cje SeniorLife

Jewish values for positive aging

Welcome

Our Mission

To enhance the quality of life and facilitate independence of older adults

"A test of a people is how it behaves toward the old" **Abraham Joshua Heschel**

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Holocaust Survivors & Dementia: What We Know and Best Practices

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Survivor Demographics

- ~180-200,000 survivors worldwide (most in Israel)
- ~50-80,000 in the U.S.
  - **80% from the former Soviet Union (FSU)**
- Longevity – Survivors may live longer than same-age peers, but with more acute & chronic health conditions (2019, JAMA)

Holocaust Community Services (HCS)

- Founded in 1999 as an inter-agency program of the **Jewish United Fund (JUF) of Metropolitan Chicago.** Administered by **CJE SeniorLife**

- **HCS** provides holistic services for Holocaust survivors
  - Financial Assistance for home care, medication, food, emergencies
  - Case management & counseling
  - Socialization & events
  - Support groups & wellness classes
  - Reparations assistance
  - Education & advocacy

  2023 data through September:

  - Serving nearly 1,800 survivors
  - 95% from FSU
  - Ages 79-104 (average 87.5, 25% over 90)
  - Attrition 2023 to date: 140 survivors (91 died)
  - Dementia: ~230 identified

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Holocaust Community Services

What is Trauma?

- Results from real or perceived threat to life or well-being
- Physical, emotional, spiritual, or psychological
- Has lasting effects on health and well-being
- Can arise from a one-time event or chronic exposure to adversity

Symptoms of Trauma

- Intrusive memories, including flashbacks and nightmares
- Avoidance of people, places, or thoughts
- Negative changes in thinking and mood, including memory problems and feelings of detachment, dysthymia/ depressed affect/anxiety
- Hypersensitivity in physical and emotional reactions including startling easily, being mistrustful or on guard, and insomnia

Delayed Onset PTSD

- Following a latent, symptom-free interval, lasting up to 4-5 decades, early exposure to traumatic events notwithstanding, new stresses, threats and/or transitional crises of aging may reactivate dormant, subclinical reactions not previously recognized or diagnosed. (Dasberg et al, 2001; Grossman et al, 2004)

Additional contributors to delayed onset:

- Decrease of physical and mental resilience - less able to “ward off”
- Decrease of financial and social resources - less support and safety
- Interaction of trauma with normative processes of aging
- Interaction with dementia

Person-Centered, Trauma-Informed Care (PCTI)

- Administration for Community Living (ACL) coined the term in 2015 to describe a holistic approach to providing services.

- Goal is to promote dignity, strength, and empowerment of trauma survivors.

- Many similarities with the person-centered Hogeweyk care model.

Excerpted from: https://acl.gov/programs/strengthening-aging-and-disability-networks/advancing-care-holocaust-survivors-older

Trauma Informed Care – The 4 Rs

REALIZES	the widespread impact of trauma and understands potential paths to recovery
RECOGNIZES	the signs and symptoms of trauma in clients, families, staff, and others involved with the system
RESPONDS	by fully integrating knowledge about trauma into policies, procedures and practices
RESISTS	re-traumatization

5th R: Resilience

Trauma-Informed Agencies

5 PRINCIPLES OF PCTI

You can create a trauma-informed environment using these five principles:

Safety
Creating areas that are calm and comfortable

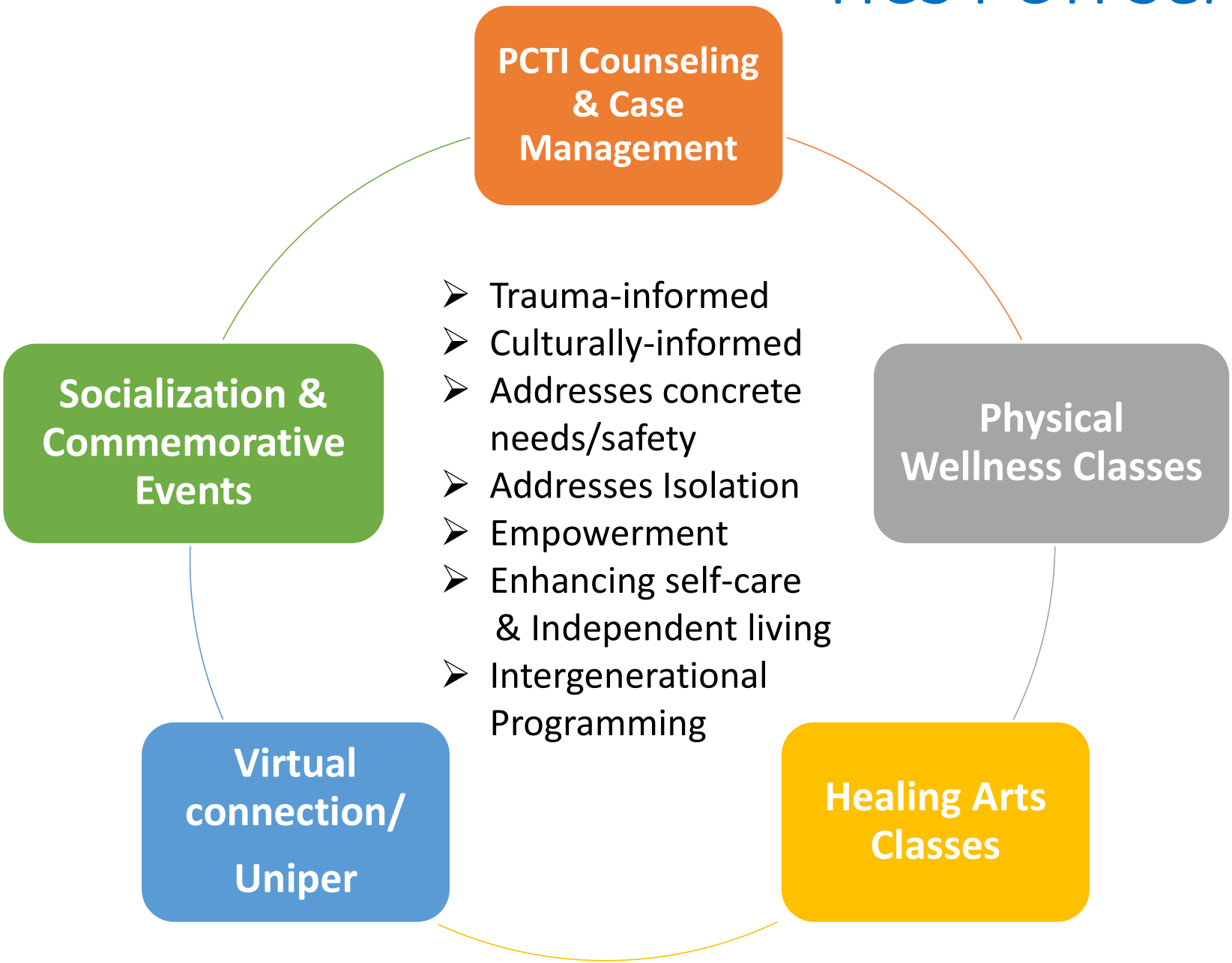
Choice
Providing an individual options in their treatment or service.

Empowerment
Noticing capabilities in an individual

Cooperation
Making decisions together.

Trustworthiness
Providing clear and consistent information.

HCS PCTI Services



Survivor Experiences: Before the War

- Different experiences BEFORE the war
  - Raised in different countries and cultures across Europe, the former Soviet Union, North Africa
  - Different languages and religious observances
  - Urban and rural
  - Educated and uneducated

Survivor Experiences: During the War

- Different experiences DURING the war
  - Ghettos and forced-labor camps
  - Concentration or extermination camps, death marches
  - Hiding or living under false identity
  - Sites of mass killings (witnessing, surviving, losses)
  - Evacuations and fleeing
  - Partisans & resistance movements
  - Alone or with others

Survivor Experiences: After the War

- Different experiences AFTER the war
  - Many who survived came to the U.S. and lived productive lives – some came as young adults and some much later
  - **FSU survivors** were older; lost professional identities, harder to adapt to language, decades of Soviet regime, poor health care, ongoing antisemitism, and late life immigration
  - Some have family and social supports/resources and some do not
  - Some want to share their experiences and some do not

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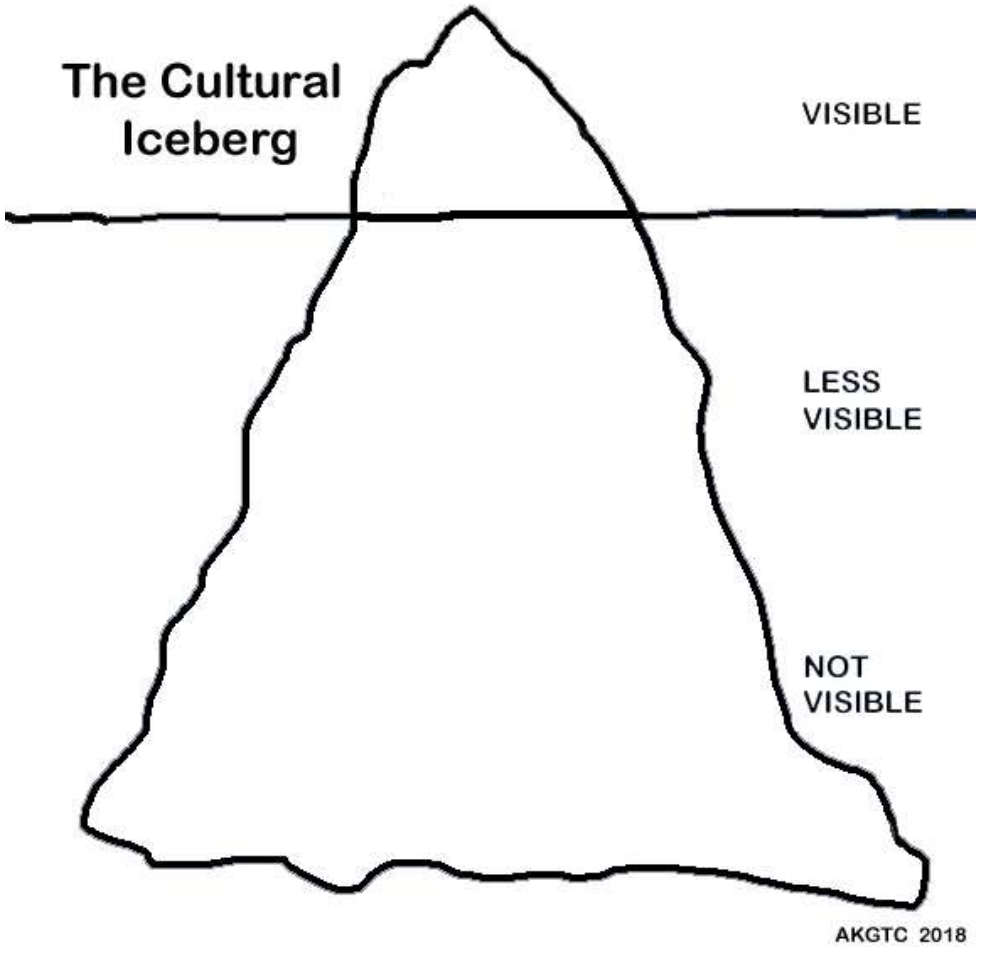
Holocaust Community Services

The Cultural Iceberg



Shared Experiences of Trauma: External

- Constant threat of death
- Overwhelming sensory input, loud noises, bombardment ; smells
- Exposure to unbearable weather
- Extreme deprivation -- thirst and hunger
- Prolonged physical & psychological abuse
- Lethal hard labor
- Extermination of entire families and communities
- Estrangement from humanity

Shared Experiences of Trauma: Internal

- Prolonged state of helplessness and vigilance
- Deprivation of individuality
- Loss of normalcy - developmental phases, schooling, boundaries, normative relationships
- Bereavement over loss of loved ones & communities
- Guilt over surviving when others did not
- Stress and stigma of immigration
- Anxiety about lack of resources
- Vulnerability to transitions

Challenges Faced by Aging Survivors

- Same challenges that most elderly face, but with a layer of traumatic history that can complicate these issues:
  - Failing health
  - Hospitalization and institutionalization
  - Poverty
  - Loss of friends, family, independence, lifestyle
- Assess for:
  - Cognitive disorders – memory decline, dementia
  - Affective disorders – depression and anxiety
  - Differential diagnosis is important

End-of-Life Issues/Dynamics in Survivors

- Lack of observation and experience with natural deaths
- Lack of family - aging role models
- Reluctance to do Advance Directives – “do not want to participate in my own death”
- Drive to active intervention; don't let them suffer
- Feeling invincible – I survived “that” … so I will live forever
- Triggering medical procedures & decisions
- Who will “remember” and tell the story?

Resilience & Protective Factors

Individual factors

- Temperament & personality traits
- Genetic predispositions & physical characteristics
- Cognitive characteristics (e.g. intelligence, processing)
- Individual skills & talents

Relational/Interpersonal factors

- Familial warmth and stability
- Familial assets & resources
- Interpersonal relationships & affiliations

Group/Collective factors

- Social & community integration and support
- Identification with groups
- Cultural stability, values, beliefs, religious observance/faith

Dementia & Trauma

Dementia and Trauma

- Sequelae associated with trauma paired with dementia symptoms: memory loss, personality changes, mood changes, loss of social skills & inhibition
- Some may have poor recall of traumatic events, but sense of safety still impacted throughout life
- Others may recall past trauma vividly but have lost the coping strategies developed prior to onset of dementia

Research Findings
Dementia Risk and Prior Trauma

- Haifa University study (Kodesh, 2019) examined risk of dementia among Holocaust survivors.
- Chance of survivors developing dementia was 21% higher than of those who did not experience the Holocaust.
- Consistent with other research demonstrating survivors have more cognitive impairment than their peers. *(Barel, Van IJzendoorn, Sagi-Schwartz, & Bakermans-Kranenburg, 2010; Sperling 2011)*
- Extreme adversities of genocide thought to heighten the vulnerability to dementia in later life.

Research Findings
Dementia Risk and Prior Trauma

- However, Ravona-Springer, Beeri & Goldbourt found the opposite.
- Relatively large sample size, longitudinal design.
- Surviving the Holocaust "might carry survival advantages that are associated with protection from dementia and mortality."
- "...for Ravona-Springer… survival ensures survival." (Vice, 2019)

Research Findings
Dementia Risk and Prior Trauma

- Further research needed to fully understand the mechanisms involved and establish more definitive conclusions.

- Regardless, all survivors fall somewhere along the vulnerability → resilience continuum.

- Where they fall will affect the aging process, adaptation to aging-relating changes and losses, & experience of dementia, whether or not they are predisposed to it.

Importance of Aging in Place for Survivors with Dementia

- Aging in place particularly important for survivors of the Holocaust.
- Institutional settings can present challenges due to the potential reactivation of traumatic memories.
- Where a nursing home or other institutional setting is the only option, relocation stress will likely be heightened.
- Creation of familiar, safe, home-like environment is key
- Attention to triggers is essential

What Are Triggers?

- Stimuli that remind a person of a traumatic event or experience
- Impossible to know what will trigger any given person, at any given time
- Can set off a series of physical, physiological, psychological, and/or emotional reactions
- Different triggers for different people even if they experienced the same event

Indicators of Re-traumatization

Less able to trust and cooperate	Fear of carers, reluctance to accept help, refusal to bathe
Mood changes; sudden or fluctuating	Lability, anxiety, depression (but r/o delirium)
New/increased physical complaints	New health condition? Somaticizing?
Hyper-arousal and vigilance	Not “turning off” TV, scanning surroundings, easily startled
Sleep difficulties	Insomnia, nightmares, hypersomnia (sleep as avoidance)
Memory disturbances	Flashbacks, worsening cognition due to stress
Hoarding as if preparing for emergency	Worry about food, meds, supplies
Increased difficulty communicating	Less verbal or coherent; some shut down

Avoiding Triggers

- **Uniformed staff.** Healthcare providers or security personnel can trigger memories of persecution and evoke fear or distress.
  - Allow staff to wear casual street clothing to create a less intimidating environment.
- **Waiting in line.** For example, to enter dining room.
  - Plan entry to activities, meals and health services so lining up is not necessary.

Avoiding Triggers

- **Physical discomforts** such as being cold, hungry or thirsty.
  - Be attentive to physical needs, including nonverbal cues of discomfort
  - Train staff to routinely ask, Are you comfortable? Are you hungry?
  - For those not be able to name a discomfort, offer a drink, a sweater.

- **Loud noises or sudden movements** may remind survivors of wartime experiences, potentially leading to anxiety or panic.
  - Create a calm, quiet environment. Minimize unnecessary noise, such as loud conversations or loudspeaker announcements.
  - Provide staff footwear that is quiet on the floors.
  - Encourage staff to approach individuals calmly, gently and to avoid sudden movements that may startle them.
  - Use incandescent rather than florescent lighting.

Avoiding Triggers

- **Medical visits, procedures, daily care** may rekindle memories of experimentation during the Holocaust as well as a general sense of being treated like an object, with loss of agency.
  - Promote personal introductions. Encourage staff to introduce themselves by name, role, and purpose of visit to establish a more personal connection and reduced sense of authority.
  - Respect personal boundaries. Ensure that personal space is respected, and privacy is maintained. Communicate with sensitivity and ask for consent before initiating any physical contact.
  - Be sensitive to how a new illness or worsening chronic condition may increase a survivors' sense of vulnerability.

Avoiding Triggers

- **Institutional rules and routines**. Strict rules or rigid routines can remind survivors of the oppressive and dehumanizing conditions they faced during the Holocaust.
  - Promote autonomy and choice. Whenever possible, involve the individual in decision-making regarding daily routines, activities, or personal preferences.
  - Foster institutional flexibility and individualized care: Whenever feasible, allow for personalized schedules and adapt institutional routines to accommodate individual needs and preferences.
  - If more rigid structure is necessary, such as during a COVID lockdown or scheduled group activity, maximize personal control and freedom of movement as much as possible.

Working with Aging Holocaust Survivors

- **Offer reassurance and understanding**, letting survivors know that their feelings are valid and that they are not alone.
- **Offer comfort and support** through gentle touch (with permission), soothing words, or familiar objects.
- **Engage the individual in activities** they enjoy or find calming, such as listening to music, singing a song, art therapy, or spending time in nature.
- **Be self-aware** of your own feelings and responses and talk with others to discuss these emotions
- **Practice self-care!**

Working with Aging Holocaust Survivors

- **Redirect the focus** to a positive or engaging activity that can help shift attention away from intrusive memories. This can include reminiscing about positive memories or engaging in sensory stimulation.

- **Avoid confrontations.** Avoid challenging or contradicting the individual's delusions or flashbacks directly, as it may increase their distress. Instead, focus on providing emotional support and reassurance. “I’m here with you.”

- **Engage in calming techniques.** Use techniques such as deep breathing exercises, guided imagery, grounding techniques, or soft music to help create a calming atmosphere and reduce anxiety.

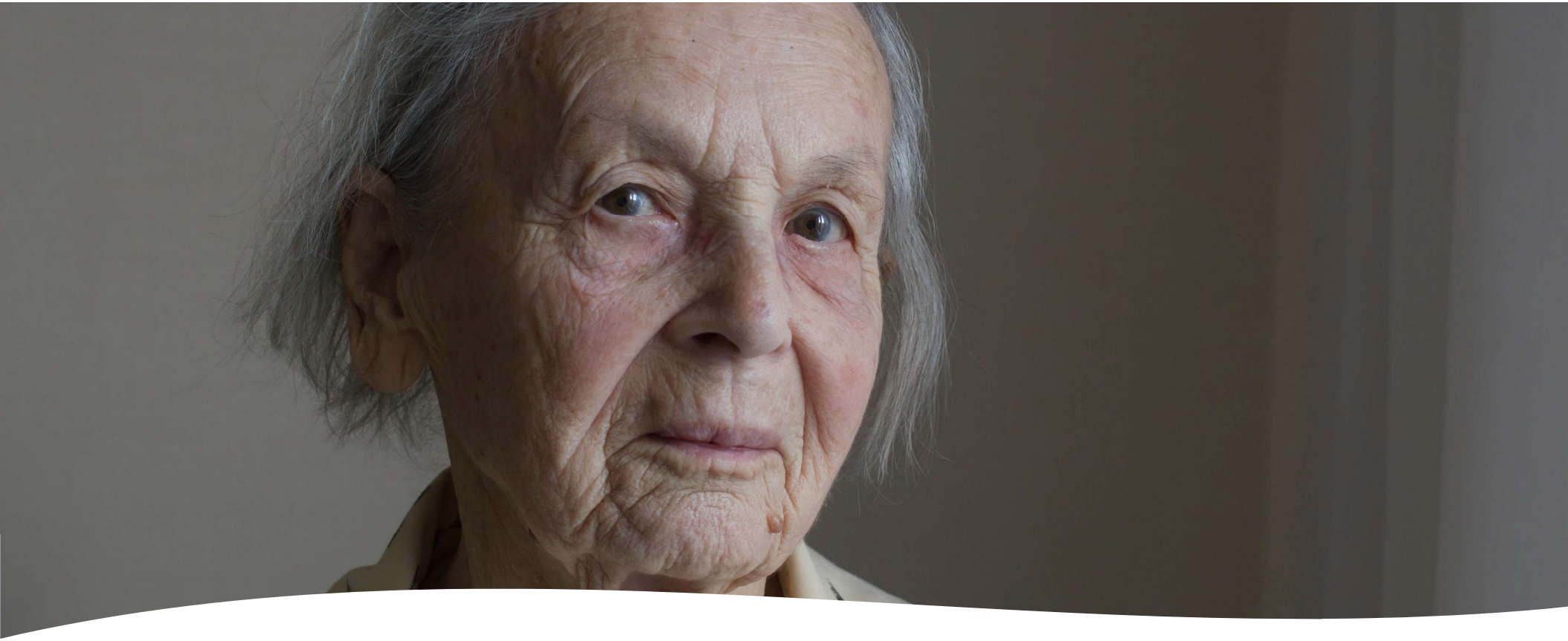
Psychotherapy with Trauma Survivors in Early Stages of Dementia

- Life review with the older adults can be effective in early-stage of dementia, helping survivors to regain a sense of continuity with one's former self.

- Can identify strengths that are likely still intact: e.g., compassion, humor, sense of adventure

- For trauma survivors, this can be more complicated as memory of past trauma emerges.

- The individual may or may not want to process those memories, and/or memories may be fragmented.



Sylvia

Sylvia was a survivor in her 80's, originally from Poland, widowed, with two sons. She presented with mild dementia as well as depression. She began to see therapist for counseling to address her symptoms of depression. In addition to discussing her Holocaust experiences and subsequent career and marriage with her therapist, she began to accuse caregivers of stealing her clothing and her daughter in law of withholding food from her.

Research Findings
PTSD and Psychosis Among Survivors

- Barak et al (2000) found significant lifelong symptoms of PTSD among Holocaust survivors, often with psychotic symptoms.
- Theorized that “cumulative trauma, recent stress, and lack of social support increase the probability of retraumatization in old age” among Holocaust survivors.
- PTSD & psychosis might best be understood along a continuum rather than viewed as distinct disorders (Hardy, 2017)

Persecutory Delusions and/or Flashbacks

- Memory loss may trigger emotions associated with past trauma – fear, vulnerability, disorientation - and delusional beliefs may arise to make sense of them.
- What appear to be “paranoid” thoughts may be a manifestation of actual past experiences, projected onto the present environment
- Those with paranoid thinking may have “recontextualized” prior traumatic experiences (Hardy, 2017)
- Use of coping mechanisms directed toward the external environment common. (Barak & Szor, 2000)

Responding to Persecutory Delusions/Flashbacks

- Try to understand the anxiety underlying the client's paranoia or delusional beliefs
- Respond in an empathic way as this can break down the sense of social isolation
- Important to accept client without either accepting or attacking delusional belief
- Reflect underlying feelings such as anger, fear or frustration.

Persecutory Delusions and/or Flashbacks

- Does the person become calmer as they share their concerns with you? If so, give them time to talk.
- Does the person become more agitated the more they talk about delusional beliefs? If so, try to gently redirect them to another topic.
- Educate others about how they can respond to the paranoid older adult in a way that is soothing rather than inflammatory.

Source: Adapted from Gero Ed Center, Mental Health Resource Review, S. McCracken & Z. Gellis.

Engage & Understand 2Gs/Family Caregivers

- Provide support to 2Gs or family caregivers -- recognize impact of trauma on subsequent generations and spouses
- Provide education to 2Gs/caregivers on PCTI approach as well as how dementia may manifest in trauma survivors
- Survivors and 2Gs less likely to plan or talk openly about end of life (2Gs benefit from such discussion)
- 2Gs are older adults themselves now
- Providing coping tools for 2Gs
  - not to be able to “fix” changes with dementia
  - possible reactivation or intensification of PTSD symptoms

Themes for Support of 2gs & 3gs

- understanding late onset PTSD & secondary trauma
- understanding commonality with other 2Gs (feeling less alone)
- anxiety & depression – tools & interventions
- abuse & forgiveness
- overprotection versus parentification
- needs of self versus parent (self-denial, independence)
- "being memorial candles"
  - **When 'Never Forget' Becomes 'I Don't Remember' (L. Felsen, Tablet Magazine 2016)**
  - legacy & generativity – research, sharing, writing
- boundaries
- sibling relationships
- impact on current attachments & relationships
- re-framing vs. blaming: behavior as coping & resilience
- end-of-life issues

http://www.iritfelsen.com/wordpress/wp-content/uploads/Dr-IritFelsen-Facilitators-Manual-for-Second-Generation-Family-Caregiver-Groups-1.pdf

Questions and Case Discussion

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Who We Are

Since 1972, CJE SeniorLife has been dedicated to helping older adults live better every day connected to the community of their choice with access to trusted care and a full range of services, rooted in Jewish values.

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What We Do

We enhance the lives of older adults and their families regardless of their faith traditions, through our many programs and services, and champion them to live life to their fullest abilities with dignity and respect.

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Thank You

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