating, thinking, and ultimately, being in the world
- Not only a product (story) but also a process (creating)
- A composition woven from time, poetics, history, culture, relationships



Berendonk et al., 2017

Broadening Our Perspectives

- Stories without a beginning, middle, end structure
- Unexpressed or silent stories (shadow stories)
- Inconsistent, incomprehensible, or incomplete stories
- Stories without coherence to us
- Embodied stories



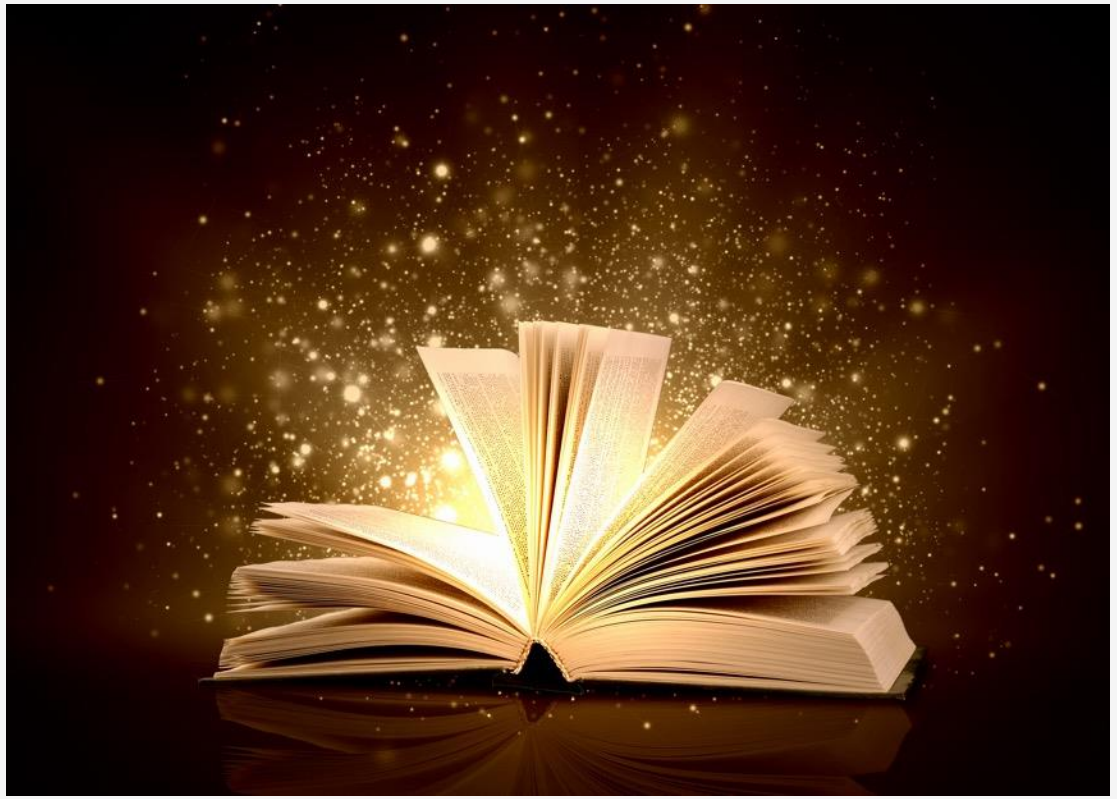
Berendonk et al., 2017

2. Narrative Agency

Ability to express oneself in a way that can be recognized

+

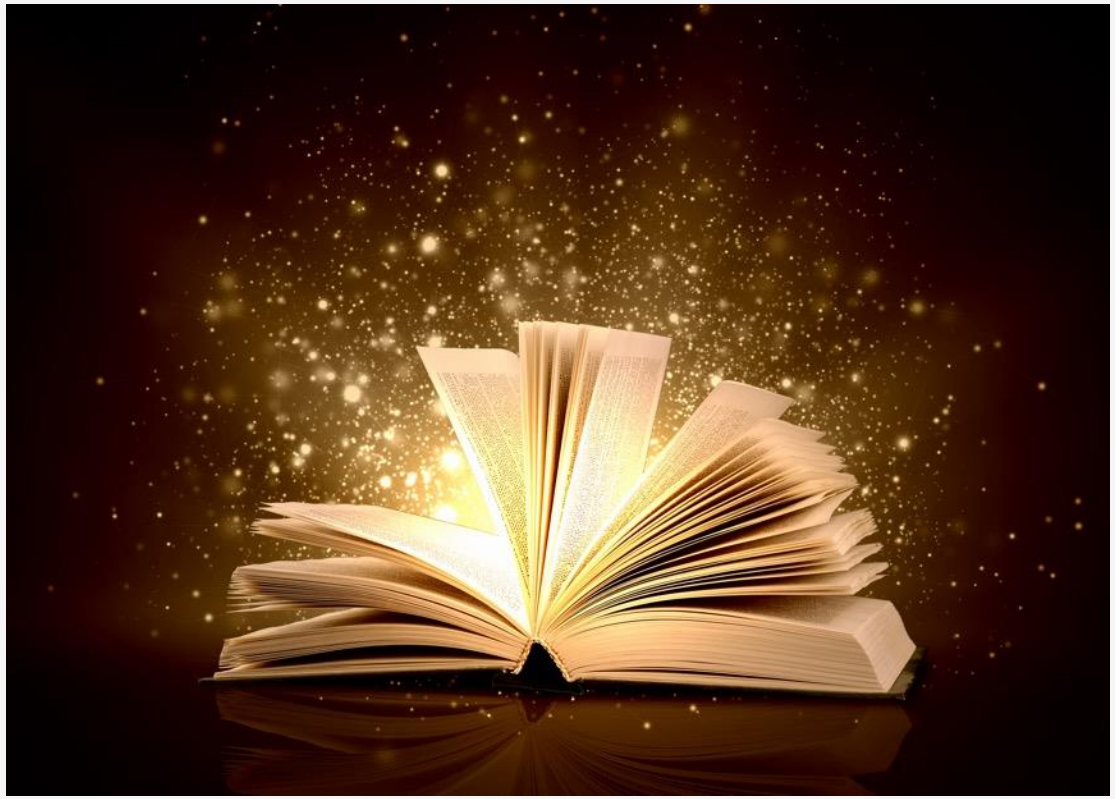
The ongoing opportunity to express oneself in community



Villar & Westerof, 2023

3. Embodied Story

- Experiences may not always be expressed verbally
- Telling AND showing
- Body memory/implicit memory
- Embodied self-hood: tacit, bodily knowing
- Storytelling is an embodied activity



Villar & Westerof, 2023

4. Big Stories vs. Small Stories

Big Stories

- Life story work
- The grand arc of oneself as an interpretable and uninterrupted narrative

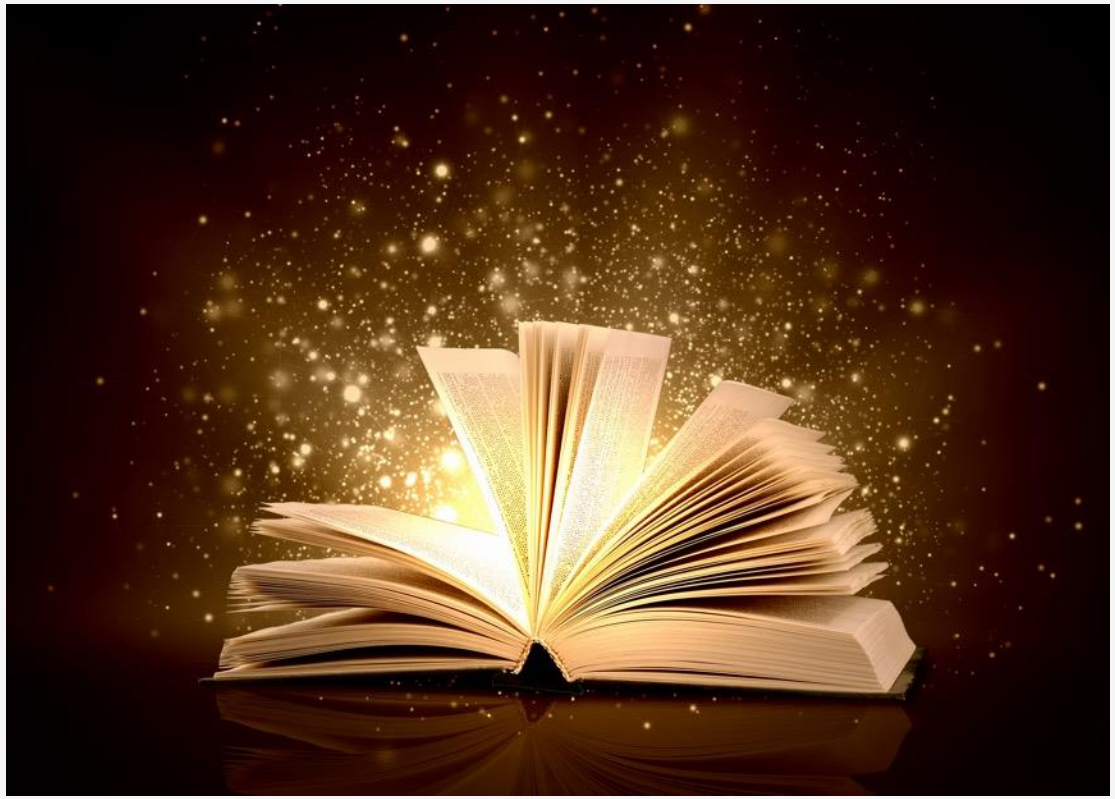
Small Stories

- Conversational
- Co-Constructed
- Everyday interactions

Villar & Westerof, 2023

Small Story Strategies Can Support Personhood, Connection, and Narrative Agency for People Living with Dementia

- Prompting and sustaining narrative where there are opportunities
- Recognizing and valuing non-verbal cues and embodied narratives
- Promoting narrative environments



Berendonk et al., 2017

5. Narrative Environments

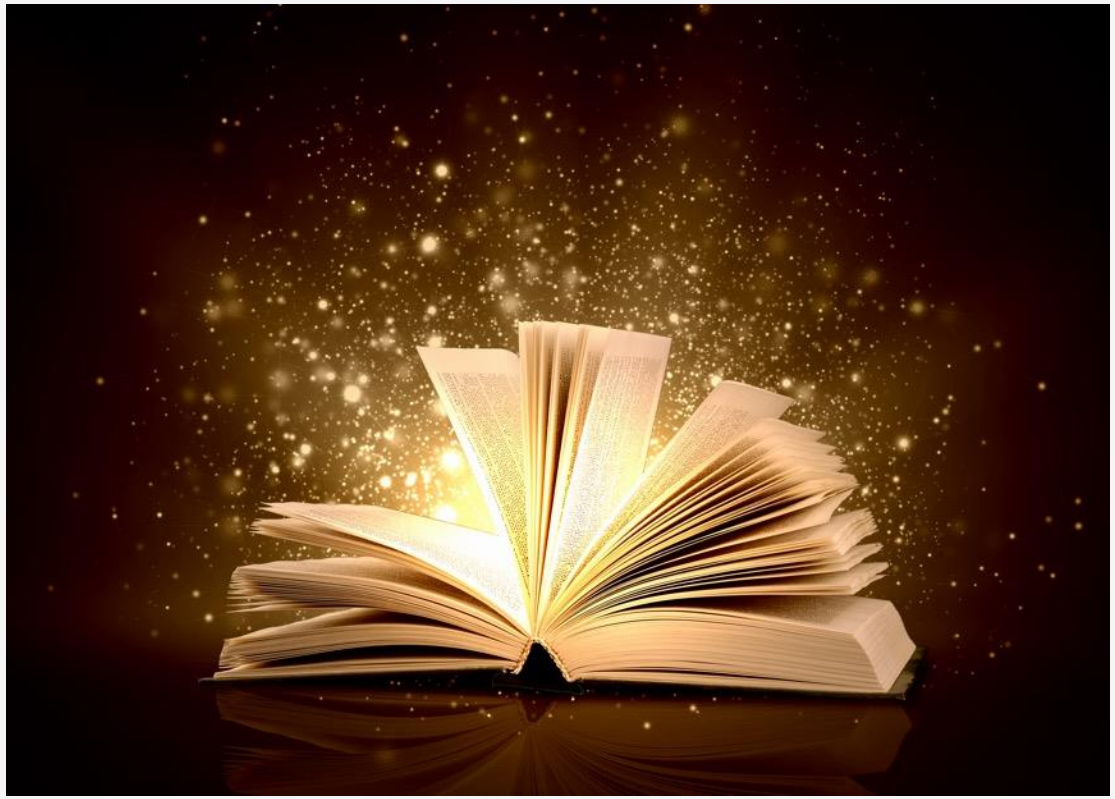
- Communities from which we derive our identities
- Families
- Groups we belong to
- Religion or Faith
- Geography
- Culture
- Neighborhood
- Facility/Community where we live
- Places where we stay or go for healing and recovery



Randall & Kenyon, 2004

6. Narrative Care

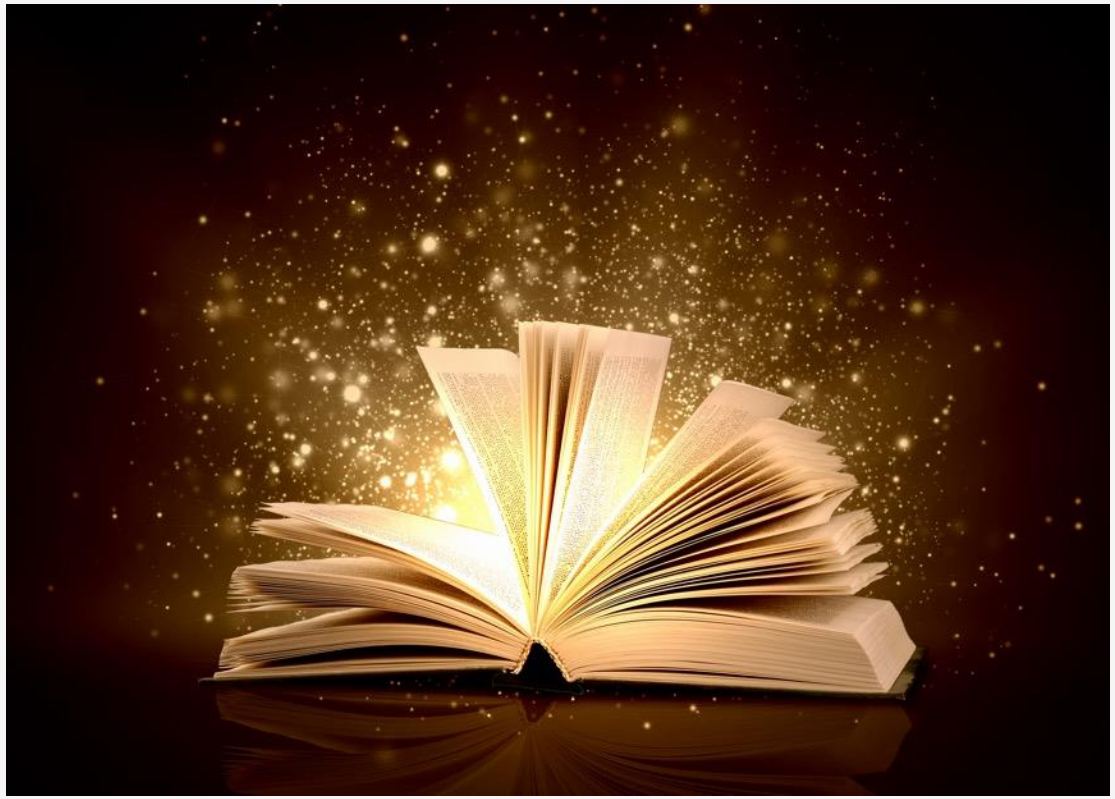
- Care itself is a narrative practice
- Participants and staff/providers are narrative beings
- Providers are co-creators of participant narratives
- Actively engaged in shaping participants' identities
- Acknowledging stories about past and co-creating new narratives in the present AND attention to the future



Randall & Kenyon, 2004

Narrative Care Skills

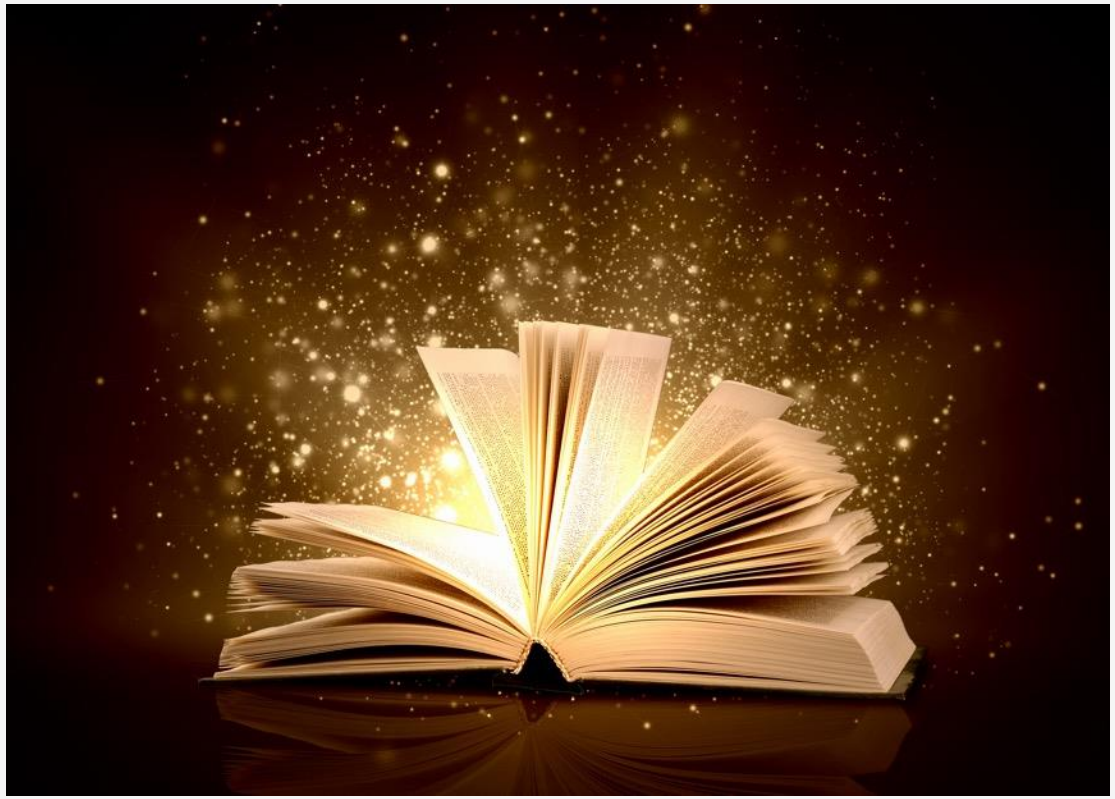
- Close listening
- Allowing our own emotions and feelings to be present, helpful, and informing
- Self-stilling, as we discern the course and source of care
- Taking time to reflect
- Imagination
- Playfulness
- World travelling (into the stories of others!)



Berendonk et al., 2017

Narrative Skills

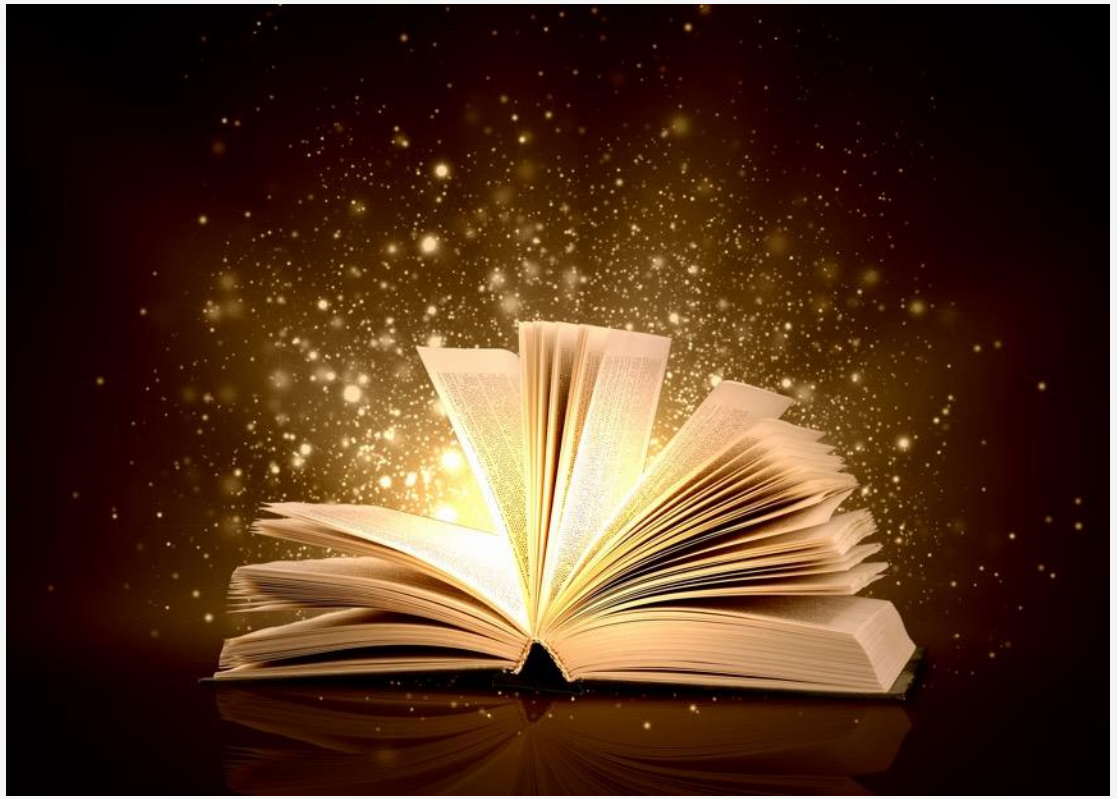
- Hints of importance verbal or embodied stories
- Repetitive retelling is important
- Interpreting embodied knowledge (specific clothing, routines, habits)
- Recognize narrators in all their diversity, strangeness, and splendor
- Stories without beginning, middle, or end



Randall & Kenyon, 2004

Avoiding Narrative Traps

- Valuing “small stories” as well as “big stories”
- Co-creating stories about the future not only the past
- Broadening our attention and valuing to include stories without a beginning, middle, and end
- Practice recognizing stories that are expressed without words
- Accepting that not all stories are expressed coherently [to us]



Randall & Kenyon, 2004

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Case Studies

Content Warning: SA

- In this story, what are the care tasks? What is the small story the staff are being asked to hear and honor?
- Whose story is this? What kind of story is Mrs. G. telling?
- Think about the 2 requirements for narrative agency. What do you notice?
- How might we proceed with honoring Mrs. G.'s voice and repairing connection? Who else might benefit from repair and connection?

Couzner et al., 2022

Meet Mrs. G., a 94-year-old woman was admitted after a fall at home. Her medical history includes a diagnosis of dementia. Mrs. G. would become distressed particularly during personal care, such as dressing and bathing. The distress was characterized by verbal and physical aggression including biting, spitting, punching, and grabbing staff. Four staff were required to assist Mrs. G. with personal care. Staff reported being afraid of her and would attend to her personal care very quickly.

Mrs. G.'s family were distressed by her behavior, telling staff that these reactions were out of character for her. Staff could not identify the triggers for this behavior until a family member asked for a private meeting and disclosed that Mrs. G. had experienced sexual abuse in the past.

Together, family and staff identified that personal care delivered by a male was triggering for Mrs. G. and staff efforts to persist with care were interpreted by Mrs. G. as disrespectful and untrustworthy.

These Feet Were Made for Dancing

- In this story, what is the care task? What is the small story practice?
- What do you notice about the dimensions of time?
- How has Cindy started a new story with Mrs. Johnson?

Mrs. Ada Johnson lives in assisted living facility. She has mild cognitive decline and appreciates time and patience to keep up with conversations. She also has pain in her feet. Over time, she has become much less mobile. Her doctor has suggested a daily application of OTC foot cream. Mrs. Johnson's regular CNA, Cindy, makes a big production of it: "These pretty feet have taken you from Norfolk to New York City and back, haven't they?" As Cindy massages the cream into the tops and bottoms of Mrs. J.'s feet, she also rubs her ankles and calves with lotion. " Yep, I'd say your feet take good care of you! 90 years of going wherever you want to go. Where to next?"

Mrs. Johnson takes a while to respond, then says, "Dancing!"

Cindy doesn't miss a beat. "Ohhhh, yes! The Valentine's Dance is Friday in the big room. They've hired a Motown cover band. Let's go!"

Marisol & Inez: Bonjour, Madam!

- What is the care task?
- What is the small story?
- What is the embodied story?
- How did Marisol participate in creating a story with Inez?
- Did, or how did, Marisol maintain personhood and narrative agency?

Marisol, diagnosed with dementia, lived at an assisted living facility in rural Virginia for the last 5 years of her life. She recently passed at the age of 80. For 30 years, she taught French at the county high school. She loved all things France! Her primary CNA, Inez, spoke simple French with Marisol every day, much to Marisol's delight. "Bonjour, Madam!" Inez would say at breakfast. Marisol's face would light up.

Whenever Inez would ask how are you by saying "Comment allez vous?" Marisol would laugh heartily. Two hundred people attended Marisol's graveside service. Inez was there in her beautiful bright pink scrubs and shimmery rose gold mask. The eulogy celebrated Inez's role in Marisol's life and the gathered community heard the story of how Inez spoke French with Marisol.

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Person- Centered, Trauma-Informed Care for People Living with Dementia

Andrea Korsunsky, BSW

Director, Center for Dementia Care

Founded in 1850

Jewish Family and Children's Services strengthens individuals, families, and community across the Bay Area and is a lifeline for people facing personal crises or challenges.

1,000

Holocaust survivors served annually throughout the Bay Area

2,800

Hours of care management, counseling, and consultation provided annually

Requires Special Attention: Trauma + Dementia

Dementia

Abilities affected by dementia:

- Judgment/reasoning
- Communication
- Orientation- unable to reference recent events to calm self
- Insight into current circumstances, limitations, and quality of life issues

Trauma

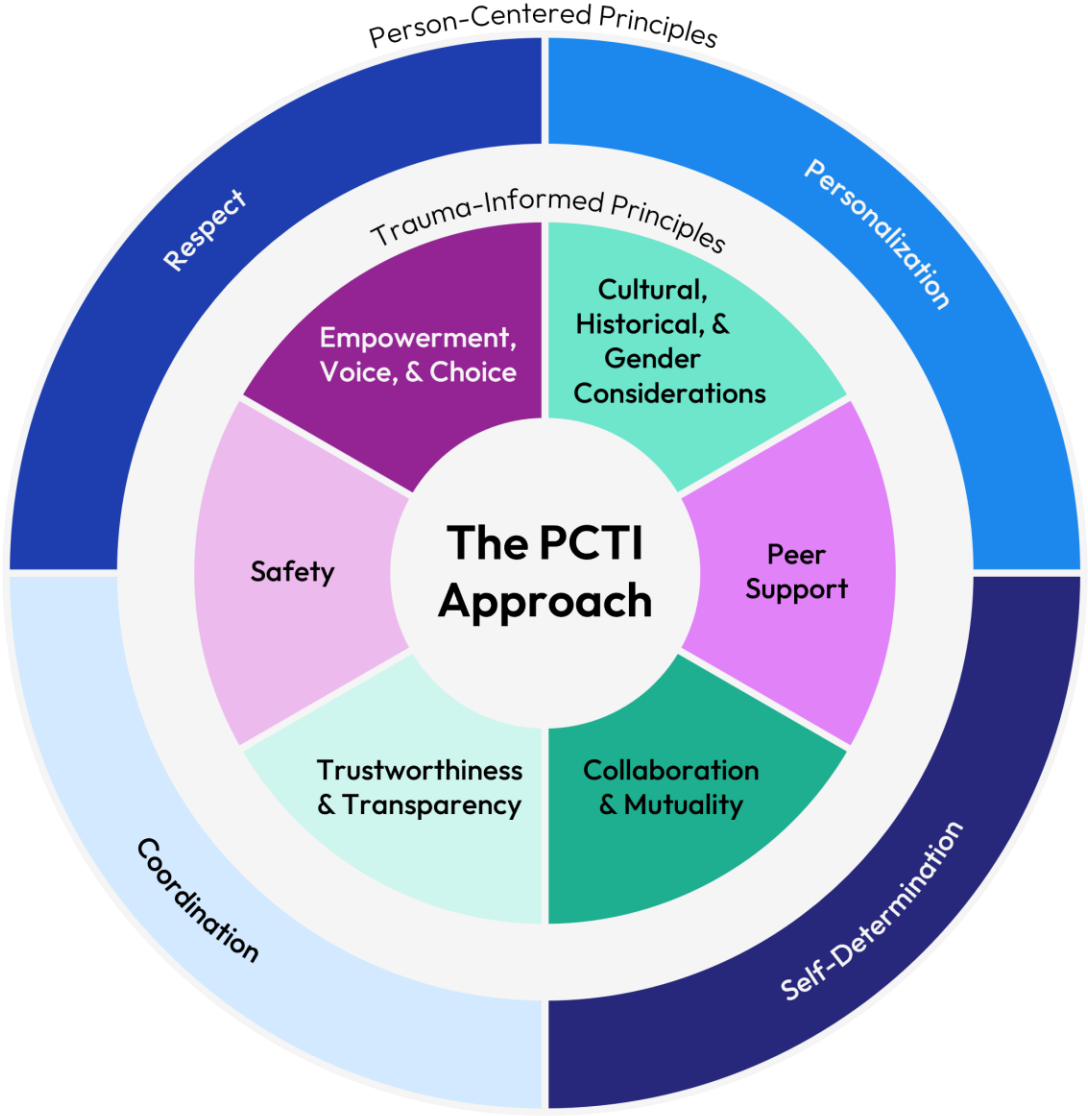
Abilities needed to cope with a trauma:

- Judgment/reasoning- to navigate getting help
- Communication- to process emotions
- Orientation/ability to reassure self in the moment
- Determination/survivor mentality

Applying the PCTI Approach

What does it mean to anticipate needs?

How do we recognize symptoms of trauma among clients with dementia?



Center on Aging, Trauma, and Holocaust Survivor Care, 2024

Common Practices to Avoid

- Limit-setting
- “Doctor’s orders”
- Strict boundaries related to time



Family Perspective

- Dementia affects the whole family for a prolonged period of time
- Stigma
- Dementia affects all aspects of a person's care needs—emotional, physical, financial
- Family dynamics/complicated relationships



Practical Approaches

- Apply PCTI: Best Practice
- Avoid Known Triggers
- Understand their reality – empower family members



Structuring Time

- Engaging in meaningful activities
  - Adapt existing interests and hobbies
  - Engage the senses
  - Instill a sense of purpose







Sympathy vs. Empathy

- Empathy is meeting them where they are
- Don’t try to fix everything
- Realistic expectations about outlook and emotions
- Driving!



Apply Best Practices

- PCTI approach
    - Understanding non-verbal cues and consider any background you may have, while reading body language
- Behavior is Communication
    - Responding to the emotion behind words
    - Anticipate needs



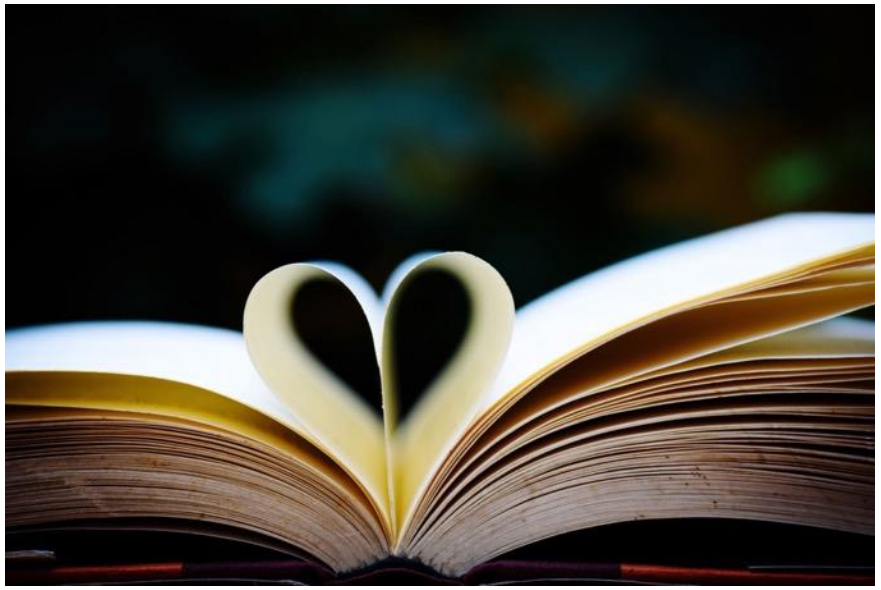
Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Person-Centered Principles

1. Respect

- This must be proven and demonstrated by your actions
  - Body language
  - Eye contact
  - Remaining flexible in your approach
  - Echo and acknowledge feelings



2. Personalization

- What's important to the individual in front of you?
- Consider their ideal outcome and find common ground.
- Normalizing vs. Generalizing



3. Self-determination

- Re-framing “help”
    - Instead of a caregiver- consider care partner
    - Instead of helping you do all the things you can no longer do, we are bolstering independence.



4. Coordination

- When building a program or service, consider first the experience of the client
    - What is it like to be introduced to a stranger?
    - What is it is like to have someone facilitate a conversation about your care needs
    - What is it like relying on someone else?



Coordination is all about anticipating the needs and feelings and ensuring that the service accommodates some of the obstacles

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Trauma-Informed Principles

1. Safety

- Utilized embodied storytelling to support engagement
- Be flexible and accommodate those needs from the beginning
- Show safety and support through body language
- Ask what safety means to the individual
- **View trauma related symptoms/behaviors as attempts to cope**



2. Trustworthiness and Transparency

- Be descriptive about your role as their advocate
- Ask questions
  - Ask the person with dementia what they feel is the best part of their day and integrate into the plan of care
  - Ask the same to the family member, separately
  - **Listen and echo what you hear**



3. Peer Support

- Normalize the situation
- Integrate follow-up support into your care plan/discharge plan
    - Ongoing support
    - Next appointment
    - Reminders
    - Group connection



4. Collaboration and Mutuality

- Communicate the care plan to all family members
- Strengthen existing support systems by facilitating communication and developing a plan
    - Support the care team with education to build skills
    - Help the family differentiate long time personality patterns and behaviors associated with dementia



5. Cultural Competency

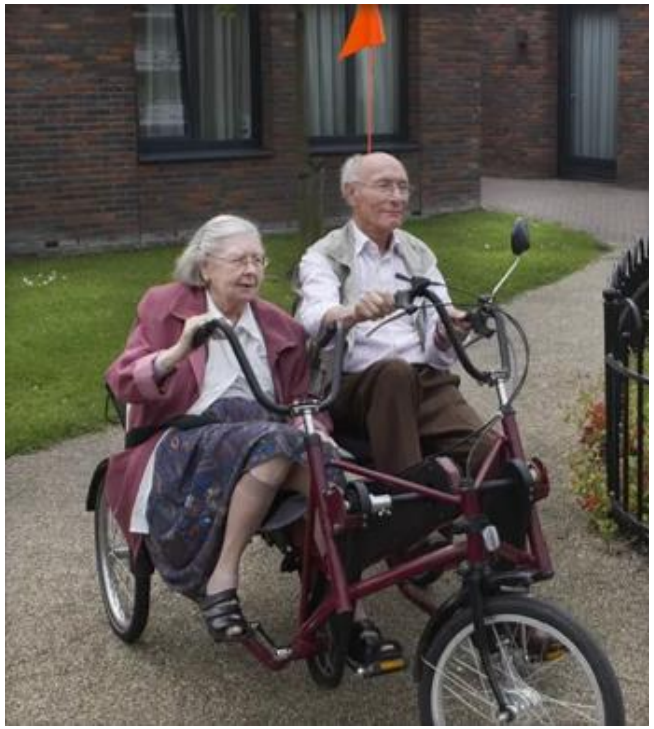
- Understand the background
- Avoid known triggers based on the person's own experiences
- Don't rely on the patient's ability to express verbally, and remain flexible as their thoughts and feelings fluctuate – avoid assumptions



6. Empowerment, Voice and Choice

Montessori Approach

Everything you do for me you take from me.



“What the hand does, the mind remembers”

"Watch me, now you try"

Seniors At Home
Better Care Starts Here

www.seniorsathome.org

SAN FRANCISCO	NORTH PENINSULA	SOUTH PENINSULA	MARIN COUNTY	SONOMA COUNTY
Miriam Schultz Grunfeld Building PO Box 159004 2150 Post Street San Francisco CA 94115	*Eleanor Haas Koshland Center* 2001 Winward Way San Mateo CA 94404	*Koret Family Resource Center* 200 Channing Avenue Palo Alto CA 94301	*Dr. George Sugarman Swift Building* 600 Fifth Avenue San Rafael CA 94901	1360 N. Dutton Ave. Suite C Santa Rosa CA 95401
415-449-3777	650-931-1860	650-688-3070	415-507-0564	707-571-8533

A PROGRAM OF JEWISH FAMILY AND CHILDREN SERVICES OF SAN FRANCISCO, THE PENNINSULA, MARIN AND SONOMA COUNTIES

Questions?

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

Thank You

Jewish Federations of North America

Center on Aging, Trauma, and Holocaust Survivor Care

References

Alzheimer's Association. 2025 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2025;21(5).

Berendonk, C., Blix, B., Randall, W., Baldwin, C., & Caine, V. (2017). Care as narrative practice in the context of long-term care: Theoretical considerations. International Journal Of Older People Nursing, 12(4), 1-9.

Blix, B. (2016). The importance of untold and unheard stories in narrative gerontology: Reflections on a field still in the making from a narrative gerontologist in the making. Narrative Works: Issues, Investigations, & Interventions, (6)2, 28-29.

Kenyon, G. M., Clark, P. G., & De Vries, B. (2001). Narrative gerontology : theory, research, and practice. Springer Pub.

Kenyon, G., Bohlmeijer, E., & Randall, W. L. (2010). Storying Later Life: Issues, Investigations, and Interventions in Narrative Gerontology (1st ed.). Oxford University Press, Incorporated.

Medeiros, K. de. (2014). Narrative gerontology in research and practice. Springer Publishing Company.

References

Rabin, C., Bedney, B., & Rubenstein, V. (2023). Aging With a History of Trauma: Strategies to provide person-centered, trauma-informed care to diverse older adults and family caregivers. Center on Holocaust Survivor Care and Institute on Aging and Trauma, The Jewish Federations of North America.

Randall, W., & Kenyon, G. (2004). Time, story, and wisdom: Emerging themes in narrative gerontology. Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 23(4), 333-346.

United States Substance Abuse and Mental Health Services Administration (2014) SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf

Villar, F., & Westerhof, G. J. (2023). A conversational, small-story approach to narrative care for people with dementia living in care institutions: Strategies and challenges. Journal of Aging Studies, 64, 101105–101105. https://doi.org/10.1016/j.jaging.2023.101105

Wonderlin, R. (2025) https://rachaelwonderlin.com/