

Supporting Family Caregivers of Older Adults with Dementia and a History of Trauma: Unique Challenges and Trauma-Informed Approaches

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Seniors at Home

August 31, 2021

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The Alzheimer's Foundation of America



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Center on Aging
and Trauma

Objectives

1

Share updates and trends about the relationship between dementia and trauma

2

Increase awareness about the unique anxieties, fears, and challenges faced by family caregivers of older adults with dementia and a history of trauma

3

Provide tips and strategies for implementing person-centered, trauma-informed care for family caregivers of older adults with dementia and a history of trauma

Speakers



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The Bi-Directional Relationship Between PTSD and Dementia

Presented by Jennifer Reeder, LCSW

Objectives

Develop

Develop a foundational understanding of dementia and trauma



Explain

Explain what chronic stress and trauma can do to the brain



Identify

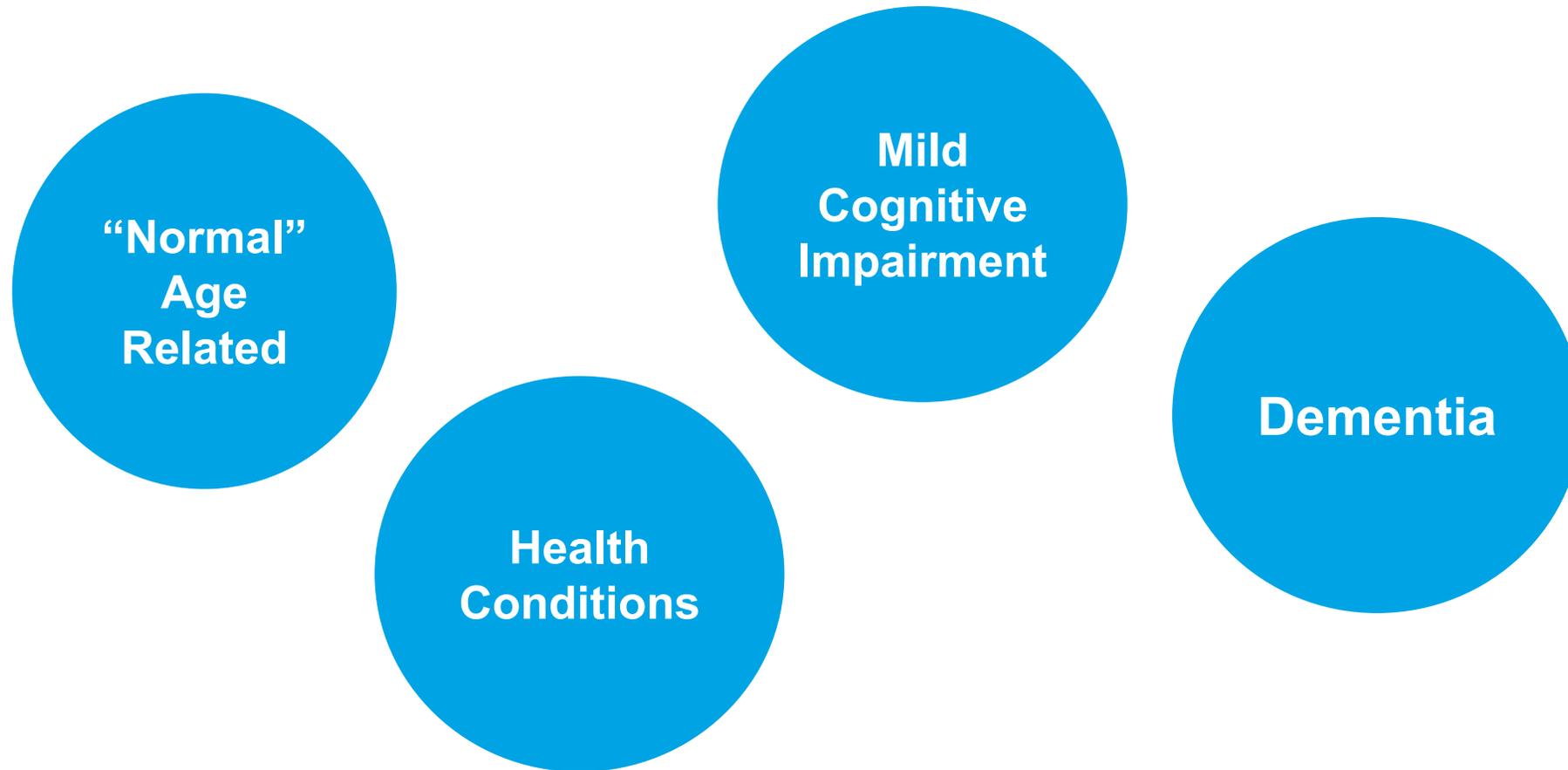
Identify the effects of untreated psychological trauma among older adults with dementia

What is Dementia?

- Dementia is a general term for a decline in mental ability that interferes with daily life.
- Most types cause a gradual worsening of symptoms over time.
- These neurodegenerative diseases lead to abnormal protein build ups in the brain.
- Impact can be seen in the following areas:
 - Memory
 - Judgement
 - Motor skills
 - Communication
 - Mood



Memory Loss: Why it Happens



Emotional Memory

- Highly emotional events that are preserved in memory
- Survivors of the 1995 Hashin-Awaji earthquake
- Two individuals with Alzheimer's Disease who lost a loved one
- Studies suggest individuals with Alzheimer's may retain memory longer for emotionally negative experiences despite progression of the disease

The Impact of Stressful Events on Brain Health

- Repeated stress has found to have an enormous impact on the brain
- Changes to the Amygdala, Hippocampus, Prefrontal Cortex
- Stressful life experiences age the brain
 - *Black Americans 4 years*
 - *1.5 years white Americans*
- Black Americans are two times more likely to develop Alzheimer's Disease
 - *Latinos/Latinx/Hispanics 1.5xs more likely*

It is imperative to think about Brain Health from BIRTH

Traumatic Events

- Traumatic events affect nearly 39% of the U.S. population within their lifetime
- Sudden, unexpected, potentially life-threatening events over which the victim has no control - or witness to the event
 - *Actual or threatened death*
 - *Serious injury*
 - *Threat to physical integrity*

Trauma and the Three Domains

When traumatic events occur, the three domains associated with good physical and mental health are disrupted:

1. Reasonable Mastery
2. Caring Attachment to Others
3. Sense of Meaningful Purpose in Life

Symptoms of Trauma

- Physical symptoms
 - *Hypervigilance, exaggerated startled response, sleep disturbance, irritability or outburst of anger, restricted range of affect*
- Intrusive, painful recollections of the event
 - *Thoughts, daydreams, nightmares, flashbacks, symbolic reminders/memory triggers*
- Avoidant symptoms
 - *Avoiding places and thoughts associated with the violent act and withdrawal from other general life events*
 - *Restricted emotions*

What Happens When Trauma is Untreated?

- When trauma does not subside, long-lasting psychological disorders develop
- Psychological Trauma is frequently untreated, especially in older adults
- The effects can manifest through substance abuse, suicide, panic attacks, depression, generalized anxiety disorder
- The higher intensity of the trauma, and the more personally involved in the traumatic event – the higher risk of PTSD

Post-Traumatic Stress Disorder

- It is expected that 7-8% of the U.S. population will develop PTSD
- About 8 million people in the U.S. reportedly have PTSD in a given year
- Men are at a higher risk of exposure to traumatic events
 - *60.7% Men*
 - *51.2% Women*
- Women are at a higher rate of developing PTSD
 - *5% Men*
 - *10% Women*



Post-Traumatic Stress and Dementia

- Severe and prolonged trauma or history of PTSD may place an elderly person at increased risk of cognitive decline and onset of dementia
- Studies show the rate of being diagnosed with dementia in those with PTSD is almost 2xs higher
- Recent studies have shown early life trauma can increase the risk of Alzheimer's Disease

Consequences for Older Adults

- Individuals who were able to manage the effects of a traumatic event are unable to do so after physical and cognitive health declines
- When an individual with Alzheimer's has recollections of a traumatic event or experience, memories may not surface clearly or may intensify
 - *Those with a cognitive impairment and short-term memory loss can become highly confused connecting the past with the present*
 - *Reactions to this re-traumatization can be easily misinterpreted resulting in restraints or unnecessary medication*

Diagnosing PTSD in Older Adults

- PTSD is underrecognized and underdiagnosed in older adults
 - Clinicians mistake early symptoms of PTSD as other medical disorders, side effects of medication, or natural conditions associated with aging
 - Coexisting medical and/or psychiatric disorders that are more frequently encountered later in life can complicate accurate diagnoses
 - Older adults with PTSD show more of the following symptoms: sleep disturbances, intrusive memories, impairment of trust, and avoidance of situations that appear stressful

A Person-Centered Approach to Trauma-Informed Dementia Care

Be	Be present
Create	Create a safe space
Understand	Help the person feel a sense of control
Seek	Seek beyond common interventions for dementia – assess the triggers
Gather	Gather information from family members
Build	Build positive emotional memories
Create	Create communal experiences
Reassess	Reassess prescribed medications

AFA Resources and Support

- AFA's National Toll-free Helpline – **NOW 7 DAYS A WEEK**
- Professional Trainings offering Continuing Education credits!
- AFA's Teal Room offers virtual therapeutic programs
- AFA's Educating America Tour
- National Memory Screening Program
- Excellence in Care Dementia Care Program of Distinction
- Care Connection monthly webinar
- Support Groups
- AFA Cares Quarterly magazine
- AFA's Education & Resource Center in New York City

www.alzfdn.org
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THANK YOU!

Reach out with questions or for more information

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

A PRESENTATION BY:

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



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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.

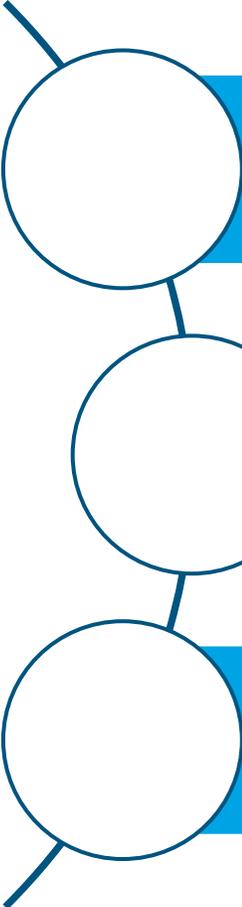
1,000

Holocaust survivors served annually throughout the Bay Area

2,800

Hours of care management, counseling, and consultation provided annually

Learning Objectives



Feel confident in your ability to respond to sudden changes in mood and behavior

Learn practical strategies in engaging a person with dementia

Understand the importance of PCTI approach

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

Common Practices to Avoid

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



Dementia and Communication



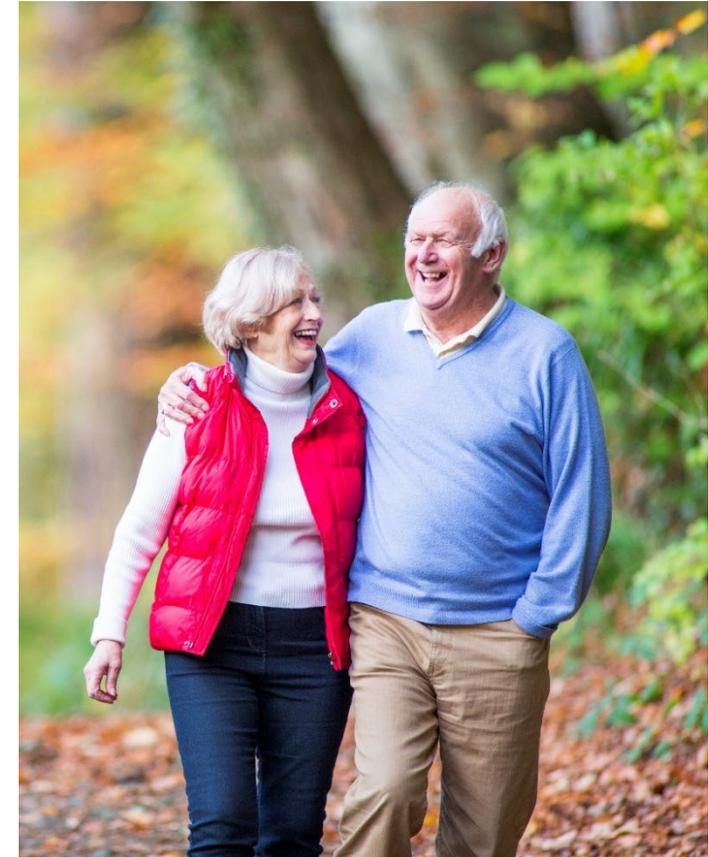
Family Perspective

- 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 Best Practices: Person-Centered Approach
- Avoid Known Triggers
- Understand Therapeutic Lying
- Adapt Trauma-Informed Care



Apply Best Practices

- Person-Centered Care
 - Understanding non-verbal cues and consider any background you may have
- Behavior is Communication
 - Responding to the emotion behind words
 - Anticipate needs



Therapeutic or Compassionate Lying

What does it mean to have dementia?

- “A shift in the way a person experiences the world around them” - Dr. G Allen Power
 - We must adapt, we cannot expect the person with dementia to adapt.
- Explain to families that their loved one relies on them to feel safe, supported and validated.
 - To illustrate the importance of not sharing the full truth/situation, explore the family member’s experience with failed attempts at explaining situations/reasoning/judgment.

Structuring Time

- Engaging in meaningful activities
- Adapt existing interests and hobbies
- Engage the senses



Sympathy vs. Empathy

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



Re-traumatization and Triggers

You must understand a patient's personal experience

This is best done through family members



Apply 6 key principals of Trauma Informed Care to your work with a person with Dementia

1. Safety
2. Trustworthiness and transparency
3. Peer support
4. Collaboration and mutuality
5. Empowerment, voice and choice
6. Cultural, historic, and gender issues

1. Safety

- Be mindful of known triggers based on past experiences
- 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**
- Environment- consider the where and when interview/service is occurring
- Be aware of an individual's discomfort or unease

2. Trustworthiness and Transparency

- Be descriptive in outlining your goals from the beginning- meet with family separately and discuss the reality of what support they can offer
- 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
 - Educate that the behaviors are not intentional
 - Help the family differentiate long time personality patterns and behaviors associated with dementia

5. Empowerment, Voice and Choice

- Support autonomy
- Ask questions
- Listen



6. Cultural, Historic, and Gender Issues

- Understand the background
- Avoid known triggers based on the person's own experiences
- Don't rely on the patient's ability to express

Sources

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For Questions, Contact:

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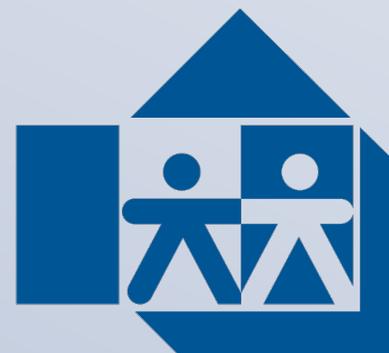
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Questions?



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Call to Action

- Check out JFNA's Center on Aging and Trauma website:
www.AgingandTrauma.org
- Strategize how you will make your office and service more PCTI
- Participate in our webinars on PCTI care
- If you have questions, please contact Aging@JewishFederations.org

Thank You

For more information,
contact the Center on Aging and Trauma at
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