Trying to Provide Best Quality Care Throughout the Journey of Dementia: Understanding Progression and How to Modify Support, Care, and Environments

Examples of Challenges
- 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
- 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
- Dehydration & malnourishment
- Contractures & immobility
- Infections & pneumonias
- Issues w/ eating or drinking

How Does It Start???
Because we miss it, we make mistakes

• Issues are inconsistent
• Worse when tired or sick OR in unfamiliar or uncomfortable setting
• BUT... Otherwise... they seem OK

MCI

• The beginning of NOT NORMAL COGNITION
  – Memory
  – Language
  – Behavior
  – Motor skills
• Not life altering – BUT definitely different... for you

Ten Early Warning Signs

• memory loss for recent or new information – repeats self frequently
• difficulty doing familiar, but difficult tasks – managing money, medications, driving
• problems with word finding, mis-naming, or misunderstanding
• getting confused about time or place - getting lost while driving, missing several appointments
• worsening judgment – not thinking thing through like before
• difficulty problem solving or reasoning
• misplacing things – putting them in ‘odd places’
• changes in mood or behavior
• changes in typical personality
• loss of initiation – withdraws from normal patterns of activities and interests
Is This ALWAYS Dementia?

- Some form of DEMENTIA
- Symptom of another health condition
- Medication side-effect
- Hearing loss or vision loss
- Depression
- Delirium
- Pain-related

Screening Options

- OLD – MMSE
- New
  - AD-8 Interview
  - SLUMS – 7 minute screen
  - Animal fluency – 1 minute # of animals
  - Clock Drawing – 2 step
  - Full Neuropsychological testing panel

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
Animal Fluency

• Name as many animals as you can
• Give one minute – (don’t highlight time limit)
• Count each animal named (not repeats)
• Establish Baseline versus Normal/Not Normal
  – 12 normal for > 65 and 18 for <65
  – Compare you to you OVER time

Clock Drawing

• Give a BIG circle on a blank sheet of paper
• Ask to draw the face of a clock - put in the numbers
• Watch for construction skills & outcome
• Ask to put hands on the clock to indicate 2:45
• Watch for placement and processing
• Scoring: 4 possible points
  – 1-12 used correct quadrants
  – minute hand correct hour hand correct

SLUMS

• Orientation – day of week, month, state (3)
• Remember 5 items – ask later (5)
• $100 – buy apples $3 and Trike $20
  – What did you spend? What is left? (2)
• Animal fluency (0-3) <5, 5-9, 10-14, >14
• Clock drawing (4) – numbers in place, time right
• Number reversals (2) – 48 – say 84...
• Shapes (2) – ID correct, which is largest
• Story recall (8) – recall of info from a story – 4?s
SLUMS - rating

<table>
<thead>
<tr>
<th>High School Education</th>
<th>Less than High School</th>
</tr>
</thead>
<tbody>
<tr>
<td>27-30 – Normal</td>
<td>25-30 – Normal</td>
</tr>
<tr>
<td>21-26 – MNCD (MCI)</td>
<td>20-24 – MNCD (MCI)</td>
</tr>
<tr>
<td>1-20 - Dementia</td>
<td>1-19 - Dementia</td>
</tr>
</tbody>
</table>

TWO Mimics to KNOW
(copy cats & concurrent illnesses)

- Delirium = **Rapid changes in thinking & alertness**
  (seek medical help immediately)

- Depression = **chronic unless treated, poor quality**, I “don’t know”, “I just can’t” responses, no pleasure
  Typical and atypical sad
  mad - can look like agitation & confusion
  (this condition can improve with attention & treatment)

- These signal a vulnerable brain – heads up!

Mimics of Dementia

- Depression
  - can’t think
  - can’t remember
  - not worth it
  - loss of function
  - mood swings
  - personality change
  - change in sleep

- Delirium
  - swift change
  - hallucinations
  - delusions
  - on & off responses
  - infection
  - toxicity
  - dangerous
Drugs that can affect cognition

- Anti-arrhythmic agents
- Antibiotics
- Antihistamines - decongestants
- Tricyclic antidepressants
- Anti-hypertensives
- Anti-cholinergic agents
- Anti-convulsants
- Anti-emetics

- Histamine receptor blockers
- Immunosuppressant agents
- Muscle relaxants
- Narcotic analgesics
- Sedative hypnotics
- Anti-Parkinsonian agents

Dementia – What Changes?

- Structural changes – permanent
  - Cells are shrinking and dying
- Chemical changes - variable
  - Cells are producing and sending less chemicals
  - Can ‘shine’ when least expected – chemical rush

DEMENTIA

Alzheimer’s Disease
  - Early - Young Onset
  - Normal Onset

Vascular Dementias
  - Multi-infarct

Lewy Body Dementias

Fronto-Temporal Lobe Dementias

Other Dementias
  - Genetic syndromes
  - Hereditary
  - FTLD, SDAD
  - Acquired
  - AIDS dementia
  - HIV encephalopathy
  - Head injuries
  - Mass effects
  - Depression
  - Other medical conditions
  - Hypothyroidism
  - Epilepsy
  - AIDS
Alzheimer’s – Two Forms

Young/Early Onset

Normal Onset

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

Young Onset

• 3 groups – genetics, Down’s, life style
• Young family – kids often involved
• Mis-diagnosis & non-diagnosis is common
• Work may be first place to notice
• Relationships are strained early - misunderstanding
• Services are a problem – usually
• Finances are problematic
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

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
- 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
- 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

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

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
- Ego-centric
- 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

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

<table>
<thead>
<tr>
<th>Normal</th>
<th>Early Alzheimer’s</th>
<th>Late Alzheimer’s</th>
<th>Child</th>
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<tbody>
<tr>
<td><img src="image1" alt="Normal Brain" /></td>
<td><img src="image2" alt="Early Alzheimer’s" /></td>
<td><img src="image3" alt="Late Alzheimer’s" /></td>
<td><img src="image4" alt="Child" /></td>
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</table>

Normal Brain | Alzheimers Brain
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
The Basics for Success...

- Be a Detective NOT a Judge
- Look, Listen, Offer, Think...
- Use Your Approach as a Screening Tool
- Always use this sequence for CUES
  - Visual - Show
  - Verbal - Tell
  - Physical - Touch
- Match your help to remaining abilities

Some Basic Skills

- Positive Physical Approach
- Supportive Communication
- Consistent & Skill Sensitive Cues
  - Visual, verbal, physical
- Hand Under Hand
  - for connection
  - for assistance
- Open and Willing Heart, Head & Hands

First Connect - Then Do

- 1st - Visually
- 2nd - Verbally
- 3rd - Physically
- 4th - Emotionally
- 5th - Spiritually - Individually
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

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!
Partnering & Doing With: Building Skills to Connect & Getting Things Done

Developed by Teepa Snow, MS, OTR/L, FAOTA
Positive Approach, LLC - 2013

Five Skill Areas
• Getting Connected
• Ways of Cueing & Helping
• Hand-under-hand Assistance
• Progression of Dementia
• Time Out Signal – for Me & You

1st Skill
Getting Connected
BEFORE You try to get the person to ‘Do Something’
1st - Get Connected

Make a Connection
Say Something Nice
Form a Positive Relationship
BEFORE You ASK

Five Ways to Connect

• Greet or Meet
• Say something NICE
• Be friendly - Share about you
• Notice something – Share what you see
• Be curious – learn something

• Greet - Meet
  – Use their preferred name
  – OR Give your name & “and you are…”
• Give a compliment - “You... “look great”, “are working hard”, “are good at that”, “are smart”...
  – use what they value - beauty, strength, brains, humor
• Share something... likes, places, people
  – “I’m from ___ and you’re from?” “I love coffee, & you...”
• Notice - Make a positive comment about ‘stuff’
  – Gesture to yourself then point to the item & say – “what a beautiful...”, “I love that..”
• Be Curious - Find out - past life – may need to choices - “Are you from ____ or elsewhere?”
Practice
‘Getting Connected’
Use PPA
Practice EACH Option

Take the Making Positive Connections Quiz

2nd Skill
Cues – Getting and Giving
How Do I Help???
Check Out Your Partner
BEFORE you get started
Use your SENSES
Are they? How are they?
Looking
Listening
‘Feeling/Doing’
Smelling
Tasting

How Do You GET
Information from People
About What They Want or
Need or Think
What they show you- How they look
What they say – How they sound
What they do – Physical reactions
How they smell – What might be going on

How Do We GIVE
Information?
Visual Cues - Show
Verbal Cues - Tell
Tactile Cues - Touch
How you help...

- Sight or Visual cues
- Verbal or Auditory cues
- Touch or Tactile cues

What should You Use 1st?

Show!!!!

Ways to Show
visual cues

- Signs
- Pictures
- Props – Objects
- Gestures
- Facial expressions
- Demonstrations
Show Your Partner...
NO Words!
• You are hungry
• You are tired
• You want to leave
• You want to go to the bathroom

Partner...
• What are they trying to tell you?
• How could you tell?

Show Your Partner...
NO Words!
• You are thirsty
• You want to go outside
• Your left foot is hurting
• You want to go get a tissue
Partner…

• What are they trying to tell you?
• How could you tell?

Auditory – Verbal – Telling Cues

What Do We Tend to DO?
What Should We Do for Success?
What should we STOP doing?

What Do We Tend to Do with our Auditory Cues?

• Get too loud!
• Sound like our mothers on a bad day!
• Talk TOO MUCH!
What Should We Do with Our Auditory Cues?

Keep it short & simple
Keep it directed
Keep it matched to what we show

Practice: Giving Cues

What Works and What Does NOT?

Tell your partner to do the following
give all instructions at one time – say it once

• Name 8 animals
• Get up, turn around 3 times, sit down, and then give you their left shoe
• Describe how to get to a bathroom from here
• Gesture how to brush your teeth, shave your face, and comb your hair
Trade Places...

Tell your partner to do the following

give all instructions at one time – say it once

• Get up, turn to the left 2 times, point to your left elbow, then rub your right knee, sit down
• Name 10 colors
• Describe how to butter a piece of bread
• Pretend you have a brush and comb your hair, then light a candle with a match, then dial a phone number on a rotary phone

Try It Again
BUT
Keep IT SHORT!

Only ONE thing at a time!!!
Then PAUSE
Then give another cue....
Tell your partner to do the following
give one at a time – just use the words

• Get up, side step to the right 3 steps, turn to the left – side step 3 steps back point to your forehead and grimace
• Describe how to put sugar and milk in a cup of coffee and stir it in
• Gesture how to button a shirt, put on earrings, sharpen a pencil
• Name 9 town in Florida

Tell your partner to do the following
give one at a time – just use the words

• Get up, turn to the left 2 times, point to your left elbow, then rub your right knee, sit down
• Name 10 colors
• Describe how to butter a piece of bread
• Pretend you have a brush and comb your hair, then light a candle with a match, then dial a phone number on a rotary phone

Now Let’s Talk

• What happened?
• How was it different for each of you?
• What was hardest?
• What if you add in dementia?
• What if... you were
  – proud  - scared
  – angry   - HoH
  – blind   - listening for another rhythm??
NOW Combine Your Cues

Start with Visual Cues + Matching Verbal Cues

(SHOW then TELL)

Tell your partner to do the following give one at a time – use VISUAL clues 1st reinforce numbers, objects, and directions

- Name 8 animals
- Get up, turn around 3 times, sit down, and then give you their left shoe
- Describe how to get to a bathroom from here
- Gesture how to brush your teeth, shave your face, and comb your hair

Tell your partner to do the following give one at a time – use VISUAL clues 1st reinforce numbers, objects, and directions

- Show me how many children you had in your family (brothers and sisters)
- Get the person to write a sentence about what they are wearing
- Imaging you are rolling out pie dough, stirring a pot of soup, flying a kite
- Name 6 vegetables that are green
What Are Some Good Words to Use…

To Get Started?
To Keep It Going?
To End?

Positive Verbal Cues to Help DO Something OR Get Something Done

Getting Things Started
Reinforce & Encourage
End with Thanks

5 Ways to Start - 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
To 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… (“Do you want to…”, “Are you ready to…”,
  “I need you to…”)
• Acknowledge the response/reaction to your info…
  • USE THEIR WORDS (with a ? OR in agreement)
  • LIMIT your words – Keep it SIMPLE
  • WAIT!!!!

Give Concrete Choices

• Two choices – NOT TOO MUCH or TOO Little
  – “this or that”
  – gesture or have options showing
• Offer one specific & the rest
  – “___ or something else”
• Two BIG categories … then dig down
  – Something to eat or something to drink? … DRINK
  – Hot or cold? … COLD
  – Sweet or plain? PLAIN
  – Water or something else (switch to specific & the rest)

“Could You Help Me?”

• Combine your Agenda with the ASK…
• THINK AHEAD…. What and How could they help?
  – Give an opinion
  – Help make a choice - decide
  – Help you get ready… or clean up
  – Do something for you OR someone else
  – Supervise you and keep an ‘eye on’ something
  – Get something started or finish something
“Could You Give it a Try?”

- Allows the person to FAIL & NOT be a FAILURE
- Allows for ‘not aware’ of need situations (bathroom issues, changing clothing, eating....)
- Acknowledges the value of EFFORT not outcome
- Allows for ‘self-image’ concerns
- Make you more of a PARTNER, not a BOSS

Break IT DOWN into Smaller Steps

- Getting started – what comes first?
- Sequencing... what next?
- Switching to the NEXT thing... changing gears
- Noticing what to do...
  - “Here you go... (offer the next item)
  - Gesture to next
  - Use automatic cues for movement
    - ‘come to me’, ‘come look’, this way – pointing
    - Demo – what you want

Let’s think back....
Tell your partner to do the following
give all instructions at one time – say it once

• Name 8 animals
• Get up, turn around 3 times, sit down, and then give you their left shoe
• Describe how to get to a bathroom from here
• Gesture how to brush your teeth, shave your face, and comb your hair

How did that...
Go?
Feel?

When we did it this way...
Tell your partner to do the following
give one at a time – use VISUAL clues 1st
reinforce numbers, objects, and directions

• Name 8 colors
• Get up, turn to the left 2 times, sit down, & then point to their right knee
• Describe how to get back to here from the front door of the building
• Gesture how to brush your hair, put on blush, blow out a candle

What was different?
Which did you like better?
WHY?

For EVERYTHING we do we LIKE to get Feedback…

Did I do it right?
Am I doing OK?
That doesn’t change with AGING or dementia!

Always let the person know you noticed!

Give Feedback to Keep It Going!

• Verbal
  – Make a positive comment – keep it adult
  – Say “Yes!”, “That’s It!””. “OK”
  – If struggling - “Good effort”, “This is hard…”
• Visuals
  – Use head nods & smiles
  – Use thumbs up
  – Look excited & interested
• Remember – SUPPORT … don’t interrupt!
When you are done…
Let me know YOU CARE!

THE Way to Finish ALL Interactions

Thanks!

Now for Touch…
ONLY after you try the Visual + Verbal
Try This: Set-up

- Your partner has crumbs all over their shirt
- Their 'significant other' is coming down the hall…. This person doesn't like seeing the person looking bad!
- Person has no limitations
- Person has only movement problems
- Person has visual & comprehension issues –
  - Diving mask, missing ¼ words
  - Binoculars, missing ½ words
  - Monocular, missing words – leaving rhythm

Care Partner

- Just use WORDS
  - No issues – Say "You have crumbs on your shirt."...
- Just use Verbal and Touch
  - Physical issues – Say "You have crumbs on your shirt. May I get them for you?" Listen to response - then WIPE
- Use Verbal, LOOK Friendly, THEN Touch
  - Diving mask – say "You have on your. Let me get it you!" – NOD yes & smile - WIPE
  - Binoculars – Say "You have your. Let get it you! OK?
    – Nod and smile, then WIPE.
  - Monocular – MUMBLE, smile & nod, WIPE.

What Happened?
How Did It Feel?
What Do You Think?
Why?
What Can We Change?
Tactile – Touch Cues

- Touching a body part
- Handing the person an item
- Using Hand under hand assist

Five Skill Areas

- Getting Connected
- Ways of Cueing & Helping
- Hand-under-hand Assistance
- Progression of Dementia
- Time Out Signal – for Me & You

Take the Matching Cues Quiz
Practice Each of These!

1. Get the person to stand and take a walk
2. Get the person to go to the bathroom
3. Get the person to go get a drink
4. Get the person to take off a shoe
5. Get the person to sit down and rest

Practice this

• Person is seated – s/he is supposed to exercise
• Get her/him up and walking for at least 10 feet
• REMEMBER –
  – PPA
  – Get Connected
  – Use a positive interaction skills
• REPEAT – using less than 10 words

3rd Skill

How to Help
Using Hand Under Hand Guidance and Assistance

Doing With
When the Person CAN’T DO IT or Doesn’t Get What You are Showing or Saying
Hand-Under-Hand Assistance

Practice: Using Hand Under Hand
1 - to comfort
2 - to start a task
3 - to use a tool or utensil
4 - to help with detail
5 - to guide/direct with movement

Five Ways to Say “I Am Sorry!”

- “I’m sorry, I was trying to help”
- “I’m sorry I made you feel (emotion) angry, irritated, frustrated, sad, isolated…”
- “I’m sorry I made you feel (intellectual capacity or relationship unequal) like a child, stupid, like an idiot…”
- “I’m sorry, this is HARD!” (for both of you)
- “I’m sorry that happened (their perspective)
4th Skill:
Progression of Dementia
Recognizing GEM Levels

Seeing the Value at Each Stage of the Condition
Creating the Right Setting & Providing the Right Care

Progression of Dementia
What Level Is the Person At?

Now for the GEMS…

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

5th Skill:
Know When to Signal
TIME OUT

Use Time Outs
Help Others with Time Outs
Monitor Yourself & Others

I Noticed Something!
or
HELP!

Using the Time-Out Signal
VISUAL CUES for each other
Time Out Signal

Practice
Using the Time Out Signal with Each Other

Go out into the community in 2’s or 3’s and practice:
- Watching each other
- Signaling each other
- Giving each other feedback

Five Skill Areas
• Getting Connected
• Ways of Cueing & Helping
• Hand-under-hand Assistance
• Progression of Dementia
• Time Out Signal – for Me & You