

The Alzheimer's Family

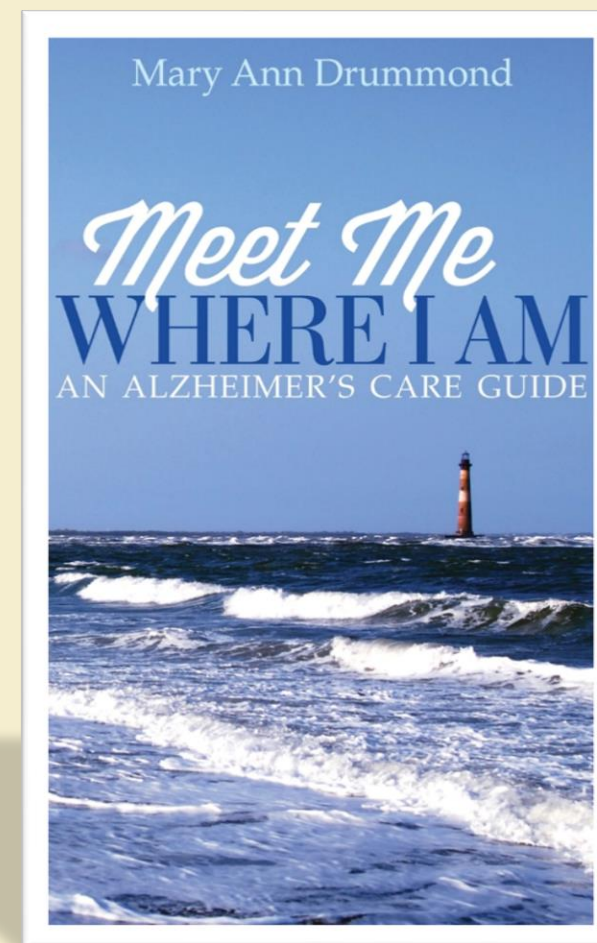
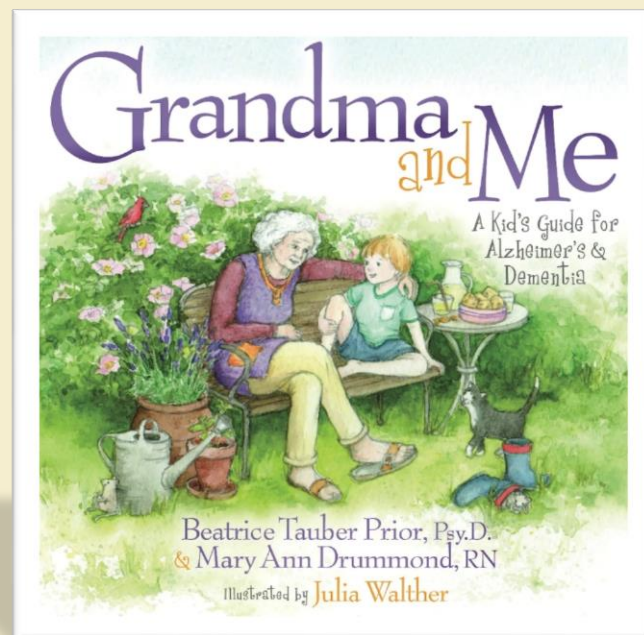
Caring – Connecting – Coping



A few tidbits about me...



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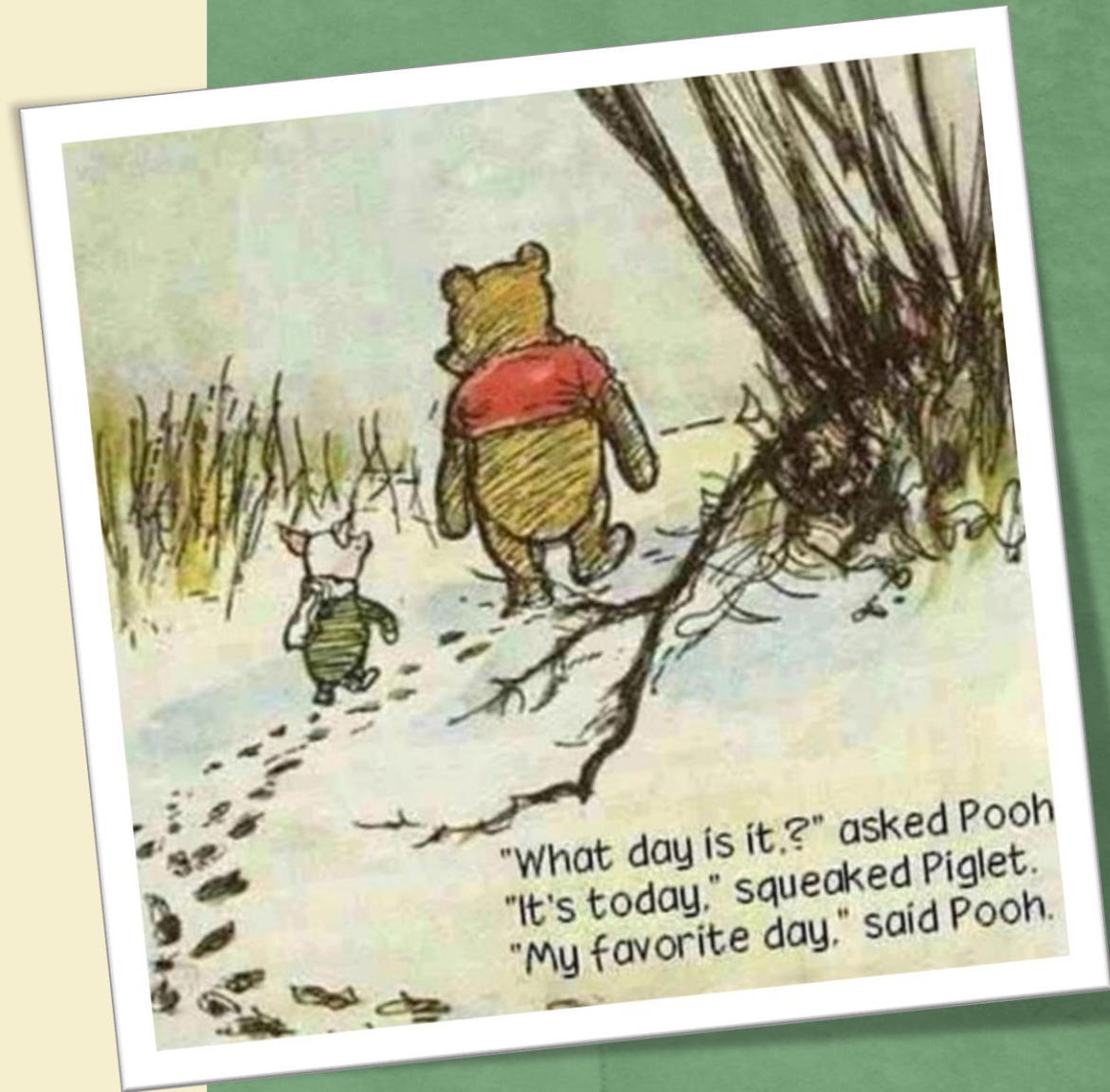


@maryanndrummondauthor



Our Time Today:

- ✓ Review the impact of Alzheimer's disease and dementia on the family
- ✓ Explore ways to maintain effective communication, interactions and positive relationships while caring, coping and connecting along the journey



"There are only four kinds of people in the world:

*Those who have been caregivers.
Those who are currently caregivers.
Those who will be caregivers and
those who will need a caregiver."*



~ Rosalyn Carter



The simple act
of caring is
HEROIC.

—Edward Albert, actor

Home Helpers®

Try this simple math question:

A bat and ball cost a dollar and ten cents. The bat costs a dollar more than the ball. How much does the ball cost?

If you are like most people, your answered the bat cost \$1 and the ball .10 cents.

And like most people, your answer is...incorrect!

Look at the numbers below...

Can you find the
the **mistake**?

1 2 3 4 5 6 7 8 9



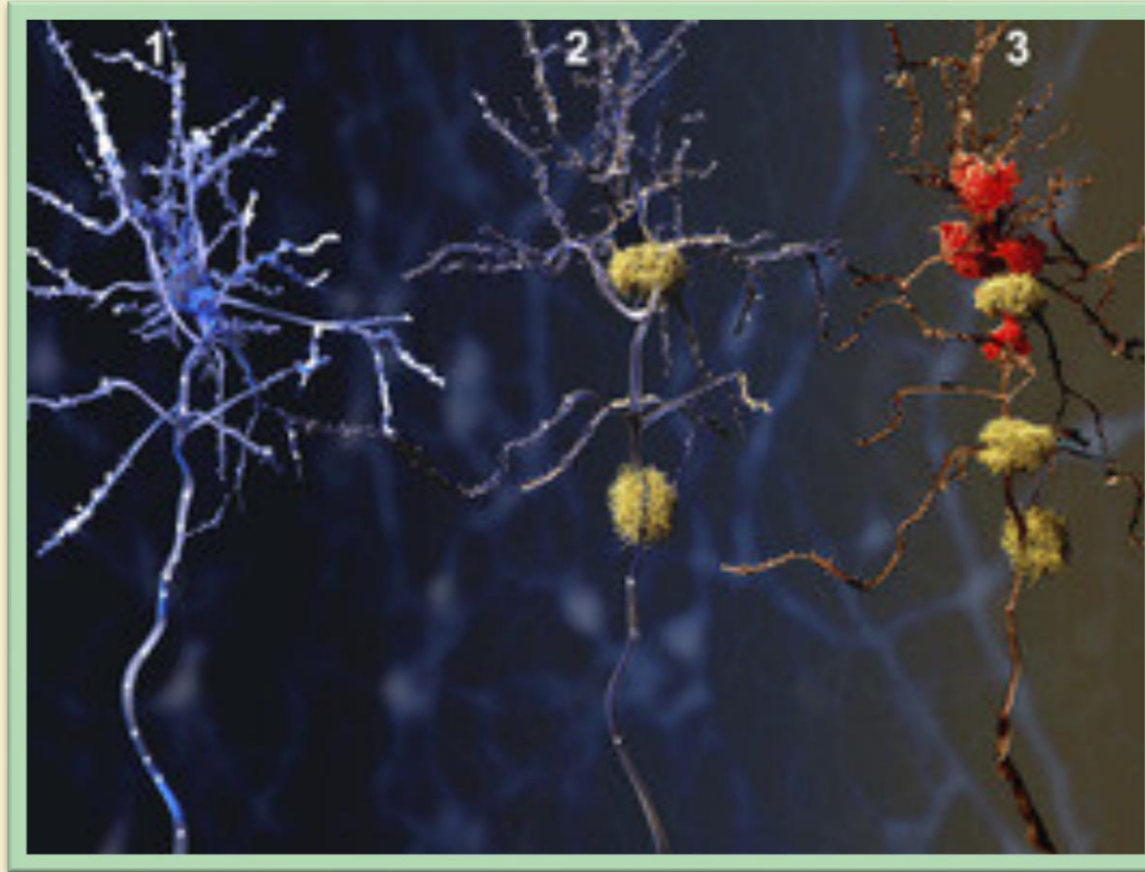
What is Dementia?

Dementia is not a specific disease...



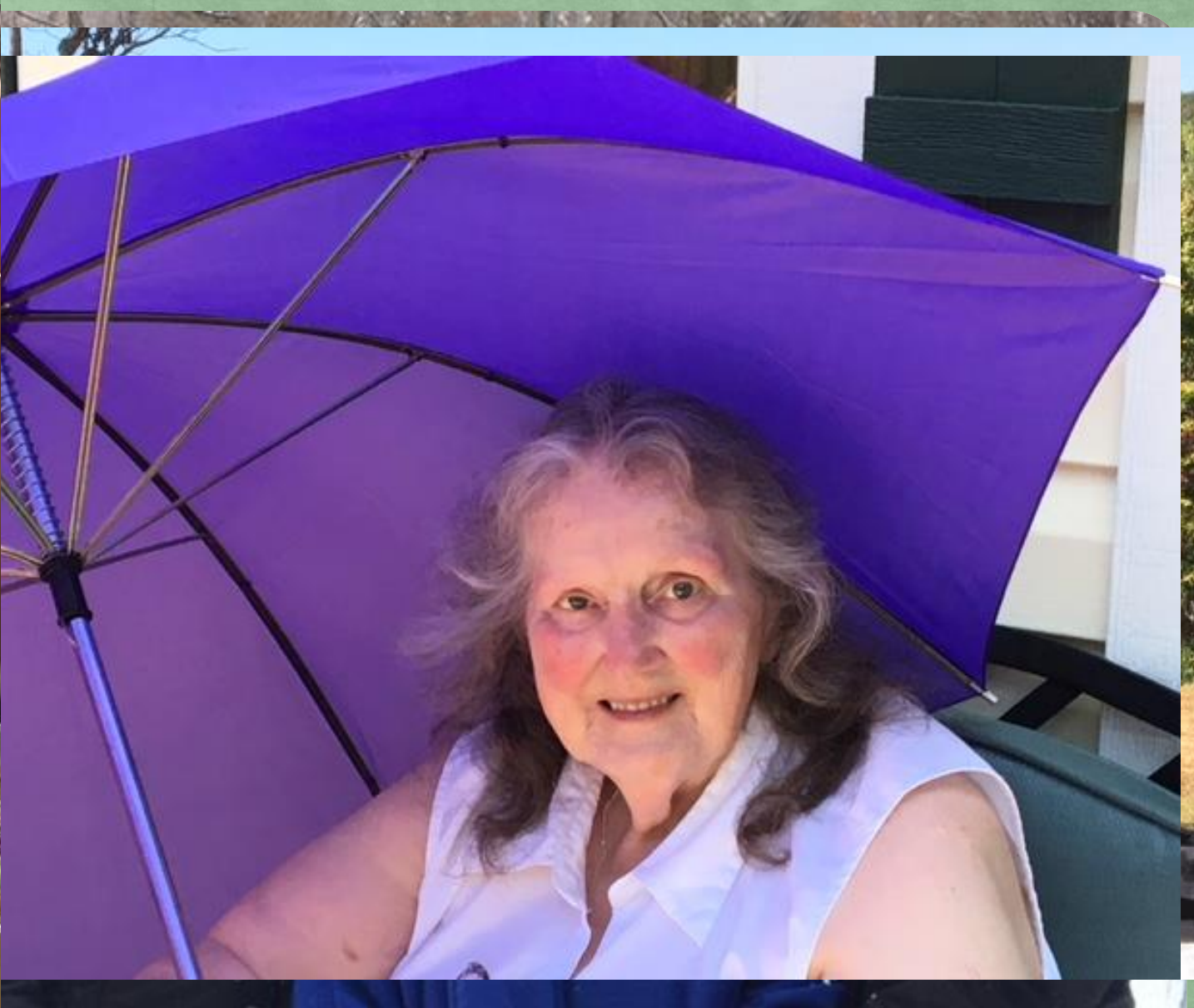
Dementia is a general term for a wide range of symptoms. It is associated with a decline in mental ability (memory or other thinking skills) severe enough to interfere with daily life.

What causes the changes seen in Alzheimer's disease?





"My memory is really terrible Mildred, so I changed my password to "incorrect." That way when I log in with the wrong password, the computer will tell me ... "Your password is incorrect"



Lessons From Sallie:

- Don't talk over me. It makes me feel like I no longer matter.
- Listen to what I have to say...even when I ramble.
- The television and the phone break...it's not my fault.
- It's not always important for you to know what I'm thinking.
- People are messing with my mind and trying to drive me crazy!
- I don't have that Alzheimer's! All my doctors tell me I'm fine
- When you finish my sentences for me...it causes me to lose my own thoughts, even when you are right.

Alzheimer's Impacts Everyone:

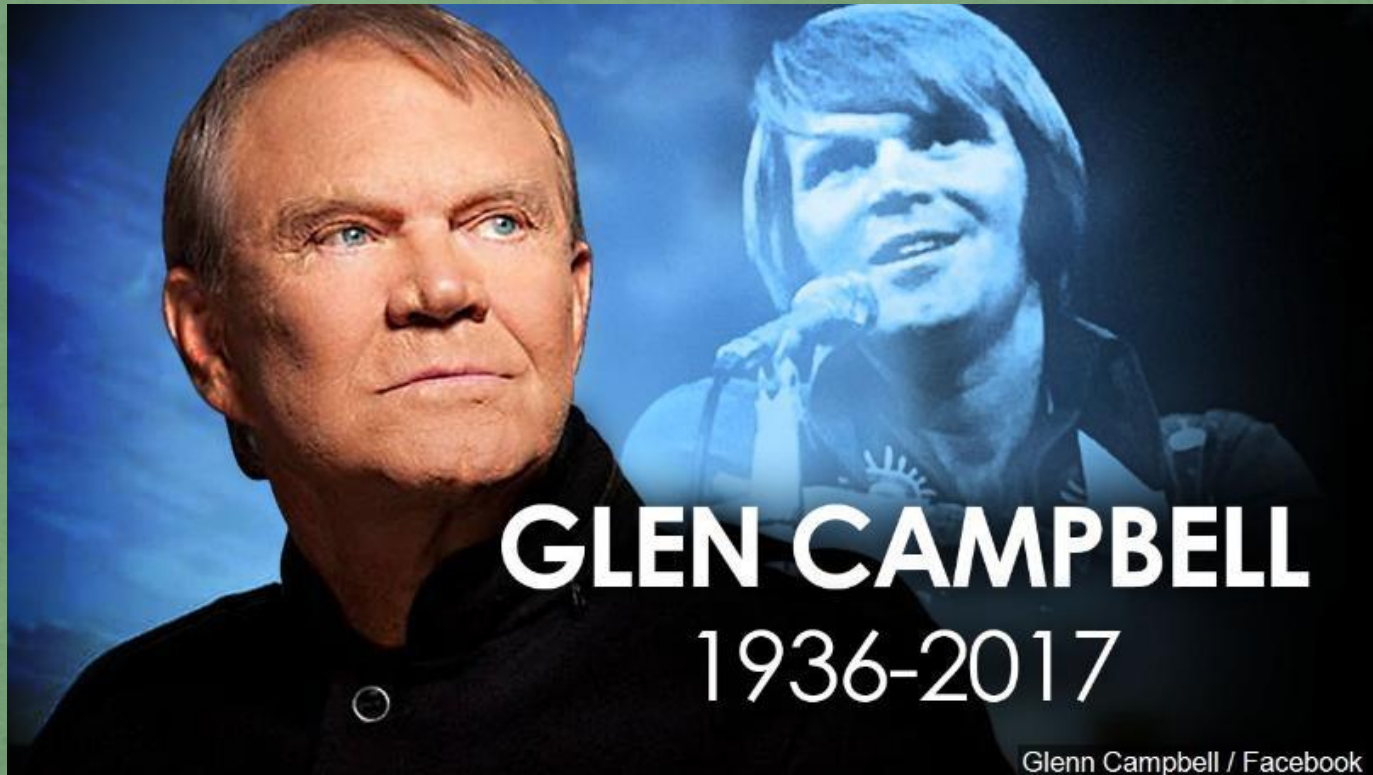
- Person Living with dementia
- Spouses
- Adult Children
- Young Children (May be grandchild, or in early onset, child of person living with dementia)
- Siblings and Friends



Special Needs of the Alzheimer's Family

- Alzheimer's disease is a progressive, terminal illness, evoking many emotions for all involved when diagnosed.
- The chronic nature of Alzheimer's and similar dementias often creates a challenge finding practical, cost effective care which may cause additional emotions to surface for both the *carer* and the *caree*.
- The physical symptoms of Alzheimer's reaches far beyond memory lost, impacting how one responds to the people in their life emotionally and physically. This creates many changes in family relationships and dynamics.
- Education, understanding, patience, support, resources and open communication are essential tools for the Alzheimer's family to navigate the journey as successfully as possible.

The Person Living With Dementia



Living your best as long as possible:

- Focus on the person over the diagnosis (Ability versus Disability)
- Healthy lifestyle quintessential
- Maximizing independence while meeting needs (*Meet Me Where I Am* care philosophy)
- Living in the moment versus fearing the future

The Alzheimer's Spouse



Loving your best for as long as possible:

- Grief over loss of companionship, comfort of life-long partner can be overwhelming.
- Anticipatory grief (fear of the loss to com) can be paralyzing.
- As roles transition from caring spouse to person providing care, feelings of isolation and abandonment are not uncommon.
- May be difficult to admit when feeling overwhelmed
- Life long plans/dreams/goals no longer in reach

Adult Children Alzheimer's Family



Caring your best for as long as possible:

- Parents often have difficulty accepting “care and direction” of adult children, when ill, even when well intended.
- Adult children often grieve for their parent’s traditional guidance and support – fear loss to come.
- The typical adult child caregiver usually is caring for a family and holding a job. Adding the role of caring for a parent can cause a great physical and emotional burden.
- May fear hereditary factor of Alzheimer’s
- May feel life has been “put on hold” for self with all their responsibilities.

Young Children Alzheimer's Family



Maintaining Connections as long as possible:

- Children often don't understand changes caused by Alzheimer's disease.
- Age appropriate explanations help to maintain connections for as long as possible.
- Using picture books like *Grandma and Me* is a great way to start conversations and allow children to ask questions
- Children need a safe way to explore their feelings
- Be prepared for the types of questions children commonly ask.

Staying Connected



The Family Community:

- ✓ **Membership:** A sense of belonging
- ✓ **Influence:** Feeling you have a say in what happens.
- ✓ **Integration/Fulfillment:** A sense of reward or recognition.
- ✓ **Shared Emotional Connection:** Members will have a history of experiences together and share more experiences together in the future.

Sense of community is a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together (McMillan, 1976).





Engagement is
Key in
Maintaining
Family
Connections

Caring and Coping



Meet Me Where I Am Care Philosophy

<https://www.youtube.com/watch?v=xcHm80LmdEA>

Ten Absolutes of Alzheimer's Care:

1. **AGREE**, never argue.
2. **REDIRECT**, never reason.
3. **DISTRACT**, never shame.
4. **REASSURE**, never lecture.
5. **REMINISCE**, never say "Do you remember?"
6. **REPEAT**, never say "I already told you".
7. Say "**DO WHAT YOU CAN**", never say "You can't".
8. **ASK** or **MODEL**, never command.
9. **ENCOURAGE** and **PRAISE**, never condescend.
10. **REINFORCE**, never force.

Caregivers must learn to care for self too:

- ✓ **Rest, relaxation, nutrition** are basic needs. (medical appointments, dentist, haircut?)
- ✓ **Recognize and reduce personal stress** as much as possible.
- ✓ **Reward self** – Support groups, educational seminars, taking time off when tired.
- ✓ **Refuse to ride the guilt train** – There is no such thing as a perfect caregiver. We all make mistakes. Accept help when offered and ask for it when needed.



They may forget
your name but
they will never
forget how you
made them feel.

Maya Angelou



Questions?