



Caring Decisions for Families

CHURCH STREET UMC

What do families and Cleopatra have in common?



Why is denial so dangerous?

- ▶ Prevents you from getting a diagnosis
- ▶ Prolongs stress of the unknown
- ▶ It's exhausting
- ▶ Prevents you from seeking/accepting help
- ▶ Prevents you from making important decisions
- ▶ Delays starting treatment
- ▶ Can leave loved ones in dangerous situations

Juggling Responsibilities!

- ▶ Employer
 - ▶ Spouse
 - ▶ Children
 - ▶ Parents
 - ▶ Friends
 - ▶ Church
 - ▶ Dual roles
-
- ▶ What are you giving to YOU?



If You Are :

- Exhausted
- Frustrated
- Angry

You Can't Provide:

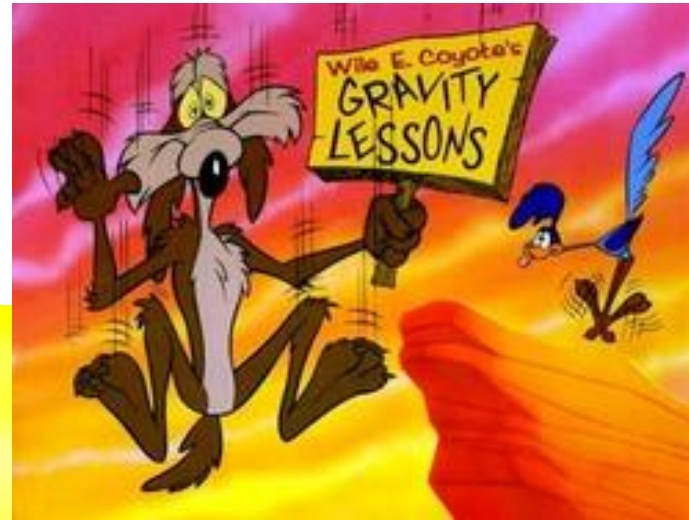
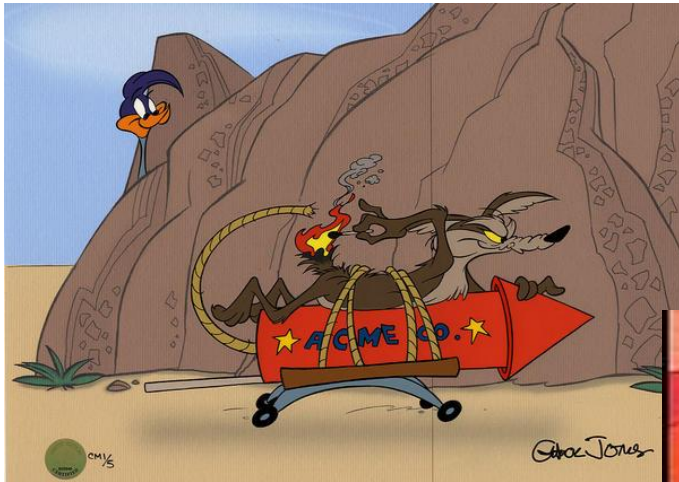
- Patience
- Compassion
- Understanding



Dealing with change

- ▶ Child becomes the parent
- ▶ Family roles get intermingled with caregiver duties
- ▶ Choosing between equally important commitments
- ▶ Watching a strong parent/ spouse get weak
- ▶ Family conflict
- ▶ Disagreeing with one needing care
- ▶ Disappointment, frustration, fear

What do caregivers do?



Expectation vs Reality

- ▶ We sometimes make things harder on ourselves.....
- ▶ Since we can't change the REALITY, we must change our EXPECTATIONS and RESPONSES

What does a caregiver need to know?

- ▶ You will likely need help. Learn to accept it.

Why is asking for help so hard?

It's a sign of weakness

It's saying I no longer want to care for him/her

It's giving up

It's not caring

It's selfish

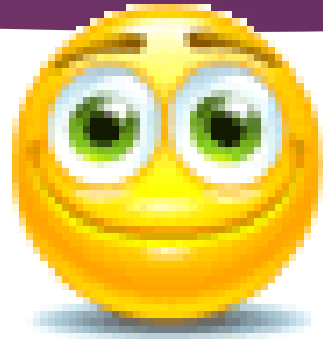
It's not honoring my vows/commitment

It's admitting I can't handle it

It creates family strife

It isn't "helpful"

Learn the best exercise and two most important words for caregivers:



YES PLEASE!

Let others help keep your cup full.

What does a caregiver need to know?

- ▶ You will need help. Learn to accept it.
- ▶ Your loved one may do and say things that are hurtful. Remember that it is the disease, not your loved one talking.

Double Vision



- ▶ There are now “ two versions” of your loved one
- ▶ My dad would never say/do that!!
- ▶ Respond to the one who is actually interacting with you. Is it dad?
- ▶ Or Alzheimer's dad? Or mom who is sick or in pain or afraid?

What does a caregiver need to know?

- ▶ You will need help. Learn to accept it.
- ▶ Your loved one may do and say things that are hurtful. Remember that it is the disease, not your loved one talking.
- ▶ You must take care of yourself physically, mentally and spiritually

Take Care of Yourself

- ▶ Education
- ▶ Support Groups
- ▶ Maintain healthy relationships with siblings
- ▶ Set boundaries
- ▶ Address guilt
- ▶ Counseling
- ▶ Make yourself a priority
- ▶ Keep your cup full

Common and normal feelings associated with caregiving

- ▶ Frustration
 - ▶ Disappointment
 - ▶ Anger
 - ▶ Helplessness
 - ▶ Embarrassment
 - ▶ Jealousy
 - ▶ Resentment
- ▶ These are all NORMAL as long as you don't get stuck there. These can lead to overwhelming stress and depression.

Guilt

Guilt: like carrying a bag of rocks



- ▶ I shouldn't feel frustrated, annoyed, angry
 - ▶ It's wrong for me to enjoy myself when she can't
 - ▶ I should never leave him/her to go somewhere
 - ▶ I am a terrible caregiver.
-
- ▶ It is NOT your fault your loved one is ill or injured. It is okay to live.
 - ▶ You didn't **cause** it, you can't **control** it, you can't **cure** it.
 - ▶ Let go of the woulda, coulda, shouldas and if onllys

Who, me? stressed?

- ▶ Short tempered
- ▶ Social withdrawal
- ▶ Anxiety
- ▶ Exhaustion
- ▶ Sleeplessness
- ▶ Irritability
- ▶ Lack of concentration/ Forgetfulness
- ▶ Health problems



Stress

Chronic stress is the greatest threat to a caregiver's well being

Common causes of stress:

- ▶ Increased feelings of responsibility for another person
- ▶ Guilt and frustration associated with unmet expectations
- ▶ Increased pressures from decision making
- ▶ Taking over responsibilities the loved one once handled
- ▶ Disruption of life and lifestyle
- ▶ Isolation from family and friends

Talking to Jesus



Or when a loved one says:

- ▶ I don't want any more treatment.
- ▶ I am ready to go.

Who is it really about?



Seek out:

- ▶ Friends who **understand**
- ▶ Support groups
- ▶ Prayer and ministry
- ▶ Counseling

Other tips for Dealing with caregiver stress

- ▶ Forgive yourself daily
- ▶ Walk away for a moment
- ▶ Laugh daily
- ▶ Practice self care techniques
- ▶ Positive self talk
- ▶ Exercise
- ▶ Pray

What does a caregiver need to know?

- ▶ You will need help. Learn to accept it.
- ▶ Your loved one may do and say things that are hurtful. Remember that it is the disease, not your loved one talking.
- ▶ You must take care of yourself physically and mentally.
- ▶ Everyone is an “expert”.

Be like Elsa



[This Photo](#) by Unknown Author is licensed under [CC BY-NC-ND](#)

Let it go, let it go

Or a duck



- ▶ Don't take it personally
- ▶ Remember: Ignorance is bliss
- ▶ Smile and nod
- ▶ Thank you, maybe I'll try that/ I will ask her doctor
- ▶ Give yourself a little credit
- ▶ Invite them to come help you
- ▶ Learn all you can so that you can weigh their advice

What does a caregiver need to know?

- ▶ You will need help. Learn to accept it.
- ▶ Your loved one may do and say things that are hurtful. Remember that it is the disease, not your loved one talking.
- ▶ You must take care of yourself physically and mentally.
- ▶ Everyone is an “expert”.
- ▶ You may need to say “I am sorry” a lot

I'm sorry

I'm sorry:

- ▶ I was trying to help.
 - ▶ I made you angry
 - ▶ I hurt your feelings
 - ▶ I embarrassed you
 - ▶ I treated you like a child
 - ▶ I made you feel like you aren't even here
 - ▶ This must be really hard
-
- ▶ Saying I'm sorry doesn't mean you are wrong. It de-escalates a situation and preserves the relationship.

What does a caregiver need to know?

- ▶ You will need help. Learn to accept it.
- ▶ Your loved one may do and say things that are hurtful. Remember that it is the disease, not your loved one talking.
- ▶ You must take care of yourself physically and mentally.
- ▶ Everyone is an “expert”.
- ▶ You may need to say “I am sorry” a lot
- ▶ Be your own best advocate
- ▶ You don’t have to handle this alone.

The promise you can keep:

- ▶ I promise I will do everything in my power to give you the best care and best quality of life possible.

Don't Wait! Be prepared

- ▶ Make copies of med lists, medical history, doctors contact, insurance cards
- ▶ Locate important documents (military, life insurance, wills)
- ▶ Know online passwords
- ▶ Talk with an elder law attorney
- ▶ Keep emergency information current and handy
- ▶ Arrange for e- bills
- ▶ Get a Silver Alert Kit from Alzheimer's Tennessee
- ▶ Divide tasks with other family members as able
- ▶ Discuss long term living arrangements in advance

Aging in place



Connect with Community

- ▶ Enlist neighbors and church friends
- ▶ Alert local authorities
- ▶ Complete Silver Alert Kit
- ▶ Volunteer visitation programs (AAAD, senior centers, sheriff's offices)
- ▶ Assurance calls
- ▶ Mobile meals

Utilize available resources

- ▶ Geriatric Care Mangers
- ▶ In home caregiver agencies
- ▶ Assisted Living locator services
- ▶ Medicaid/VA/Long term care insurance
- ▶ Discharge planners and social workers
- ▶ Elder law attorneys/life care plans

Make the Home Safer

- ▶ Install ramps
- ▶ Remove throw rugs
- ▶ Remove excess clutter
- ▶ Remove weapons, dangerous chemicals and old medications
- ▶ Hire a cleaning service/ clear refrigerator
- ▶ Utilize technology (www.alztennessee.org/safety)
- ▶ Assess driving safety (At the Crossroads)

A decision to make



How do I know it's time?

- ▶ Can I duplicate myself?
- ▶ Can I learn all the skills needed?
- ▶ Can I stay awake 24 hours a day?
- ▶ Can I ensure safety?
- ▶ Is it negatively impacting my marriage, family, job?
- ▶ Are their physical, emotional, psychological, spiritual needs being met?
- ▶ Falling or wandering

Changing one word

- ▶ How could you do that TO your mother?
- ▶ I will never do that TO my husband!
- ▶ I can't believe what you did TO your dad!

See the Difference?

- ▶ I am going to do this FOR my mother.
- ▶ I am doing the very best thing FOR my husband.
- ▶ I am glad I can provide this FOR my dad.

Feeling that you are dumping your loved one



Benefits of a community for you

- You get to be the child/spouse
- No more arguing over baths, PT, medication
- 24 hour care with fresh staff every 8-12 hours
- In house medical care
- You can worry less
- You can sleep
- You can be you to everyone else

Number one predictor of longevity?



Benefits for Your Loved One

- ▶ Social interaction
- ▶ Activities
- ▶ Learning new skills
- ▶ Meals
- ▶ Exercise
- ▶ Cared for by non relative



All of those are good for

- ▶ Physical, emotional and brain health!
- ▶ Therefore good for your loved one!

A common question...

- ▶ How often should I visit?

Answer:

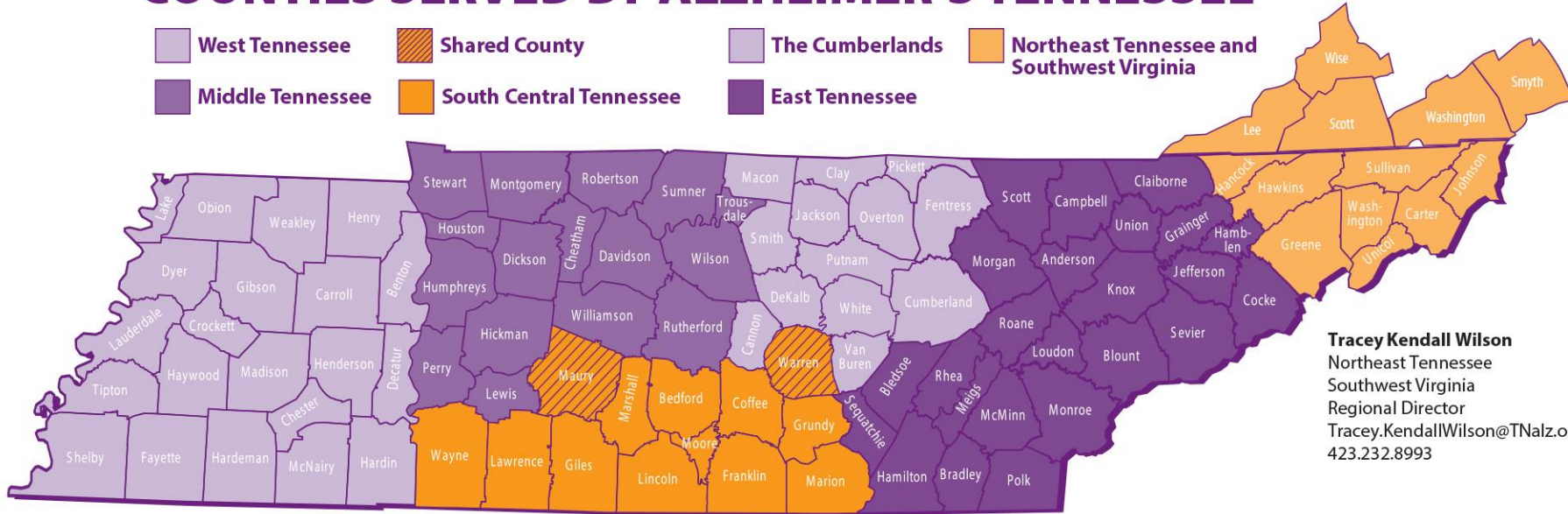
- ▶ How often did you visit when he/she lived at home?
- ▶ What is the purpose of your visit?
- ▶ Who are you visiting for?

Grace, mercy, forgiveness

Nobody is the PERFECT caregiver but tomorrow is a new day!

COUNTIES SERVED BY ALZHEIMER'S TENNESSEE

- West Tennessee
- Shared County
- The Cumberlands
- Northeast Tennessee and Southwest Virginia
- Middle Tennessee
- South Central Tennessee
- East Tennessee



Tracey Kendall Wilson
 Northeast Tennessee
 Southwest Virginia
 Regional Director
 Tracey.KendallWilson@TNalz.org
 423.232.8993

Amanda Barlow Leitch
 West Tennessee Director
 Amanda.BarlowLeitch@TNalz.org
 731.694.8065

Lynn Drew
 Cumberlands Regional Director
 Lynn.Drew@TNalz.org
 931.526.8010

Janice Wade-Whitehead
 President & CEO
 Janice.Wade@TNalz.org
 865.544.6288 x222

Mary Lynne Payne
 Development & Public Relations
 MaryLynne.Payne@TNalz.org
 865.544.6288 x234

Larry Effler
 Communications Director
 Larry.Effler@TNalz.org
 865.544.6288 x225

Cheryl Blanchard, LMSW
 MiddleTennessee Regional Director
 Cheryl.Blanchard@TNalz.org
 615.580.4244

Fran Gray
 South Central Coordinator
 Fran.Gray@TNalz.org
 931.434.2348

Linda Johnson
 Director of Programs
 Linda.Johnson@TNalz.org
 865.544.6288 x227

Katie Harbin
 Development & Public Relations
 Katie.Harbin@TNalz.org
 865.544.6288 x229

Kay Watson
 Kay.Watson@TNalz.org
 865.544.6288 x230

Main Office

5801 Kingston Pike, Knoxville TN 37919

865.544.6288

www.facebook.com/AlzTN

Make Alzheimer's a Memory