

## Untangling the Web: Understanding the Relationship Between Dementia and Behavioral Health Conditions

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## Special Thanks

- Mary O'Hara, LCSW
  - Rocky Mountain Neurobehavioral Associates




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## Overview

- Understanding dementia
- Diagnosis
- Relationship between mental health conditions and dementia
- Treatment considerations
- Special considerations around trauma treatment & treatment in later stages
- Working with family members/caregivers
- Barriers to treatment




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## • UNDERSTANDING DEMENTIA

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### What is dementia?

- Not a specific disease
- Describes a group of symptoms
- Has multiple causes
- May see the term ADRD (Alzheimer's Disease and Related Dementias)
- Decline in memory or other thinking skills
- Severe enough to impact daily activities




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### Facts and Figures: U.S.

- ADRD the 6<sup>th</sup> leading cause of death
- 16.1 million provide unpaid care
- 1 in 3 seniors dies with ADRD
- 5.7 million people with Alzheimer's
  - By 2050: 14 million
- Every 65 seconds someone develops the disease

◦ Alzheimer's Association Facts & Figures




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## DSM-V Change

- Neurocognitive Disorders
  - Primary clinical deficit is cognitive function
  - Acquired, rather than developmental
  - Represent a decline in a previously attained level of functioning
  - Unique in that underlying pathology and often etiology can potentially be determined.
  - Inclusive of conditions that affect younger individuals, such as impairment secondary to TBI or HIV infection.
  - Less severe level of cognitive impairment, *mild neurocognitive disorder*, also recognized and allowed to be a focus of care.
    - American Psychiatric Association, 2013

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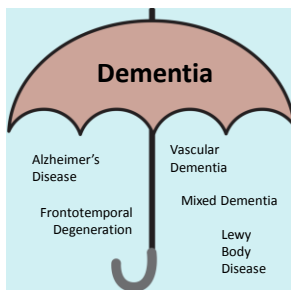
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## Dementia vs. Alzheimer's



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## What is Alzheimer's?

- Most common form of dementia
- <https://www.youtube.com/watch?v=ECbjK4Ra-Ys>

Jefferson  
Center  
—With you in mind—

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## ° DIAGNOSING DEMENTIA

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## 10 Warning Signs

- Memory loss
- Trouble planning or problem-solving
- Trouble completing familiar tasks
- Confusion with time or place
- Trouble with visual images or spatial relationships
- Trouble with words in speaking or writing
- Misplacing things and not being able to retrace steps to find it
- Impaired judgment
- Withdrawing from work or social activities
- Changes in mood or personality




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## Differential Diagnosis of Dementia

- Substance use or misuse
  - Medication interactions
- Medical conditions
  - Infections
  - Thyroid problem
  - Vitamin deficiencies
  - NPH
  - Sleep Apnea
  - B12 Deficiency
  - Head Trauma
- Mental Health Conditions
  - Depression




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## Screening Tools for Dementia

- Mini-Cog
  - Minimal language content, reduces educational and cultural bias
  - Give three words, have them draw a clock, have them repeat 3 words
- MMSE, SLUMS, MOCA
  - SLUMS and MOCA available through public domain.
  - Instructions for administering available online.

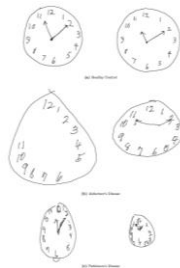


Photo Credit: MIT  
Management Sloan  
School

## Delirium vs. Dementia vs. Depression

- How to differentiate:
  - Onset
  - Attention
  - Fluctuation
- Most common cause of delirium for older adults living in the community?

Alcohol



Comparison of DEPRESSION, DELIRIUM And DEMENTIA

	Depression	Delirium	Dementia
<b>Definition</b>	A change in mood which lasts at least 2 weeks and includes sadness, negativity, loss of interest, pleasure and/or decline in functioning.	An acute or sudden onset of mental confusion as a result of a medical, social, and/or environmental condition.	Progressive loss of brain cells resulting in decline of day-to-day cognition and functioning. A terminal condition.
<b>Duration</b>	At least 6 weeks, but can last several months to years, especially if not treated.	Hours to months, dependent on speed of diagnosis.	Years (usually 8 to 20)
<b>Thinking</b>	May be indecisive and thoughts highlight failures and a sense of hopelessness.	Fluctuates between rational state and disorganized, distorted thinking with incoherent speech.	Gradual loss of cognition and ability to problem solve and function independently.
<b>Mental status testing</b>	Capable of giving correct answers, however often may state "I don't know."	Testing may vary from poor to good depending on time of day and fluctuation in cognition.	Will attempt to answer and will not be aware of mistakes.
<b>Memory</b>	Generally intact, though may be selective. Highlights negativity.	Recent and immediate memory impaired.	Inability to learn new information or to recall previously learned information.
<b>Sleep-wake cycle</b>	Disturbed, usually early morning awakening.	Disturbed. Sleep-wake cycle is reversed (up in night, very sleepy and sometimes non-responsive during the day).	Normal to fragmented
<b>Hallucinations &amp; delusions</b>	Can be present in a severe depression. Themes of guilt & self-loathing.	Often of a frightening or paranoid nature.	Can be present. May misperceive. In Lewy Body dementia visual hallucinations are present.
<b>Diagnosis</b>	May deny being depressed but often exhibit anxiety. Others may notice symptoms first. Increased complaints of physical illness. Social withdrawal is common.	Diagnosis based on rapid onset of fluctuating symptoms. Can be mistaken for progression of the dementia.	Usually diagnosed approximately 3 years after onset of symptoms. Must rule out other cause of cognitive decline, e.g. depression or delirium.

## HOW DO MENTAL HEALTH CONDITIONS OVERLAP WITH DEMENTIA?




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## Depression & Dementia

- People with dementia often experience depression
  - Depression can mimic dementia
  - Depression may happen in response to early cognitive decline
  - Depression may put someone at risk for dementia, or be an early sign of dementia
    - Earlier life depression potentially a risk factor
    - Later life depression potentially an early symptom
- Byers & Yaffe, 2011




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## Anxiety & Bipolar Disorder

- Anxiety is also a risk factor for developing dementia
  - Gimson, Schlosser, Huntley, et al., 2017
- As number of episodes of depression or bipolar disorder increase, so does risk of dementia
  - Vessing & Andersen, 2004




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## Schizophrenia & Dementia

- Schizophrenia also associated with increased presentation of dementia
  - de Vries, Honer, Kemp, et al, 2001
- May be due to the fact that people with schizophrenia have other adverse health outcomes that increase their risk of dementia
  - Rohde, C., Agerbo, E., & Nielsen, P. R., 2016




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## Trauma & Later Life

- 70 – 90% aged 65 better exposed to at least one traumatic event
- 7-15% older adults have sub-clinical levels of PTSD symptoms
- 70% older men; 41% women\*
- May not always identify as having experienced trauma
- Vets with PTSD have 2x the risk of developing dementia

◦ Yaffe et al, 2010



www.jcmh.org

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## Substance Use and Dementia Risk

- Excessive alcohol use linked to dementia, especially early-onset
  - Schwarzingner et al, 2018
- Other drugs such as tobacco, benzodiazepines, and cannabis linked to cognitive impairment, but association with dementia is less clear
  - Hulse, Lautenschlager, Tait, & Almeida, 2005
- One study out of the UK showed a slightly *increased* cognitive ability among former recreational drug users
  - Dregan & Gulliford, 2011




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## Medications and Dementia Risk

- Certain anticholinergic drugs (such as Benadryl, bladder medications, and tricyclic antidepressants) were shown to lead to an increase risk of dementia.
  - Gray et al, 2015
- Benzodiazepines also associated with an increased risk of dementia.
  - Takada, Fujimoto, & Hosomi, 2016




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## Dementia and Suicide Risk

- Unclear if dementia increases suicide risk
  - Rohde, Agerbo, & Nielsen, 2016
- Concern of suicide should not be a reason to withhold a diagnosis.
- Important to assess for suicide risk, particularly for:
  - Men...
  - ...In the early stages of dementia...
  - ...with symptoms of depression or anxiety...
  - ...who have access to firearms.
    - Rohde, Agerbo, & Nielsen, 2016

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## DIFFERENT TYPES OF DEMENTIA




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## Behavioral and Emotional Concerns with Alzheimer's Disease

- Early Stages
  - Depression
  - Anxiety
  - Poor Sleep
  - Decreased Activity
  - Increased Isolation



- Feeling Ambiguous Loss




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## Behavioral Symptoms of Lewy Body Disease

- Increase risk of depression
- Rapidly fluctuating cognition
- Acting out dreams: REM sleep disorder
- Recurrent, complex visual hallucinations that are well-formed and detailed
- Delusions
- Movement symptoms—similar to PD




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## Behavioral Symptoms of bvFTD

- Lack of Insight
- Disinhibition/Impulsivity
- Apathy and lack of initiative
- Emotional Blunting
- Compulsive or Ritualistic Behaviors
- Hyperoral Behavior
- Deficits in Executive Functioning
- Abrupt mood changes

◦ [www.theaftd.org](http://www.theaftd.org), 2018




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## Wernicke-Korsakoff Syndrome

- Most commonly caused by heavy, prolonged alcohol use
- Early presentation:
  - Confusion
  - Nystagmus ("dancing eyes")
  - Ataxia (stumbling, lack of coordination)
- Later stages
  - Agitation
  - Anger
  - Hallucinations
  - Confabulations



• Gossman & Newton, 2017




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## Chronic Traumatic Encephalopathy (CTE)

- Associated with repeated blows to the head
  - Dementia pugilistica or "punch-drunk syndrome"
- Causes problems with thinking & memory
- Causes Personality & Behavioral Changes
  - Aggression
  - Depression
  - Suicidal thoughts

-Alzheimer's Association

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## Other behavioral presentations

- Vascular dementia
  - Behavioral symptoms may vary based on the parts of the brain affected
- Pseudobulbar affect (PBA)
  - Associated with many neurological conditions
  - Often mistaken for a mood disorder
  - Uncontrolled crying or laughing that is out of proportion with the context of the situation.
  - Often a significant impact on social interactions
    - Ahmed & Simmons, 2013




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## TREATMENT CONSIDERATIONS: MEDICATIONS

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## Medications for Dementia

- Namenda (memantine), NMDA receptor antagonist, approved for moderate to severe Alzheimer's.
- Cholinesterase inhibitors (e.g., donepezil) improve memory.
- Dopamine agonists (e.g., bromocriptine, amantadine) and CNS stimulants (e.g., methylphenidate, modafinil) improve cognition, concentration and focus.

- (Yoder, Norman, & Friedman, 2016)

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## Medications for NPS of Dementia

- SSRIs are safe and usually well-tolerated.
  - Citalopram may also reduce agitation (Porsteinsson et al, 2014)
- Anticonvulsants are useful for seizure prevention and mood stabilization.
- Atypical antipsychotics are useful for aggression, agitation and irritability.
  - Black box warning from FDA (increased risk of death in elderly people with dementia).
- Andrenergic beta blockers are useful in the most severe cases of aggression, agitation and irritability.

- (Yoder, Norman, & Friedman, 2016)

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## Antipsychotics and Dementia

- Largest # of rx for atypical antipsychotics written for neuropsychiatric symptoms (NPS) of dementia.
  - Up to 97% of people with dementia have NPS
- No atypical antipsychotic is FDA-approved for the tx of any NPS in dementia.
- Antipsychotics show a 1.5-1.7 x increased risk of death in those with dementia.
- 2-3 times higher risk of cerebrovascular events.
- Worsen cognition, more frequent infections and falls.
- Recommended they only be used when "nonpharmacological options have failed and patient is threat to self or others."
  - Steinberg & Lyketsos, 2012.

## Special Considerations with LBD & Antipsychotics

- People with Lewy Body Disease can have severe reactions to antipsychotic medications
  - Worsening cognition, sedation, increase in parkinsonian symptoms,
  - In rare cases, can cause "neuroleptic malignant syndrome"
    - Fever, muscle rigidity, kidney failure, death
- Typical (first generation) antipsychotics should NOT be used
  - Haloperidol
- Atypical (Second Generation) antipsychotics should be used conservatively



## Anxiolytics and Dementia

- RCTs comparing benzodiazepines with placebo for behavioral and psychological symptoms of dementia are lacking.
- Given serious concerns about adverse events, such agents are not recommended except for management of an acute crisis.
  - Kales, Gitlin, & Lyketsos, 2015.

News &gt; Medscape Medical News &gt; Neurology News

**Rate of Benzodiazepine Use in Alzheimer's 'Alarming'**Pauline Anderson  
November 10, 2015

23 Read Comments

Benzodiazepines, which are typically prescribed to treat anxiety, agitation, and sleep disturbances, are not recommended in patients with dementia, but a new study shows that more patients with Alzheimer's disease (AD) take these drugs than people without this disorder.

**Cannabis and Dementia**

- Research currently being done to examine:
  - If cannabis is effective for tx or prevention of ADRD
  - If cannabis is effective for tx of behavioral symptoms of ADRD

**Early Stage Memory Loss**

- Based upon work of Robyn Yale, LCSW
- Designed for those who are struggling with how the disease is impacting their daily life, sense of self, relationships and their plans for the future.
- Customized to the goals of each family
- Short-term
- Focus on capacity for resilience in face of hardship



## What we know is helpful

- Maintaining a sense of control
  - Structure and routine
  - Remaining active and involved
  - Feeling safe
- Having emotional support
  - Opportunities to feel successful
  - Purpose and meaning
  - Social, physical and mental activity
- Opportunities for expression

Morhardt, D. Alzheimer's Care Quarterly, 2004. "Top 10 Ideas for Enhancing Quality of Life by Diagnosed Individuals and Families Living with Alzheimer's disease and Related Disorders"




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## TREATMENT CONSIDERATIONS: PSYCHOTHERAPY

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## Dimensions of Loss in AD/DRD

- Primary and Progressive Loss of Cognitive Skills
- Secondary loss
  - Identity and Sense of Self
  - Future Goals and Dreams
  - Meaning
  - Relationships
  - Financial security
  - Safety
  - Faith
  - Embarrassment
  - Anhedonia




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## The Paradox of Pain in Context of Loss

- “The only way to the other side is through”
  - Helen Keller
- Alan Wofelt’s Work around loss: Accepting reality, feeling pain, search for meaning, letting others help.
- In order to heal from pain, we must let ourselves experience pain
- We must create safe spaces for clients to journey through the pain in order to cope.
- The space between diagnosis and the ability to move forward can be crossed




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## Individual Counseling for Cognitive Changes

- Goals
  - Better understanding the diagnosis
  - Managing worry, stress, sadness, changes in mood
  - Reconnecting with your sense of self and sense of belonging
  - Living a full and meaningful life despite the cognitive changes
  - Moving forward with resilience




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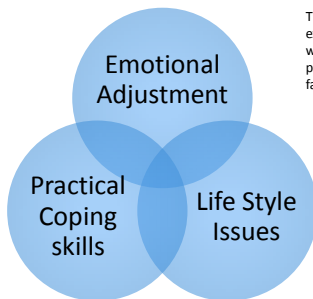
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## Framework for Coping



These domains exist regardless of whether or not a person is ready to face/accept them.




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## Identifying Goals: Emotional Adjustment

- Understanding, acknowledging and becoming more accepting of my condition.
- Working toward finding new meaning/purpose in life
- Redefining my identify and feeling good about who I am
- Expressing feelings (positive and negative) about my situation
- Having an attitude of being strong and capable
- Letting others know that I want to be treated with respect




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## Identifying Goals: Lifestyle

- Doing and/or developing new and social and meaningful activities
- Talking about and making future legal, financial, health and care planning decisions
- Acknowledging and working on challenges with my family
- Asking for and accepting help from others
- Using early stage support services
- Taking steps to problem solve safety issues such as driving, managing finances.




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## Identifying Goals: Practical Coping

- Learning and using stress management techniques
- Using memory aids and strategies
- Paying more attention to physical exercise, diet, rest, and general health
- Enhancing my ability to communicate and informing others about it.
- Doing more memory and other cognitive exercises.
- Getting emotional support from others




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## Adjustments for Therapy Sessions

- Go at a slower pace.
- Avoid covering too many topics during a single session.
- Content may be repeated from session to session—that's okay!
- Provide written materials and summaries at the end of the session.
- When appropriate, bringing in family members may be helpful.

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## Criteria for Termination

- Lowered insight into the cognitive changes
- Disorientation
- Increasingly tangential in their conversation
- Discussing termination
  - What will it be like?
  - Fears, concerns, plans
  - Referrals to Alz Assoc. Early Stage Programs
  - What is next?




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## SPECIAL CONSIDERATIONS FOR TRAUMA TREATMENT AND LATE STAGE DEMENTIA

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## PTSD & Dementia: Assessment

- Nightmares, trauma hx, and agitation in response to specific cues warrant evaluation for PTSD.
- PCL-5 has preliminary support as an assessment measure
  - (Yoder, Norman, & Friedman, 2016)




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## PTSD & Dementia: Psychotherapy

- Some individuals with mild dementia can benefit from psychotherapy for PTSD.
    - Case by case
    - PE & CPT
    - Modifications may include using memory aides, adding more structure, longer sessions, increasing the number of sessions per week, and combining group and individual therapy.
- (Yoder, Norman, & Friedman, 2016)




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## PTSD & Dementia: Pharmacotherapy

- First line medications are SSRIs and venlafaxine.
  - Second line tx are mirtazapine, nefazadone and older antidepressants (e.g., tricyclics (TCAs) and MAO inhibitors
  - Prazosin is recommended for traumatic nightmares
  - Specific medications contraindicated for PTSD include benzodiazepines, risperidone and most mood stabilizers / anticonvulsants.
- (Yoder, Norman, & Friedman, 2016)

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## PTSD & Dementia: Later Stages

- Important to identify triggers:
  - TV shows, movies, or news coverage
  - Being bathed
  - Male or female caregivers for someone who has been physically or sexually assaulted
  - Smells (e.g., bodily smells, wounds, fires, certain foods).
  - Sounds (e.g. songs, foreign languages, loud noises such as alarms).
  - Perceived threats or physical touch.
- Once triggers are identified, the staff can try to problem-solve ways to ameliorate the triggers.
  - Minimizing the patient's contact with specific triggers
  - Interventions such as providing social support or engaging in positive activities may also be effective in reducing stress or problem behaviors.

(Yoder, Norman, & Friedman, 2016)

## Behavioral Changes in Later Stages

- Paranoia, due to confusion
- Frustration with inability to communicate
- Responding to a perceived threat with fear, aggression
- Restlessness, pacing
- Sleep Disruptions
- Hallucinations
- Delusions



## Interventions for Behavioral Changes in Later Stages

- Screen for delirium
- Assess for unmet needs
- Routines
- Calm environment
- Exercise
- Natural light
- Art or Music Therapies
- Distractions from cause of concern
- OT, SLP, PT Referrals
- Providing caregiver training: Feelings are more important than facts!
- Medications



# The Neuropsychiatric Symptoms of Dementia:

*A Visual Guide to  
Response Considerations*

Michelle Niedens, L.S.C.S.W.  
Alzheimer's Association – Heart of America Chapter

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## WORKING WITH FAMILY MEMBERS AND CAREGIVERS

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## Working with Family

- Family caregivers at increased risk for:
  - Anxiety, depression
  - Social Isolation
  - Poorer physical health
  - Financial hardship
  - Death

- 63% higher than non-caregivers  
Brodsky & Donkin, 2009; Tremont, 2011



Jefferson  
Center  
*With you in mind*

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## 10 Symptoms of Caregiver Stress

- **Denial** about the disease and its effect on the person.
- **Anger** at the person with Alzheimer's or frustration that he or she can't do the things they used to be able to do.
- **Social withdrawal** from friends and activities that you used to enjoy.
- **Anxiety** about the future and facing another day.
- **Depression** that breaks your spirit and affects your ability to cope.
- **Exhaustion** that makes it nearly impossible to complete necessary tasks.
- **Sleeplessness** caused by a never-ending list of concerns.
- **Irritability** that leads to moodiness and triggers negative actions.
- **Lack of concentration** that makes it difficult to perform familiar tasks.
- **Health problems** that begin to take a mental and physical toll.

Alzheimer's Association, 2018




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## Other Reactions to Loss

- **Emotional**
  - Guilt or Regret
  - Ambiguity of Loss
  - Shame
  - Not feeling normal anymore
  - Sense of isolation
  - Self-doubt
- **Physical**
  - Sleep Disturbances
  - Somatic Complaints
  - Time distortion
  - Lethargy and fatigue




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## What we know is helpful

- **Emotional Support**
- **Taking care of themselves physically and mentally**
- **Breaks from caregiving responsibilities**
- **Maintaining relationships with others**
- **Disease Education**
  - Understanding changing behaviors as part of the illness
  - Adapting communication methods to person's ability
- **Feeling that they have the best medical care**
- **Learning to control guilt**
- **Learning to prioritize differently**

Marhardt, D. Alzheimer's Care Quarterly 2004. "Top 10 Ideas for Enhancing Quality of Life by Diagnosed Individuals and families living with Alzheimers disease and related dementias"




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## Common goals of therapy for family members/caregivers

- Managing stress, fear, worry and sadness, anxiety, guilt or depression
- Navigating changes in relationships, roles and expectations
- Recognizing and accepting their limitations
- Nurturing their own needs
- Reconnecting with who and what they value most
- Accessing appropriate support and resources
- Focusing on moving forward with resilience




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## Therapeutic Interventions

- Driven by goals of client
- Normalize grief experience
- Understand reactions to loss
- Concept of ambiguous loss
- Place to name and process their emotions
- Disease education
- Breathing and mindfulness practice
- Cultivating self-compassion
- Exploring forgiveness
- Education about resources




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## Resources for Caregiver Training

- Bathing without a Battle
  - <http://bathingwithoutabattle.unc.edu/>
- Teepa Snow, OT
  - Youtube
  - <http://teepasnow.com/>
- Alzheimer's Association Online Courses
  - <https://alz.org/help-support/resources/care-training-resources>
- The Savvy Caregiver
  - <http://www.hcinteractive.com/SavvyFamily>

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## Disease-Specific Organizations

- Alzheimer's Association
  - [www.alz.org](http://www.alz.org)
  - 800-272-3900
- Lewy Body Dementia Association
  - [www.lbda.org](http://www.lbda.org)
  - 844-311-0587
- The Association for Frontotemporal Degeneration
  - [www.theaftd.org](http://www.theaftd.org)
  - 866-507-7222

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## Support in Colorado

- Alzheimer's Association offices
  - Denver
  - Fort Collins
  - Greeley
  - Colorado Springs
  - Boulder (Louisville)
  - Pueblo
  - Durango
  - Grand Junction
  - [https://alz.org/co/about\\_us/office\\_locations](https://alz.org/co/about_us/office_locations)

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## • BARRIERS TO TREATMENT

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## Barriers to Treatment

- Stigma
- Cost or Insurance issues
- Logistical
  - Transportation
  - Privacy
  - Coordinating multiple medical appointments
- Memory Loss
  - Forgetting appointments
  - Following up on “homework”
  - Ability to carryover between sessions
  - Can the person benefit?




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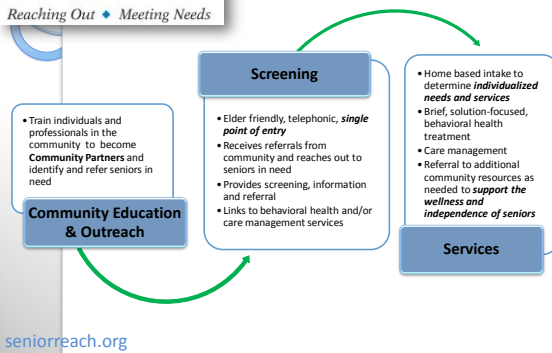
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## Key Components




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## Key Takeaways

- Relationship between dementia & mental health is complex
- Emotional well-being of the person with dementia should always be monitored & prioritized.
  - Assessment and available interventions will change as the disease progress
  - Interventions are possible at any stage!
- Support for caregivers is critical, and improves outcomes for everybody.




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## Q&A



## Resources

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## Resources

[https://www.alz.org/national/documents/topicsheet\\_hallucinations.pdf](https://www.alz.org/national/documents/topicsheet_hallucinations.pdf)

[https://www.alz.org/alzheimers\\_disease\\_treatments\\_for\\_behavior.asp](https://www.alz.org/alzheimers_disease_treatments_for_behavior.asp)

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