Why Do They Do That?:

Understanding the Symptoms and Behaviors of Dementia
PET and Aging

PET Scan of 20-Year-Old Brain

PET Scan of 80-Year-Old Brain

ADEAR, 2003
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
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’
Brain Failure

The person’s brain is dying
Positron Emission Tomography (PET)
Alzheimer's Disease Progression vs. Normal Brains

Normal | Early Alzheimer’s | Late Alzheimer’s | Child

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Learning & Memory Center
Hippocampus
BIG CHANGE
Understanding Language — BIG CHANGE
Hearing Sound – Not Changed
Sensory Strip
Motor Strip
White Matter Connections
BIG CHANGES

Automatic Speech Rhythm – Music Expletives PRESERVED

Formal Speech & Language Center HUGE CHANGES
Executive Control Center
Emotions
Behavior
Judgment
Reasoning
Vision Center – BIG CHANGES
What is Dementia?...

It is BOTH
- a chemical change in the brain
AND
- a structural change in the brain

- So...
  Sometimes they can & sometimes they can’t
Brain atrophy

the brain actually shrinks
cells wither then die
abilities are lost
with Alzheimer’s area of loss are fairly predictable
… as is the progression
BUT the experience is individual…
Memory Loss

Losses
- Immediate recall
- Attention to selected info
- Recent events
- Relationships

Preserved abilities
- Long ago memories
- Confabulation!
- Emotional memories
- Motor memories
Understanding

Losses

- Can’t interpret words
- Misses some words
- Gets off target

Preserved abilities

- Can get facial expression
- Hears tone of voice
- Can get some non-verbals
- Learns how to cover

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Sensory Changes

Losses

• Awareness of body and position
• Ability to locate and express pain
• Awareness of feeling in most of body

Preserved Abilities

• 4 areas can be sensitive
• Any of these areas can be hypersensitive
• Need for sensation can become extreme
Self-Care Changes

Losses
• initiation & termination
• tool manipulation
• sequencing

Preserved Abilities
• motions and actions
• the doing part
• cued activity
Language

Losses

• Can’t find the right words
• Word Salad
• Vague language
• Single phrases
• Sounds & vocalizing
• Can’t make needs known

Preserved abilities

• singing
• automatic speech
• Swearing/sex words/forbidden words
Impulse & Emotional Control

Losses

• becomes labile & extreme
• think it - say it
• want it - do it
• see it - use it

Preserved

• desire to be respected
• desire to be in control
• regret after action
Use empathy & Go with the flow

No Reality Orientation

No Telling Lies
How you talk…

- **How** you say it…
- **What** you say…
- **How** you respond…
How can we help... better?

- It all starts with
- your approach!
To Connect

Start with the Positive Physical Approach
Your Approach

- Use a consistent positive physical approach
  - pause at edge of public space
  - gesture & greet by name
  - offer your hand & make eye contact
  - approach slowly within visual range
  - shake hands & maintain hand-under-hand
  - move to the side
  - get to eye level & respect intimate space
  - wait for acknowledgement
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!
Supportive Communication

- Make a connection
  - Offer your name – "I’m (NAME)"... "and you are..."
  - Offer a shared background – “I’m from (place) ...and you’re from...”
  - Offer a positive personal comment – “You look great in that ....” or “I love that color on you..."
Support to ‘Get it GOING!’

- Give SIMPLE & Short Info
- Offer concrete CHOICES
- Ask for HELP
- Ask the person to TRY
- Break the TASK DOWN to single steps at a time
Give SIMPLE INFO

- USE VISUAL combined VERBAL (gesture/point)
  - “It’s about time for...“
  - “Let’s go this way...”
  - “Here are your socks...”

- DON’T ask questions you DON’T want to hear the answer to...

- Acknowledge the response/reaction to your info...

- LIMIT your words – Keep it SIMPL

- WAIT!!!!
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!
So… What is Dementia?

- It changes everything over time
- It is NOT something the person can control
- It is NOT always the same for every person
- It is NOT a mental illness
- It is real
- It is hard at times
Positron Emission Tomography (PET)
Alzheimer’s Disease Progression vs. Normal Brains

Normal  Early Alzheimer’s  Late Alzheimer’s  Child

G. Small, UCLA School of Medicine.
How Do We Measure Progression?

- Screening – Assessment
- Observed Behavior & Demonstrated Skills
- Three Scales Used
  - 1-3 – Alzheimers (Early, Middle, Late)
  - GDS – 7 point scale (1-7)
  - Cognitive Disability Theory – ACL (6-1)
Gem Levels = Allen Levels

- Not numbers - Each is precious & unique
- Each requires a special ‘setting’
- Each requires the ‘just right’ care
  • Visual, verbal, touch cues
- Each can shine
- Dynamic & Fluid – in the moment behavior
  • Accounts for chemistry as well as structure
- Takes 2 concepts & connects
  • familiar & new, better use & application
Now for Progression…
think GEMS not just loss

Sapphires
- Diamonds
- Emeralds
- Ambers
- Rubies
- Pearls
Now for the 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
Dementia can be treated

- With knowledge
- With skill building
- With commitment
- With flexibility
- With practice
- With support
- With compassion
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 it’s 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
Find Humor – Moments of ‘Funny’

- 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…
10 Minute Stress Tamers

- **Sit quietly** in calm surroundings with soft lights and pleasant scents.

- **Aromatherapy** – lavender, citrus, vanilla, 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...
Reach Out to Someone Else

- Hold someone’s hand – hand-under-hand
- Give someone a hand rub
- Say yes to a hand rub or shoulder rub from someone else
- Breathe while they do the work – SWITCH
Remember & Believe:

Taking Care of YOU
Is the First Step in Caring for the Person You Love!