Learning How to Navigate on This Journey

REALIZE …
- It Takes TWO to Tango … or tangle…
- Learn How to Dance with Your Partner!

It’s the relationship that is MOST critical
NOT the outcome of one encounter

Intervention & Programming to:
- physical activity
- mental activity
- social activity
- spiritual involvement
- well-being and self-worth
- minimize ‘risky’, challenging, or ‘dangerous behaviors
- reduce anxiety or distress

So What Is Needed for a Successful Journey?

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

Alzheimer’s – Two Forms

Young/Early Onset
Late Life Onset

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

Normal Brain  Alzheimers Brain
**Young Onset**
- Groups – genetic, Down, head injury, lifestyle, +
- Young family – kids often involved
- Mis-diagnosis & non-diagnosis is common
- Work may be first place to notice
- Relationships are strained early - misunderstood
- Services are a problem – usually
- Finances are problematic
- Executive decision making & sequencing DOWN

**Alzheimer’s**
- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 m – 1 yr
- Lasts 8-12 years

**Typical treatment for Alzheimer’s**
- Start with AChEI as soon as diagnosis is made
- If side-effects are too much – try another one
- Stay on the AChEI until --- 2 groups of thought
- Placement in a ‘facility’
- Considering other med stops – near end
- Add Namenda – mid-stage disease
- Stay on Namenda – as above

**Normal Brain Cells**
- Neurotransmitters (AChE) – being sent – message being communicated to the next cell
- Enzymes (AChE inhibitors) – get to them BEFORE they deliver their message

**Brain Cells with Alzheimer’s**
- Enzymes (AChE inhibitors) – get to them BEFORE they deliver their message
- Plaques, tangles
- Further to go to get to the next cell

**Normal Brain Cells**
- Once the message is sent, then enzymes lock onto the messenger chemicals and take them out of circulation so a new message can be sent
Alzheimer's drugs provide FAKE messenger chemicals that distract the enzymes. They attach to the Fake AChE & the message can get thru.

What do Alzheimer's drugs DO?

- Aricept, Exelon, Reminyl (Razadyne)

One Other Dementia Drug

- Memantine - Namenda
  - from Europe - 10 years of research
  - came 4.5 years ago to the US
  - different effect
  - moderates glutamate absorption
  - Works best in combination with AChE inhibitors

Keeps the cell from getting so much glutamate in it

Can use it with AChE inhibitors... two actions

Vascular Dementias

Secondary
Old term – MID
Many variations
CADASIL - genetic

Vascular Dementia

- Sudden changes – stepwise progression
- Other conditions: DB, HTN, heart disease
- So, damage is related to blood supply/not primary brain disease: treatment can plateau
- Picture varies by person (blood/swelling/recovery)
- Can have bounce back & bad days
- Judgment and behavior ‘not the same’
- Spotty loss (memory, mobility)
- Emotional & energy shifts

Vascular dementia

CT Scan
The white spots indicate dead cell areas - mini-strokes

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Latest Thinking About Vascular Treatment?
- Lots of similarity with Alzheimer’s
- Manage blood flow issues CAREFULLY!
- Watch for and manage depression

Latest Thinking about Lewy Body Treatment
- Try AChls – Start Low & Go Slow
- Then Try Namenda early – Start Low & Go Slow
- BE VERY careful about anti-psychotic meds – (not Haldol)
- Balancing movement losses & aid to function – not working?
- Parkinson’s meds – may/may not help movement BUT may make hallucinations and delusions worse
- Anti-depressants – may be used to help anxiety, sleep, & depression – can increase confusion, movement & drowsing
- Sleep aids or Anti-anxiety meds – can cause paradoxical rxs

Lewy Body Dementia
- Movement problems - Falls
- Visual Hallucinations – animals, children, people
- Fine motor problems – hands & swallowing
- Episodes of rigidity & syncopy
- Nightmares or Insomnia
- Delusional thinking
- Fluctuations in abilities
- Drug responses can be extreme & strange
- Can become toxic, can die, can become unable to move
- Can have an OPPOSITE reactions

Fronto-Temporal Dementias
- Many types – Typically Younger Onset
- Frontal – impulse and behavior control loss (not memory issues)
- says unexpected, rude, mean, odd things to others
- Dis-inhibited – food, drink, sex, emotions, actions
- OCD type behaviors
- Hyperorality
- Temporal – language loss
- Can’t speak or get words out
- Can’t understand what is said, sound fluent – nonsense words

FTDs
- FvFTD – frontal variant of FTD
- FTD – frontal-temporal lobe dementia
- TLD – non-fluent aphasia
- TLD – fluent aphasia
- CTE – chronic traumatic encephalopathy
FvFTD

- Misbehavior
- Impulsivity
- Dis-inhibition
- Inertia
- Obsessive compulsive behaviors
- Inattention
- Lack of social awareness
- Lack of social sensitivity
- Lack of personal hygiene

Becomes sexually over-active or aggressive
Becomes rigid in thinking
Stereotypical behaviors
Manipulative
Hyper-orality
Language may be impulsive but unaffected or may be reduced or repetitive

FTD (Pick’s Disease)

Frontal Issues
- Poor decision making
- Problems sequencing
- Reduced social skills
- Lack of self-awareness
- Hyper-orality
- Egocentric
- Dis-inhibited – food, drink, words, actions
- OCD behaviors early
- Excessive emotions

Temporal Issues
- Reduced attempts to talk
- Reduced content in speech
- Poor volume control
- Public use of ‘forbidden words’
- Sing-song speech
- Can’t understand others’ words

Temporal Lobe

Non-Fluent Aphasia

- Can’t NAME items
- Hesitant speech
- Not speaking
- Worsening of speech production over time
- Echolalia
- Mis-speaking
- Word salad

Receptive inability
Other skills intact – early
25% never develop global dementia

Fluent Aphasia

- Has smooth delivery
- More nonsense words
- Word salad
- May think they make sense
- Expect rhythm back
- Fixates on a few phrases
- Chit-chats if enjoying company

Volume control varies – limited awareness of others’ needs
There are frequently 1-2 ‘value words’ mixed in to speech
They pick up on ‘value words’ they hear – they then connect & want to talk more

Chronic Traumatic Encephalopathy

- Caused by repeated head injuries or concussions – doesn’t happen to all
- Symptoms
- Frontal lobe issues
- Temporal lobe issues
- Sometimes rapid progression into ‘Alzheimer’ patterns
- Sometimes rapid progression into FTD patterns

Pick’s Disease

PET Scan
Latest Thinking About FTD Treatments
- Consider Namenda earlier
- Look at SSRI medications
- May use medications used to treat OCD
- May NOT use AChI Medications

What if it doesn’t seem to be one of these?
- Atypical or other dementias
- Mixed picture

Other Dementias
- Genetic syndromes – Huntington’s Chorea
- ETOH related – Wernickes or Korsakoffs
- Drugs/toxin exposure – heavy metals, pesticides
- White matter diseases – MS
- Mass effects – tumors & NPH
- Depression and Other Mental Conditions
- Infections – BBB cross – C-J, HIV/Aids, Lyme
- Parkinson’s – 40% about 5-8 yrs in
- Progressive Supranuclear Palsy

Alcohol-Drug Related Dementia
May be called - Wernicke’s & Korsakoffs syndrome
- Possibly caused by neurotoxicity &/or Vitamin B1 & thiamine deficiency
- Common Symptoms
  - Decreased ability to learn ‘new’
  - Decreased interest in valued activities, people, life
  - Impaired judgment and decision making
  - Emotional liability or apathy
  - Problems with balance and coordination
  - Problems with social control and behaviors
  - Problems with initiation & termination

Dual Diagnosis – Young Dementia
- Underlying psychiatric illness
- Diagnosed and treated
- Undiagnosed but suspected
- Undiagnosed and unrecognized
- Newer onset of symptoms of dementia
- Diagnosed and treated
- Undiagnosed but suspected
- Undiagnosed and unrecognized
Mixed picture

- Can have multiples
- can start with one and add another
- Can have some symptoms – not all
- Also can have other life-long issues and then develop dementia (Down’s, Mental illness, personality disturbances, substance abuse)

So, You are NOTICING CHANGES…

What Should You DO?
Get it assessed –
Go see the doctor!

Why Bother Getting a Good/Complete Diagnosis

- Future plans
- Progression & prognosis
- Finances
- Health
- Being in control
- Medications can make a difference in quality of life

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 information
- Can’t make sense of words
- Gets off target
-Preserved abilities
- Can get facial expression
- Hears tone of voice
- Can get some non-verbals

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

How can we help... better?
It all starts with your approach!

Your Approach

- Use a consistent positive physical approach
- pause at edge of public space
- approach within visual range
- approach slowly
- offer your hand & make eye contact
- call the person by name
- stand to the side to communicate
- respect personal space
- wait for a response

How you talk...

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

Use empathy & Go with the flow

- Reality Orientation
- Telling Lies

How you help...

- Sight or Visual cues
- Verbal or Auditory cues
- Touch or Tactile cues
Four Probabilities
On This Journey

Road Blocks
Detours
Rest Stops
Scenic Overlooks & WOW Moments

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

NOT CONTROL
- The person & who they have been
  - Personality, preferences & history
- The level of dementia … NOW
- Other medical conditions & 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
Keep Travel LOGS…
- Behavior Log
- Medication Log
- Doctor Visit Log

Unexpected & Sometimes NASTY Detours
- Be Ready for Possible Detours
- They will Probably Happen at Some Point!

Hospitalizations & Dementia
- What Should Every Care Partner Know?
- How Can You Be Ready?

Info of Interest – Example NY
- Dementia is the primary diagnosis for admission in only about 9% HOWEVER
- Dementia is a secondary diagnosis in over 45% of a variety of chronic diseases for those over 65
- More women admitted than men with dx of dementia (35% versus 66%) for those over 65

More info…
- If an ‘emergency’ or urgent admit – incidence of dementia is above 50%
- If dementia is a dx – 3X as likely to go to a NH
- If dementia is dx – 25% more likely to need support services to return to prior residence
- If dementia is dx – 30-40% more likely to have a functional decline at d/c compared to pre-admission info
- Close to 50% of people with moderate to severe dementia go to the hospital each year

Pain Management
- Comparing patients with dementia and without dementia admitted for hip fx repair
- Same number of procedures
- Same types of procedures
- ¼ the pain medications
- 3 times the antipsychotics
Some Stats and Info of Note
- Feeding tubes are still be placed
- Feeding tube placement did not affect outcome
- Having an infection coming in did worsen risk for death
- Average survival with or without a feeding tube was 6 months

Advance Planning Helps
- 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
- Survival outcomes at 3 months not changed

If admitted acutely ill with a Dx of Dementia the primary Dx is typically:
- Pneumonia
- Aspiration pneumonia
- UTI
- Dehydration
- Fall related injury – fx, head injury

When dementia is a 2° Dx
- Treatment of 1° condition is impacted in over 75% of cases
- Stays are longer
- Functional losses are more common
- Costs of care are higher
- Outcomes are less positive
- Additional acute issues occur in 50-60% of cases

Acute Problems Connected to Hospital Stays & Dementia
- Falls & fall related injuries
- Wandering or elopement attempts
- New onset incontinence
- Acute confusion – delirium
- Skin tears and skin breakdown
- Physical aggression toward care providers
- Pulling out tubes and monitoring equipment
- Inability to use call system
Possible problem areas

- Quick start of behavioral control meds to ‘deal with’ agitated or aggressive behaviors
- Pre-morbid baseline measures of cognitive status
- Screening for 3Ds at admission
- Interpretation of verbal reports & behavioral symptoms
- ID of acute versus gradual onset of change
- Protocol for monitoring when dementia or delirium is identified

More possible problems

- Use of environmental and human resources to support and prevent 2nd care issues
- Pain assessment & management
- Communication systems
- I & O monitoring
- Ability to tolerate inactivity, isolation, & immobility
- Ability to interpret & tolerate sensory experiences

Still more...

- Pre-admission decision making r/t advance directives
- Timely & honest discussions on what is possible, probable, and desirable based on presence of dementia, other health conditions, functional status, and quality of life
- Acute versus continued care concerns & issues

So...

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

What Can We Do to Help?

- Get Ready – Hospital BAG
- Build a TEAM – Share the load
- Consider your Options
- What is Possible VERSUS What Makes Sense
- Evaluate How It Is Going
- Now
- Probable Outcome
- Re-Consider
- Learn from the Experience

A Great Resource:

**Hospitalizations Happen**

ADEAR - NIH

http://www.nia.nih.gov/Alzheimers/Publications/happens.htm
Rest Stops
- Take Advantage of ‘Rest Stops’
- To Re-Energize

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

Taking Care of Yourself:
- We All Need a Break!
- Especially Caregivers

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Step #1
- Become Aware of Yourself
- What is most important to you? Top priorities…
- What is necessary for you to keep going?
  - How much sleep?
  - Physical health issues?
  - Breaks?
  - $$$?
  - Time to meet other demands?
  - Someone to listen?
- What is necessary for you to THRIVE?

Step #2
- Think & Remember…
When was the last time you felt really good?
- What were you doing?
- Where were you?
- Were you with someone? Who?
- What made it great?
- How did you feel?

Step #3
- Think and Remember…
- When have you been really miserable?
- What were you doing?
- Where were you?
- Was anyone with you?
- What made it awful?
- How did you get over it?
Step #4

- Where are you NOW?

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…

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…
Don't Forget to Check Out…

- The Beautiful Scenery
- &
- Moments of Joy

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…

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!!!