



Making Moments of Joy:

It's What YOU Choose to Do as a Caregiver

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Laughing VS Surviving

- The goals...
 - Understanding of what's happening with the person with dementia
 - Support so you can survive
 - Insight for the moments of joy

REALIZE ...

- *It Takes TWO to Tango ...
or two to tangle...*

If you 'push' your help AND get RESISTANCE

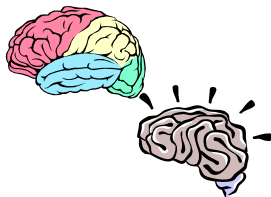
- STOP
- Pull back
- Notice the person's emotions & 'state'
- Acknowledge their words and position
- Apologize.... (even though you didn't do anything 'wrong')

My Examples

- | | |
|---|---|
| <ul style="list-style-type: none"> • No F PoA or HC PoA – • Going to MD problems • 'Losing' Important Things • Getting Lost – time, place, situation • Unsafe task performance • Repeated calls & contacts • Refusing help & care • 'Bad mouthing' you to others • Making up stories - confabulation • Undoing what is done • Swearing/cursing, sex talk, racial slur, ugly words • Making 911 calls • Mixing day & night • Sleep problems – too much or too little • Not following care/rx plans - denying • No initiation – can't get started • Perseveration – can't stop repeating • Not talking any more | <ul style="list-style-type: none"> • Paranoid/delusional thinking • Shadowing - following • Eloping or Wandering • Seeing things & people not there - hallucinations • Getting 'into' things • Threatening caregivers • Undressing in public – not changing when needed • Problems w/intimacy & sexuality • Being rude - intruding • Feeling 'sick' – not doing 'anything' • Use of drugs or alcohol to 'cope' • Striking out at others • Falls & injuries • Contractures & immobility • Infections & pneumonias • Problems w/ eating or drinking |
|---|---|

Why Do These Things Happen?

- | | |
|--|---|
| <ul style="list-style-type: none"> • EVERYTHING is affected <ul style="list-style-type: none"> – Thoughts – Words – Actions – Feelings • It is progressive <ul style="list-style-type: none"> – More brain dies over time – Different parts get hit – Constant changing • It is variable <ul style="list-style-type: none"> – Moment to moment – Morning to night – Day to day – Person to person | <ul style="list-style-type: none"> • Dementia is predictable <ul style="list-style-type: none"> – Specific brain parts – Typical spread – Some parts preserved |
|--|---|



Why Might These Things **NOT** Happen?

- Dementia is individualistic
- The person 'doesn't have it in them...'
- The situation doesn't come up
- Other conditions keep it from happening
- Caregivers have great skills
- The dementia isn't bad enough yet
- You get LUCKY!

What Makes 'STUFF' Happen?

- **SIX pieces...**
 - **The person & who they have been**
 - Personality, preferences & history
 - **Other medical conditions & sensory status**
 - **The level & type of dementia ... NOW**
 - **How the helper helps -**
 - Approach, behaviors, words, actions, & reactions
 - **The environment – setting, sound, sights**
 - **The whole day... how things fit together**

What Can YOU Control? OR NOT!

CONTROL...

- The environment – setting, sound, sights
- The whole day... how things fit together
- How the helper helps -
 - Approach, behaviors, words, actions, & reactions

NOT CONTROL

- The person & who they have been
 - Personality, preferences & history
- The level of dementia ... NOW
- Other medical conditions & sensory status



What is Dementia?

What's Happening?

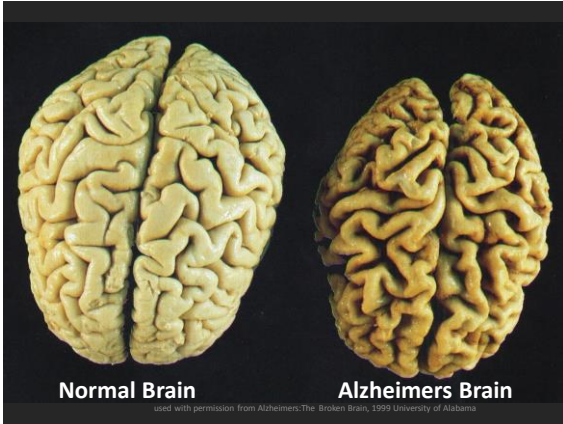
How Can I Help?

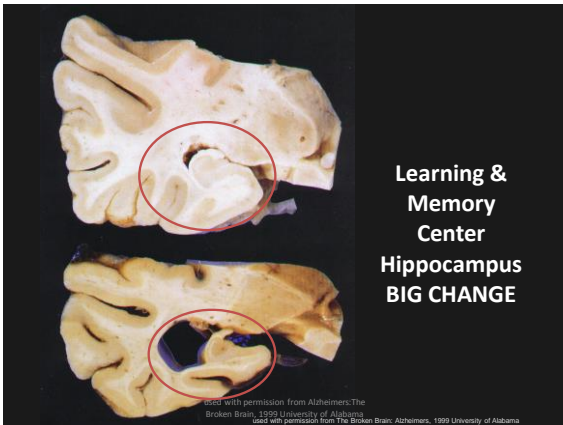
Risk Factors

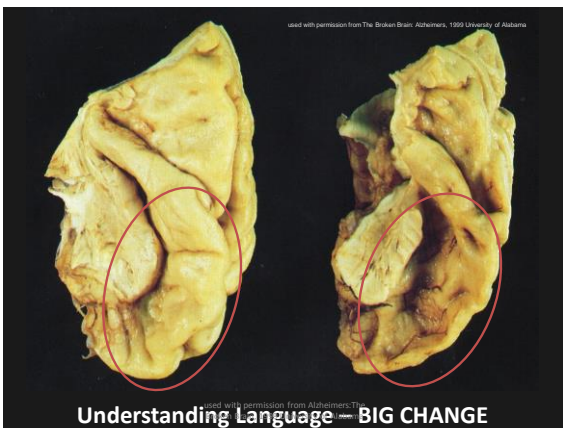
- Increasing Age
- Life Style Choices
 - No Exercise
 - Bad Diet
 - Cognitive stagnation
 - Social Isolation
 - **Stress**
 - Sleep Issues
 - Head injuries
- Genetics
 - Can run in families
 - Certain types are dominant genes
 - Other types are 'risk factor' genes
 - Some types are 'spontaneous mutations'

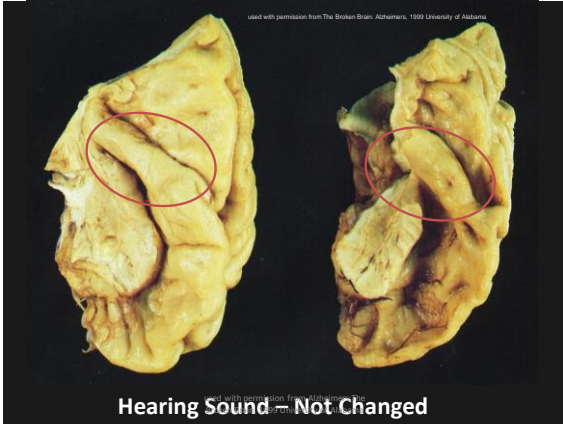
Four Truths About Dementia

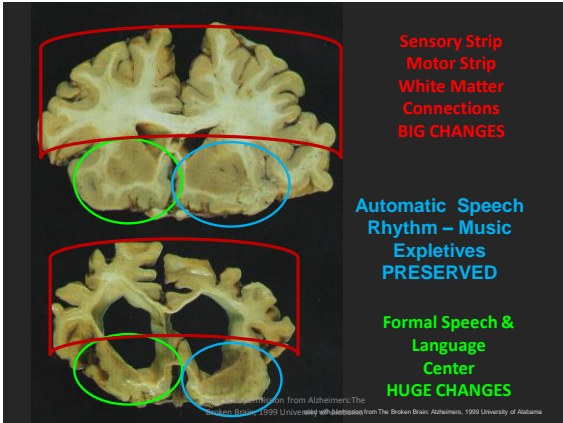
- At least 2 parts of the brain are dying
 - One related to memory & the one other
- It is chronic – can't be fixed
- It is progressive – it gets worse
- It is terminal – it will kill, eventually



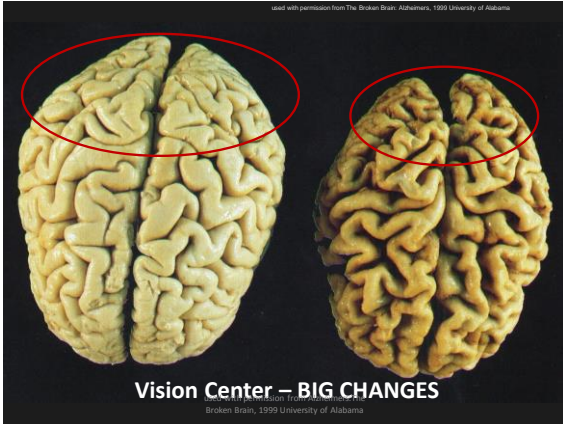












So... what 's happening to them?

- Memory damage
 - Can't learn new things
 - Forgets immediate past
 - Does time & space travel
 - Uses old memories like new
 - May not ID self or others correctly
 - CONFABULATES
 - Follows visual cues
 - Seeks out the familiar
 - Can get stuck on an old emotional memory track
- Language damage
 - Has very concrete understanding of words
 - Misses 1 out of 4 words – may miss "Don't..."
 - Word finding problems
 - Word salad problems
 - COVERS
 - Follows your cues
 - Gets very vague & repeats
 - Uses automatic responses
 - Mis-speaks

So... what's happening to them?

- Impulse Control Problems
 - Say whatever they are thinking
 - Swear easily
 - Use sex words or racial slurs when stressed
 - Act impulsively
 - Not think thru consequences
 - Can't hold back on thoughts or actions
 - Responds quickly & strongly to perceived threats
 - Flight, fight, fright
- Performance Problems
 - Thinks they can do better than they can
 - Can sometimes DO BETTER under pressure – sometimes worse
 - Uses old habits
 - Attempts can be dangerous or fatal
 - They will tell you one thing and then do another...
 - Families may over or under 'limit' activities

Positive Progression GEMS...



- Sapphires
- Diamonds
- Emeralds
- Ambers
- Rubies
- Pearls



Seeing What is Possible - GEMS...

- Sapphires – True Blue – Slower BUT Fine
- Diamonds – Repeats & Routines, Cutting
- Emeralds – Going – Time Travel – Where?
- Ambers – In the moment - Sensations
- Rubies – Stop & Go – No Fine Control
- Pearls – Hidden in a Shell - Immobile

Diamond

- Uses Routines & Old Habits to function
- Can complete personal care in 'familiar place'
- Follows simple prompted schedules - mostly
- Misplaces things and can't find them
- 'Resents takeover' or bossiness
- Notices other people's mis-behavior & mistakes
- Territorial – refusals!
- Varies in lack of self-awareness

Personal Care Issues

- **IADLs**
 - Money management
 - Transportation - Driving
 - Cooking
 - Home maintenance & safety
 - Caring for someone else
 - Pet maintenance
 - Med administration
- **Unfamiliar settings or situations**
 - Hospital stay
 - Housing change
 - Change in family
 - Change in support system
 - MD visits
 - New diagnoses
 - Traveling or vacations

Help?

- Apologize! - "I'm SORRY!" – "I didn't mean to..."
- Friendly NOT bossy
- "Let's try" – temporary...
- Share responsibility not take over
- Use as many 'old habits' as possible
- Give up being 'RIGHT'
- Go with the FLOW
- Give other 'job' when taking away another

Use empathy & Go with the flow



How you talk...

- **How** you say it...
- **What** you say...
- How you **respond**...

Emerald

- Limited awareness of time sensitive needs
- Needs some “HELP” – not doing for or to
- Wants the familiar ... hard to find it
- Asks a lot about “What...? Where...?”
- Increasing mistakes and errors
- Likes to ‘stay busy’ with familiar tasks
- Fears being seen as ‘incompetent’

Personal Care Issues

- Doesn’t do care routinely – thinks did
- Makes mistakes in sequence – unaware
- Repeats some care routines over & over
- Resists or refuses help
- Gets lost – can’t find where to do care
- Limited awareness of ‘real needs’ –
 - Hunger, thirst, voiding, bathing, grooming...
- Has other ‘stuff’ to do...

How to Help

- Learn about “SO WHAT!” ... is it worth it?
- Provide ‘subtle’ supervision for care
- Provide visual prompts to do
 - Gestures, objects, set-up, samples, show
- Hide visual cues to ‘stop’/prevent
 - Put away, move out of range, leave
- Use the environment to cue – SHOW
- Use ‘normal’, humor, friendliness, support

What NOT to DO...

- DO NOT point out errors – or focus on ‘wrong’
- DO NOT offer – physical assist 1st
- DO NOT offer “Let me HELP you”
- DO NOT try to ‘go back and fix it...’
- DO NOT continue arguing about ‘reality’
- DO NOT treat like children...

Positive Physical Approach



A Positive Approach

(To the Tune of Amazing Grace)

Come from the front

Go slow

Get to the side,

Get low

Offer your hand

Call out the name then WAIT...

If you will try, then you will see

How different life can be.

For those you're caring for!

Amber

- LOTS of touching, handling, mouthing, manipulating
- Focus on fingers and mouth
- Get into things
- All about sensation....
- Invade space of others
- Do what they like AVOID what they do NOT

How to Help

- Provide step-by-step guidance & help
- Give demonstration – show
- Hand-under-hand guidance after a few repetitions, uses utensils (not always well)
- Offer something to handle, manipulate, touch, gather
- Limit talking, noise, touch, other activities
- SUBSTITUTE don't SUBTRACT

Hand-Under-Hand Assistance



Ruby

- Big movements – walking, rolling, rocking
- Hand actions – not fingers
- Tends toward movement unless 'asleep'
- Follows gross demonstration & big gestures for actions
- Limited visual awareness
- Major sensory changes
- Major movement skill loses
- Fine motor skill lost – mouth & hands

How to Help

- Hand under hand
- Move with first – then guide
- Learn about patterns of 'needs'
- Gradual transitions - go to stop
- Use music and rhythms – help get or stop movement
- Use touch with care
- Combine cuing & do SLOW

Pearl

- Immobile – can't get started
- Bed or chair bound
- Has more time asleep or unaware
- Has many 'primitive' reflexes present -Startles easily
- May cry out or mumble 'constantly
- Increases vocalizations with distress
- Difficult to calm
- Knows familiar from unfamiliar
- Touch and voice make a difference in behaviors

How to Help

- Hand under hand help & care
- Check for reflexes – modify help and approach to match needs
- Guide movements
- Use calm, rhythmic movements and voice
- Come in from back of extremities to clean
- Stabilize with one hand and work with other

How can we help... better?

It all starts with
your approach!

How you help...



• Sight or Visual cues



• Verbal or Auditory cues



• Touch or Tactile cues

Believe -

People with dementia

Are doing

The BEST they can!

What shouldn't we do???

- Argue
- Tell 'WHOPPERS' – that relate to emotions
- Ignore problem behaviors
- Try a possible solution only once
- Give up
- Let them do whatever they want to
- Force them to do it

So WHAT should we do???

Remember
who
has the healthy brain!

So What Can You Do????

Seven Ways to Help

**How Can You Be Prepared & Respond
When Something Does Happen?**

- Think..., then act & respond
- Use the positive physical approach
- Reflect on the emotional message
- Figure out the 'need'
- Use old & familiar to help with new
- Take time & energy to problem solve... after
- If its not working ... STOP, Back off, try again

So... What Should You Do?

- Plan for the probabilities
- Create environments that reduce risk
- Get skilled or find someone who is
- Get others on board
- Keep track of 'what is'
- Watch for signs of changes
- Get help early – call or contact
- Be flexible



How *You* Feel is **REAL & Important!**

- However you feel is OK, its how you feel!
- It's not about judgment, its about support!
- Acknowledge the feelings...
- Then decide what to do about it...
- Is it what you want to feel?
- IF YES, go with it...
- If NO, work to change it!

If You are having a HARD TIME...

- Think about...
 - What **HELPS** YOU
 - What you **NEED**
 - What is **MISSING**
 - What you are struggling with
 - Who else might help
 - What will happen if you don't do something
 - What might happen if you do...

Some Ideas for changing...

- Pick one thing
- Plan on baby steps
- Get support for you
- Build a routine
- Check in on your feelings
- Add something before giving something up
- Believe it - Not everyone is meant to do hands on care
- Give it a try... not permanent... just try

A Few More Ideas

- Set aside a few minutes – use a timer!
- Breathe
- Smile ... Laugh! – look for some funnies
- Remember a good time
- What do you get out of the relationship
- Use at least one of the STRESS TAMERS

What is There is Laugh About?

- What the person says
- What the person does
- What the person says VERSUS what is done
- Your mistakes and OOPS
- Your moments of joy
- Your moments of insight
- Their moments of insight... awareness... or humor
- Other people and their behaviors or words
- Things you see, hear, read...

History According to Kids

- Ancient Egypt was old. It was inhabited by gypsies and mummies who all wrote in hydraulics. They lived in the Sarah Dessert. The climate Of the Sarah is such that all the inhabitants have to live elsewhere.
- Solomon had three hundred wives and seven hundred porcupines. He was an actual hysterical figure as well as being in the bible. It sounds like he was sort of busy too.

- Socrates was a famous old Greek teacher who went around giving people advice. They killed him. He later died from an overdose of wedlock which is apparently poisonous. After his death, his career suffered a dramatic decline.
- In the first Olympic games, Greeks ran races, jumped, hurled biscuits, and threw the java. The games were messier then than they show on TV now.
- Madman Curie discovered radio. She was the first woman to do what she did. Other women have become scientists since her but they didn't get to find radios because they were already taken.

- Sir Francis Drake circumcised the world with a 100 foot clipper which was very dangerous to all his men.
- Johann Bach wrote a great many musical compositions and had a large number of children. In between he practiced on an old spinster which he kept up in his attic. Bach died from 1750 to the present. Bach was the most famous composer in the world and so was Handel. Handel was half German, half Italian, and half English. He was very large.

- The greatest writer of the Renaissance was William Shakespeare. He was born in the year 1564, supposedly on his birthday. He never made much money and is famous only because of his plays. He wrote tragedies, comedies, and hysterectomies, all in Islamic pentameter.
- Louis Pasteur discovered a cure for rabbits but I don't know why.
- Joan of Arc was burnt to a steak and was canonized by Bernard Shaw for reasons I don't really understand. The English and French still have problems.

10 Minute Stress Tamers

- **Sit quietly** in calm surroundings with soft lights and pleasant scents.
- **Aromatherapy** – lavender, citrus, cinnamon, peppermint, fresh cut grass.
- **Breathe deeply** – rest your mind & oxygenate
- **Soak** - in a warm bath, or just your hands or feet
- **Read** - Spiritual readings, poetry, inspirational readings, or one chapter of what you like...
- **Laugh and smile** - Watch classic comedians, Candid Camera, America's Funniest Home Videos, look at kid or animal photos...
- **Stretch** – front to back, side to side, & across
- **Garden** – work with plants

10 Minute Stress Tamers

- **Beanbag heat therapy.** Fill a sock with dry beans and sew or tie closed. Heat bag and beans in a microwave for 30 seconds at a time. Place on tight muscles and massage gently; relax for ten minutes.
- **Remember the good times** - Record oral memories - scrapbooks, photo journals, keepsake memory picture frames. Just jot!
- Do a *little* on a favorite **hobby**.
- Have a **cup of decaffeinated tea or coffee**
- Play a **brain game** – crosswords, jigsaws, jeopardy, jumbles...
- Look through the **hymnal** and find a favorite – hum it all the way through...

10 Minute Stress Tamers

- **Books on Tape** - Rest your eyes and read
- **Soothing sounds** –
 - Music you love
 - Music especially for stress relief
 - Recorded sounds of nature
- Listen to **coached relaxation recordings**
- **Pamper Yourself** – think of what you LOVE and give yourself permission to do it for 10 minutes
- **Neck rubs or back rubs** – use the ‘just right’ pressure
- **Hand Massages** – with lotion or without – its up to you...

10 Minute Stress Tamers

- **Take a walk.**
- **Sit** in the sun.
- **Rock** on the porch.
- **Pray** or read a passage from scripture
- **Journal** - Take the opportunity to “tell it like it is.”
- Cuddle and stroke a **pet**.
- Have that cup of coffee or tea with **a special friend** who listens well.
- Pay attention to **your personality**.
 - If you rejuvenate being alone, then *seek solitude*.
 - If you rejuvenate by being with others, *seek company*.

BREATHE!!!

- Take a deep breath in
- BLOW it all the way out
- Take another breath in
- BLOW it out
- Take one final breath in AND
- SING IT OUT....

- Feel what happened to you...
- Look at what happened to the people around you...
- Think about how and when you might do this...

Let Go:

- How it “used to be”
- How it “should be”
- How you “should be”

Identify

- What you’re good at...and what you’re not
- Who can help...and how they can help
- What really matters

Final Suggestions

- Back off, change something and try again
- Adopt a “SO WHAT” mentality
- Try a support group
- Accept yourself, and the person with dementia
- Look for the JOY!!!
