Navigating the Journey of Dementia
PET and Aging:

PET Scan of 20-Year-Old Brain

PET Scan of 80-Year-Old Brain

As we age, our processing speed may slow, but we do not lose function in our brains, unless…

Something Goes Wrong With Our Brains

Normal vs. Not Normal Aging:

Normal Aging:
- Slower to think
- Slower to do
- Hesitates more
- More likely to ‘look before leaping’
- Know the person but not the name
- Pause to find words
- Reminded of the past
- Harder

Not Normal Aging:
- Can’t think the same
- Can’t do like before
- Can’t get started
- Can’t seem to move on
- Doesn’t think it out at all
- Can’t place the person
- Words won’t come – even later
- Confused about past versus now
- Very different!
Ten Early Warning Signs for Alzheimers and Some Other Dementias:

1. Memory loss for recent or new information, repeats self frequently
2. Difficulty doing familiar but difficult tasks: managing money, medications, driving
3. Problems with word finding, mis-naming, or misunderstanding
4. Getting confused about time or place, getting lost while driving, missing several appointments
5. Worsening judgment, not thinking thing through like before
6. Difficulty problem-solving or reasoning
7. Misplacing things or putting them in 'odd' places
8. Changes in mood or behavior
9. Changes in typical personality
10. Loss of initiation: withdraws from normal patterns of activities and interests

Four Truths About Dementia:

1. At least 2 parts of the brain are dying: -One related to memory and another part
2. It is chronic – it can’t be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually

Positron Emission Tomography (PET)
Alzheimers Disease Progression vs. Normal Brains
Executive Control Center: Emotions Behavior Judgment Reasoning

Wiring – connecting, bringing data in and sending data out

Storage units - data

Hippocampus Big Changes:
- Learn and remember
- Way-finding
- Passage of time
Changes in Language Skills
- Vocabulary
- Comprehension
- Speech Production

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 and Language Center: Huge Changes
Executive Control Center Changes:

- Being logical, reasonable, rational
- Controlling impulses
- Making decisions
- Initiating-sequencing-terminating-transitioning
- Being self-aware
- Seeing other perspectives

Vision Center – Big Changes

Dementia does not equal Alzheimers does not equal Memory Problems
Alzheimer’s:
- Two forms: Early/Young Onset and Normal Onset
- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months – 1 year
- Lasts 8-12 years

Dementia:
- Vascular Disease: (multi-vascular)
- Single Infarct
- Sub-cortical
- Inflammatory

Alzheimer’s:
- Memory problems: falls
- Visual disturbances
- Delusional thinking
- Poor recent memory
- Loss of judgment
- Increased need for help
- Changes in personality
- Drug responses may change
- Related to decreased 
  production of neurotransmitters

Four Truths About All Dementias:
- At least two parts of the brain are dying
- It keeps changing and getting worse – progressive
- It is not curable or reversible – chronic
- It results in death – terminal
Vascular Dementia:
- Sudden changes: stepwise progression
- Other conditions often present: diabetes, hypertension, heart disease
- Damage is related to blood supply, not primary brain disease, so treatment can plateau
- Can have good days and bad days
- Judgment and behavior ‘not the same’
- Spotty loss (memory, mobility)
- Emotional and energy shifts
- Lots of similarity with Alzheimer’s
- Watch for and manage depression

Lewy Body Dementia:
- Movement problems, falls
- Visual hallucinations: animals, children, people
- Fine motor problems: hands, swallowing
- Episodes of rigidity and syncopy
- Nightmares or insomnia
- Delusional thinking
- Fluctuations in abilities
- Drug responses can be extreme and strange: toxicity, paralysis, death, or can have the opposite of the intended effect

Fronto-Temporal Dementias:
- Many types
- Frontal types: impulse and behavior control loss (not memory issues)
  - Says unexpected, rude, mean, odd things to others
  - Disinhibited with food, drink, sex, emotions, actions
- Temporal types: language loss
  - Can’t speak or get words out, nonsense words
  - Can’t understand what is said
As part of the disease people with dementia tend to develop typical patterns of speech, behavior, and routines.

These people will also have skills and abilities that are lost while others are retained or preserved.

Now for the GEMS®:

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

Why Use GEMS® States?
- Uses familiar concepts to talk about a difficult subject
- Focuses on what is valued rather than on a number or amount of ‘decline’
- Like people, gems are precious and unique, with common characteristics
- Allow to us to get beyond the words ‘dementia’ and ‘Alzheimers’
- Opens the door to talking about changes
- Allow us to speak in a ‘code’ to protect dignity
Sapphires:
- Us on a good day
- Clear and true to ourselves
- May feel ‘blue’ over changes
- Can typically choose our behavior
- May have other health issues that affect behaviors
- Recognize life experiences, achievements and values
- Can follow written info and hold onto it

Diamonds:
- Sharp, hard, rigid, inflexible, can cut
- Many facets, still often clear, can really shine
- Are usually either Joiners or Loners
- Can complete personal care in familiar place
- Usually can follow simple prompted schedules
- Misplace things and can’t find them
- Resent takeover or bossiness
- Notice other people’s misbehavior and mistakes
- Vary in lack of self-awareness
- Use old routines and habits
- Control important roles and territories, use refusals

Emeralds:
- Changing color
- Not as clear or sharp, more vague
- On the go, need to ‘do’
- Flaws may be hidden
- Time traveling is common
- Are usually Doers or Supervisors
- Do what is seen, but miss what is not seen
- Must be in control, but not able to do it correctly
- Do tasks over and over, or not at all
Ambers:
- Amber Alert - Caution!
- Caught in a moment
- All about sensation and sensory tolerance, easily over or under stimulated
- May be private and quiet or public and noisy
- No safety awareness
- Ego-centric
- Lots of touching, handling, tasting, mouthing, manipulating
- Explorers, get into things, invade others’ space
- Do what they like and avoid what they do not

Rubies:
- Hidden depths
- Major loss of fine motor finger and mouth skills, but can do gross motor skills like walking, rolling, rocking
- Comprehension and speech halted
- Wake-sleep patterns very disturbed
- Balance, coordination, and movement losses
- Eating and drinking patterns may change
- Tends toward movement unless asleep
- Follows gross demonstration and big gestures
- Limited visual awareness
- Major sensory changes

Pearls:
- Hidden in a shell: still, quiet, easily lost
- Beautiful and layered
- Spends much time asleep or unaware
- Unable to move, bed or chair bound, frequently fall forward or to side
- May cry out or mumble often, increases vocalizations with distress
- Can be difficult to calm, hard to connect
- Knows familiar from unfamiliar
- Primitive reflexes
- The end of the journey is near, multiple systems are failing
- Connections between the physical and sensory world are less strong but we are often the bridge
So What Is Needed for a Successful Journey?

Believe:

People with dementia are doing the best they can!

Some Basic Skills:

1. Positive Physical Approach™
2. Hand-under-Hand® for connection and assistance
3. Consistent and skill-sensitive cues
   - Visual, verbal, physical
4. Supportive Communication

More about these in the next presentation!
Other Tips for the Journey:

Keep Travel Logs:
- Behavior Log
- Medication Log
- Doctor Visit Log

Unexpected and Sometimes Nasty Detours
Be ready for possible detours—they will probably happen at some point!
Hospitalizations and Dementia:

Hospitalizations happen
Hospital stays are risky for those with dementia
Hospital stays are stressful to staff and family members
Standard communication and monitoring systems are frequently ineffective

What Can We Do to Help?
- Have a hospital bag packed
- Build a team to share the load
- Consider your options
- Think about what is possible versus what makes sense
- Evaluate how it is going now
- Think about probable outcome
- Reconsider the situation
- Learn from the experience

Advance Planning:

When advanced planning takes place in advance:
- There is greater satisfaction on the part of family and care providers
- Quality of care is described as better

When decisions are ‘forced’ by immediate circumstances:
- More dissatisfaction with decisions
- Longer hospital stays, more procedures done
Taking Care of Yourself!

We All Need a Break, Especially Care Partners!

Why do we care about you?
- Dementia caregiving is very hard work!
- Over 40% of the time we will lose a caregiver before we lose the person with dementia
- Your emotional state affects the person you are caring for
- You are just as important as the person with dementia!

To Reduce Your Risk of Dementia:
- Lower your numbers: weight, blood pressure, ‘bad’ cholesterol, blood sugar
- Exercise several times weekly
- Avoid tobacco
- Eat whole grains, fish, fruits, vegetables, nuts
- Drink water
- Reduce stress
- Try new activities, experiences, and keep learning!
What is There to Laugh About?
- What the person says
- What the person does
- What the person says versus what is done
- Your mistakes and ‘oops’ moments
- 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

A Few Ideas to Reduce Stress:
- Set aside just a few minutes for yourself — use a timer!
- Breathe
- Smile, laugh, look for some funnies
- Remember a good time
- Think about what you get out of the relationship
- Use at least one of the Teepa’s 10-Minute Stress Tamers

Teepa’s 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 and oxygenate
- Soak: in a warm bath, or just your hands or feet
- Read: spiritual readings, poetry, inspirational readings, or one chapter of a book 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, and across
Teepa’s 10 Minute Stress Tamers:
- **Beanbag heat therapy**: fill a sock with dry beans and sew or tie closed, heat 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, or 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 a hymnal and find a favorite and hum it all the way through**
- **Garden**: work with plants

Teepa’s 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

Teepa’s 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
Let Go:

How it ‘used to be’

How it ‘should be’

How you ‘should be’

Being ‘right’ doesn’t necessarily translate into a good outcome for both of you

It’s the relationship that is most critical, not the outcome of one encounter

It takes two to tango...or tangle
Learn how to dance with your partner!

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!!!