The Dementia Journey:  
Changing Abilities, Self-Awareness, Emotional Responses, and How We Help Matters
PET Scan – Meth Abuser

Glucose Metabolism
Red = High
Light Blue = Low
Purple = None – Open areas

Bipolar Mood Disorder – Variable Metabolism

The Depressed Brain
PET scans show that brain energy consumption rises and falls with mania and depressive episodes.

Anxiety - Glucose Consumption?

Anxiety Disorders
- PET scan of brain of patient with obsessive compulsive disorder
- High metabolic activity (red) in frontal lobe areas involved with directing attention
As we age, our brains may slow, but we do not lose function, unless…

**Something Goes Wrong With Our Brains**

**But**

What if There is Already Something Wrong with Our Brains?

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**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!

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**Ten Early Warning Signs for Dementia:**

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
What Could it Be Other Than Dementia?
- Another medical condition symptom
- Medication side effect
- Hearing loss or vision loss
- Depression/anxiety
- Acute illness, delirium
- Pain or medication for pain
- Other things

So, What is Dementia?
- It is not part of normal aging! It is a disease!
- It is more than just forgetfulness, which is part of normal aging
- It makes independent life impossible, eventually
- 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

Dementia Alzheimers Memory Problems
About 90-95% of the general public think

Dementia ≠ Alzheimers ≠ Memory Problems

Better Answer:

Dementia ≠ Alzheimers ≠ Memory Problems

Best Answer:

Dementia ➔ Alzheimers ➔ Memory Problems
Having dementia does not equal and is more than just Alzheimer's does not equal and is more than just Memory Problems

What is Dementia?
It is both a chemical change in the brain and a structural change in the brain
So...
Sometimes they can and sometimes they can't

Four Truths About Dementia:
1. At least 2 parts of the brain are dying
2. It is chronic – it can’t be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually
The person’s brain is dying

Same
Not normal: changes starting
- Inconsistent
- Worse when tired or sick or in unfamiliar or uncomfortable setting
- About 50% will be the first to notice and about 50% will not think anything is different inside (anosognosia)

Different
Not normal: changes starting
- More likely first noticed at work with changes in competence, performance, or personality
- More likely to be mis-identified as ‘stress,’ ‘mid-life crisis,’ or psychological issues
- Less likely to be identified as ‘brain failure’ for longer combined with more looking for a ‘cure’
MCI:
The beginning of ‘not normal’ cognition
- Memory
- Language
- Behavior
- Motor skills
- Already life altering: not life stopping, but definitely different for you and those around you

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, misnaming, 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

What’s Unique about Young Onset?
- Episodes of change may be less consistent
- The individual may try multiple avenues for self-management or treatment of symptoms without realizing what is actually happening
- Resources and options for support and care are much more limited
- Financial issues happen faster, especially if income is eliminated or changed
- Relationships are damaged yet cause is not appreciated, more likely to be seen as ‘the norm’
Are these changes always associated with YO Alzheimers?

- Some other form of dementia: FTD, LBD, VaD
- Symptom of another health condition
- Medication/drug effect, side effect, interaction
- Mental health condition: new onset
- Pain-related: physical, emotional, spiritual
- S/p Head Injury: TIA, non-emergency head injury that is repeated

AD8 Dementia Screening Interview:

- Does your family member have problems with judgment?
- Does your family member show less interest in hobbies/activities?
- Does your family member repeat the same things over and over?
- Does your family member have trouble learning how to use a tool, appliance, or gadget?
- Does your family member forget the correct month or year?
- Does your family member have trouble handling complicated financial affairs?
- Does your family member have trouble remembering appointments?
- Does your family member have daily problems with thinking or memory?
- Scores: Changed, Not Changed, Don’t Know

Amygdalae:

- Threat
- Dangerous
- Aroused/Risky
- Alert/Aware
- Needs + Pleasure
- Need
- Want
- Like
**Primitive Brain is in Charge of:**

**Survival:**  
- Autonomic protective: Fright, flight, fight + hide or seek  
- Pleasure seeking: Meeting survival needs and finding joy

**Thriving/Running the Engine:**  
- Maintain vital systems: BP, BS, Temp, Pain, Oxygen  
- Reflexes: Breathe, suck, swallow, digest, void, defecate  
- Circadian rhythm  
- Infection control

**Learning New and Remembering:**  
- Information  
- Places: spatial orientation  
- Passage of Time: temporal orientation

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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.

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Positron Emission Tomography (PET)  
Alzheimer’s Disease Progression vs. Normal Brains

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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

Understanding Language - Big Change

Changes in Language Skills
- Vocabulary
- Comprehension
- Speech Production
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
For all that is lost, some remains!

- 1/3 of brain remains
- Know what still works
- Know how we support in areas of loss
Alzheimers:
- 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

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 Alzheimers
- 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 syncope
- 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

**Now for the GEMS®:**
- Sapphires
- Diamonds
- Emeralds
- Ambers
- Rubies
- Pearls
Sapphires

- Us on a good day
- Clear and true to ourselves
- May feel ‘blue’ over changes
- Some are ‘stars’ and some are not
- Can typically choose our behavior
- Can connect ABCs and make contracts
- 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 Loner
- Can complete personal care in familiar place
- Usually can follow simple prompted schedules
- Misplaces things and can’t find them
- Resents takeover or bossiness
- Notices 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 space of others
- Do what they like and avoid what they do not like


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 for actions
- 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?

Realize:

It Takes Two to Tango …or Tangle!

Learn how to dance with your partner!

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

Believe:

People with dementia are doing the best they can!

How You Look At Dementia Matters!

- It is not all about loss
- It is not 'untreatable'
- It is not unpredictable
- Behaviors don't come out of nowhere
- Dementia doesn't just affect the person with the disease – it impacts all of us
Dementia cannot be cured, but it can be treated:
- With knowledge
- With skill building
- With commitment
- With flexibility
- With practice
- With support
- With compassion

So how can we help?
It all starts with your approach!

Positive Physical Approach™
Positive Physical Approach™
- Pause at edge of public space (6 feet)
- Greet with your open hand next to your face, smile
- Call the person by name, if possible
- Move your hand into handshake position
- Approach slowly and within visual range
- Move from a handshake to Hand-under-Hand® position
- Shift into a Supportive Stance on their side
- Get low by standing or kneeling, but don’t lean in
- Make a connection and wait for their response

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!

Hand-under-Hand® Assistance
Then, Connect Emotionally:
- 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.”
- Make a positive observation: “What beautiful flowers!” or “Great photo!”

Connecting Emotionally:
- Identify a common interest
- Say something nice about the person or their place
- Share something about yourself and encourage the person to share back
- Follow their lead and listen actively
- Use some of their words back to keep the flow going
- Remember it’s often the ‘first time’ for them, so expect repeats
- Use the phrase “Tell me about…”

How You Communicate:
How you say it
What you say
How you respond
Use empathy and go with the flow!

Reality Orientation

Telling Lies

Ways of Cueing and Helping:
- Sight or Visual cues
- Verbal or Auditory cues
- Touch or Tactile cues

Visual Cues:
- Signs
- Pictures
- Props/objects
- Gestures
- Facial expressions
- Demonstrations
Verbal Cues:
- Keep it simple and short
- Directed
- Matched to visual cues
- Offer concrete choices
- Break the task down to single steps at a time
- Ask the person to ‘try’ or for their ‘help’

Touch Cues:
- Touching a body part
- Handing the person an item
- Using Hand-under-Hand® assist

To Communicate When They’re Distressed:
First – Connect Emotionally
Then - Use Supportive Communication
Finally - Move Together to a New Location, Activity, or Conversation
To Connect Emotionally:

- Send visual signal of connection:
  - Look concerned!
- Send a verbal signal of connection:
  - Use the right tone of voice
- Send a physical signal of connection:
  - Give a light squeeze or sandwich the hand
  - Offer an open palm on shoulder or back
  - Offer a hug if the person is seeking more contact

Then, Use Supportive Communication:

- Repeat a few of their words, with a question
- Listen!
- Offer empathy:
  - "Sounds like..."
  - "Seems like..."
  - "Looks like..."
- Go slow
- Avoid confrontational questions
- Use just a few words
- Validate their emotions

Be a Detective, Not a Judge!

Try to figure out what is being communicated:
- Words
- Thoughts
- Actions
- Needs
- Beliefs

Don’t assume or presume
Don’t discount the message because of how it is delivered
For All Communication:

If what you are trying is not working:
- Stop!
- Back off
- Think it through, then:
- Re-approach
- Try something slightly different

Four Probabilities On This Journey:
1. Road Blocks
2. Detours
3. Rest Stops
4. Scenic Overlooks and ‘Wow’ Moments
Road Blocks:

Something is not working!!!!

What Are the Most Common Issues With Dementia?

- Not going to the doctor
- No financial or health care PoA
- Losing important things
- Getting lost
- Unsafe task performance
- Repeated calls and contacts
- Refusing
- 'Bad-mouthing' you to others
- Making up stories
- Resisting care
- Swearing and cursing
- Making 911 calls
- Mixing day and night
- No solid sleep time

- Paranoid/delusional thinking
- Shadowing
- Elop ing or wandering
- Seeing things and people
- Getting 'into' things
- Threatening caregivers
- Undressing
- Being rude
- Feeling 'sick'
- Striking out at others
- Falls and injuries
- Infections and pneumonias
- Not eating or drinking
- Contractures and immobility

Why Do These Things Happen?

- Everything is affected:
  - Thoughts
  - Words
  - Actions
  - Feelings

- It is progressive:
  - More brain dies over time
  - Different parts get hit
  - Constant changing

- It is variable:
  - Moment to moment
  - Morning to night
  - Day to day
  - Person to person

- Dementia is predictable:
  - Specific brain parts
  - Typical spread
  - Some parts preserved
What Makes ‘Stuff’ Happen?

Six Pieces of the Puzzle:
1. The type and level of dementia
2. The person and who they have been: personality, preferences and history
3. The environment: setting, sound, sights
4. Other medical conditions and sensory status
5. The whole day and how things fit together
6. How the helpers help: approach, behaviors, words, actions, and reactions

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, and reactions

Not Control:
• The person and who they have been: personality, preferences and history
• The level of dementia now
• Other medical conditions and sensory status

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
Intervention and Programming is Needed For:

- Physical activity
- Mental activity
- Social activity
- Spiritual involvement
- Well-being and self-worth
- Minimizing risky, challenging, or dangerous behaviors
- Reducing anxiety or distress

Rest Stops:

Take Advantage of ‘Rest Stops’
To Reenergize

Taking Care of Yourself!

We All Need a Break!
Especially Caregivers
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!

In Simple Words:
Lower Your Numbers and Raise Your Activity!
Don’t Forget to Check Out:
The Beautiful Scenery
and
Moments of Joy

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, freshly 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
- Take a walk
- Sit in the sun
Teepa’s 10 Minute Stress Tamers:
- 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!!!

Progression of the Condition
To the tune of ‘This Old Man’
Sapphire true, you and me,
The choice is ours, and we are free
To change our habits, to read, and think and do,
We’re flexible, we think it through!

Diamond bright, share with me,
Right before, where I can be,
I need routine and different things to do,
Don’t forget, I get to choose!

Emerald – Go, I like to do,
I make mistakes, but I am through!
Show me only one step at a time,
Break it down and I’ll be fine.
Amber – Hey! I touch and feel,
I work my fingers, rarely still.
I can do things, if I copy you,
What I need is what I do!

Ruby – skill – it just won’t go,
Changing something must go slow
Use your body to show me what you need,
Guide, don’t force me, don’t use speed!

Now a Pearl, I’m near the end,
But I still feel things through my skin,
Keep your handling always firm and slow,
Use your voice to calm my soul.
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