



Memory Care Matters

Fostering Empathy & Hope for folks living with Dementia
and the caregivers who love them .

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EMPATHY VS. SYMPATHY-HOW UNDERSTANDING THE DIFFERENCE CHANGES ATTITUDES AND APPROACHES LEADING TO IMPROVED CONNECTIONS FOR FOLKS LIVING WITH DEMENTIA

“As human beings we are wired to connect with others, it is what gives us purpose and meaning, without it there is suffering” -Brene Brown, P.h.D., LMSW

Dementia at it's most basic, biological level starts with **disconnection**. As parts of the brain are progressively damaged and deteriorating, there are less neurological connections taking place, resulting in the person living with dementia becoming progressively disconnected in everyway. From the very early stages of symptoms, it is paramount that caregivers-professional and family- seek to help the person living with Dementia **connect** in any way possible at every opportunity possible. Understanding the difference between empathy and sympathy changes our attitudes and approaches with folks living with dementia leading to improved levels of emotional connections. It is the first place we can start in enhancing connections for folks living with dementia.

Empathy is the ability to experience the feelings of another person. It goes beyond sympathy, which is caring and understanding for the suffering of others. Both words are used similarly and often interchangeably (incorrectly so) but differ in their **emotional meaning**. For the person living with Dementia who is experiencing losses functionally, physically and cognitively , the ability to feel and respond to emotion remains. Thus, attention to emotional meaning for the person living with dementia is essential .

When we express sympathy toward someone, while it is caring and compassionate, we are sending the message that they are “less than” not equal to us-it sets up a dynamic that does not foster true connection or optimal connection. Folks living with Dementia need to feel that we still see them as equals, despite their changes. When they perceive we are not seeing them as equals, they feel worse about themselves, they may withdraw more. **Sympathy drives disconnection. Empathy fuels connection. Empathy is feeling WITH people.** Our natural response is to talk folks out of how they feel instead of validating how they feel, especially when faced with difficult situations. When a person living with dementia shares a difficult emotion or feeling , well-meaning caregivers/family members try to make things better by our responses. The truth is, rarely , if ever, can a response make something better. What makes something better is connection. If I share something very difficult with you, I'd rather you say “I am sorry, I don't even know what to say right now. I am just so glad you told me. I am here for you.” Rather than telling me why I shouldn't feel that way.





Caring for a loved one can be challenging and stressful, caring for a loved one living with Dementia brings a whole different level of stress inducing challenges. The person living with Dementia is dependent on others for multiple parts of every day life, care and functioning, not to mention the concern for safety that is ever present as they suffer with impaired judgment while still being very physically active in many cases. Often times there are uncontrolled and /or frequent changes in emotions with the person living with Dementia . The caregiver is constantly making adjustments on every plane. It can be overwhelming and exhausting. Caregiving can

Emotional Memory

Emotional memory is different from retained memories of events. Various studies show that for the person with Alzheimer's disease, emotional memories, or the memory of the feelings, stay with the person long after the memory of the event has vanished. While an event may no longer be recalled they are still filled with the feelings from the emotional memory of the experience. After a positive family visit, a meaningful event, warm shower, good meal, funny movie or a pleasant walk in a garden, the feelings of love, calm, connectedness, laughter or happiness stay long past the duration of the event. These feelings often influence the mood of the person with Alzheimer's for hours or days after the event. The same can be said for negative emotional memories. If a person with Alzheimer's experiences a frightening, confusing, overwhelming or sad event, those emotions or associated feels of distress linger for hours or days. For the person with Alzheimer's or related dementia, their memory loss already results in feelings of confusion, loss, fear, embarrassment or distress. Therefore, creating and connecting them with as many positive emotional memories as possible is part of good Dementia practices that caregivers, both professional and family can utilize with folks living with Alzheimer's or related Dementia's.

Here are 12 things we can do to offer the person living with Dementia to experience the benefits of positive emotional memories that are generated from experiences of happiness, connectedness, joy, love, humor and hope.

1. **Get to know the person's life story**-the more you know about the person and what their life story facts are, the more comfortable /connected they feel and the easier it is to connect them to past experiences that evoke positive emotional memories.
2. **Use empathy based approach techniques**-communicates you're

be just as demanding (sometimes more) than a full-time job . Ignoring stress is not an option! If you do not care for yourself, you cannot be of any help to your loved one. In fact, if you are exhausted and frustrated, your loved one will feel that energy and could experience worse symptoms as they respond to your

emotions of frustration and fatigue.

CAREGIVER STRESS TIPS:

- ***Ask for help-give yourself permission to be human and take a break!***
- ***Access supports and support groups.***
- ***Know your limits-if you are having a bad day before you visit your loved one, perhaps it is not a good time to visit.***
- ***Eat right and get enough rest.***
- ***Educate yourself about the symptoms of Dementia, it will help you know what to expect/not expect.***

“People will forget what you said, people will forget what you did, but people will never forget how you made them feel.” - Maya Angelou

RESEARCH NEWS

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The Religious Orders Study, a research project following more than 1,100 clergy members across the United States since 1994 who have undergone regular psychological testing, revealed some telling results. The study was headed by David Bennett, MD, and a team at Rush University in Chicago. The team has collected and examined tissues from over 350 brains. The study results revealed that cognitive exercises (keeping the brain active through crosswords, reading, learning new skills, and having responsibilities) was protective. So were social activity, social networks and physical activity. The participants with diseased neural tissue (evidence of Alzheimer's or other Dementias) but no cognitive symptoms had built up what is known as **COGNITIVE RESERVE**. As areas degenerated, other well-exercised areas took over those functions.



- ♦ **Practice meditation—research reveals daily 12 minute sessions can improve blood flow to the brain and possibly increase levels of an enzyme that slows cell aging.**
- ♦ **Heart Healthy Living decreases cognitive decline, this includes but is not limited to: not smoking, keeping body mass index (BMI) under 25, remaining physically active –150 minutes of exercise a week which is about 20 minutes a day, healthy cholesterol (under 200), healthy blood pressure (under 120/80), healthy blood sugar (under 100mg), balanced diet.**
- ♦ **Lift weights! Women who strength train twice a week had increased blood flow to their brain and decreased levels of cognitive impairment.**
- ♦ **Exercise regularly—exercise improves vascular health, but recent research shows that it also combats chronic neuroinflammation observed in Alzheimer's, depression, and other brain diseases.**
- ♦ **Sing a song! Listening or playing music stimulate and activates many parts of the brain. Keeping the pathways and highways of the brain healthy.**



Exercise your Creative Expressive Side—studies show that folks who draw, paint, sculpt have to focus on details and spatial calculations.



- ♦ **Outsmarting Alzheimer's –Kenneth S. Kosik, MD**





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in tune with their feelings through your choice of words and your actions-always approach from the front where they can see you, get to their eye level. Avoid asking questions that have one correct answer or test memory.

3. **First Seek to Connect:** we must connect with the person with dementia before we initiate action. Often times we fail in our attempts to connect with others because we take too little time to sense and understand their needs.
4. **Live in the moment and enjoy their company.** When looking at family photos, instead of asking the names and relationship to the person, remark on the event in the photo. Ask for advice about their beliefs. They still have a lot of wisdom to share with us!
5. **Facilitate connections between folks who have dementia.** Introduce them to each other and attempt to connect them through commonalities.
6. **Encourage opportunities for meaningful self-expression.** Self expression through the creative arts enables us to build personal and meaningful connections with individuals affected by Dementia.
7. **Ensure dignity, privacy and choice-**Don't just knock as you are entering a person's room-consider the emotional memory that may be generated by a stranger who enters your house while knocking at the same time. Don't talk about the person as though they are not there.
8. **Think about the words you use.** Are we speaking with empathy or are we using words that describe a task or a disability rather than a person.
9. **Empower people with opportunities for independence and choice.** Avoid doing too much for a person and causing excess disability. Offer physical and verbal cues to help the person continue to participate. The longer folks can do things for themselves, the better they feel.
10. **Create a calm environment-**the person with dementia does not understand extraneous noises. Too much noise in the environment can cause fear, anxiety even anger for the person living with dementia. It can distract them from focusing on something they are enjoying.
11. **Maximize uninterrupted sleep-**When people sleep better, they eat better, they feel better and they are more able to connect.
12. **Identify and respond to pain and physical needs.** Recognize signs of distress as communication of unmet needs . Resource: Alzheimer's Resource Center, Plantsville, CT.



Maybe

When I wander don't tell me to come and sit down, wander with me.

It may be that I am hungry, thirsty, need the toilet, or maybe I just need to stretch my legs. When I call for my mother (even though I am ninety)! Don't tell me she has died. Reassure me, cuddle me, and ask me about her.

It may be that I am looking for the security that my mother once gave me.

When I shout out please don't ask me to be quiet...or walk by. I am trying to tell you something, but I have difficulty telling you what. Be patient. Try to find out. I may be in pain. When I become agitated or appear angry, please don't reach for the drugs first. I am trying to tell you something. It may be too hot, too bright, too noisy. Or maybe it's because I miss my loved ones. Try to find out first.

When I don't eat my dinner or drink my tea it may be because I've forgotten how to, show me what to do, remind me. It may be that I just need to hold my knife and I may know what to do then. With all my thoughts and maybes, perhaps it will be you who reaches my thoughts, and understands my fears.

Maybe it will be you who I will need to thank, if I only knew how. –Anonymous

“When the person with Dementia is giving you a hard time, they are having a hard time.”



“Love, the best medicine, if it does not work, increase the dose!”