Understanding the World of Dementia:

It's so much more than words & memory loss

It’s a journey for everyone!
Beliefs

• People with Cognitive Impairment are Doing the BEST they can in that MOMENT
• We must learn to DANCE with our partner
• What we choose to do MATTERS
• We can change their WORLD with help
• We must be willing to CHANGE ourselves
• We must be willing to STOP & BACK OFF
How Can We Become Better Care Partners?

Let go of the past to be in the MOMENT
Go with their FLOW
Be willing to try something new
Be willing to learn something different
Be willing to see it through another’s eyes
Be willing to fail & try again
Caring for Someone with Cognitive Impairment... What Works BEST?
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
How Do We Connect & Communicate?

Five Major Ways to get Info IN and OUT

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Understanding the world – FIVE Senses

• 1\textsuperscript{st} – what you see
• 2\textsuperscript{nd} – what you hear
• 3\textsuperscript{rd} – what you feel/touch
• 4\textsuperscript{th} – what you smell
• 5\textsuperscript{th} – what you taste
Getting Info In – FIVE Senses

• 1\textsuperscript{st} – Vision
• 2\textsuperscript{nd} – Hearing
• 3\textsuperscript{rd} – Touch
  – temperature
  – texture
  – pressure
  – movement
• 4\textsuperscript{th} – Smells
• 5\textsuperscript{th} – Tastes
Giving Information

• 1\textsuperscript{st} – Show
• 2\textsuperscript{nd} – Tell
• 3\textsuperscript{rd} – Touch
• 4\textsuperscript{th} – Scents & Aromas
• 5\textsuperscript{th} – Tastes
Connect

• 1\textsuperscript{st} – let them see you – use props & demo
• 2\textsuperscript{nd} – use a FEW words – match to ‘show’
• 3\textsuperscript{rd} – offer friendly touch then guide
• 4\textsuperscript{th} – match then guide emotions to safety
• 5\textsuperscript{th} – Know the person & use preferred name
What Happens When Someone Develops Dementia?

- ‘Everything’ changes
- It is not ‘memory problems’, it is ‘brain failure’
- What I can take in – is changing
- What I process – is changing
- What I put out - is changing
- I am doing the best I can with what I have left
- My skills will vary moment to moment....
Positron Emission Tomography (PET)
Alzheimer’s Disease Progression vs. Normal Brains

G. Small, UCLA School of Medicine.

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Learning & Memory Center
Hippocampus
BIG CHANGE

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Hearing Sound – Not Changed
Sensory Strip
Motor Strip
White Matter
Connections
BIG CHANGES

Formal Speech &
Language Center
HUGE CHANGES

Automatic Speech
Rhythm – Music
Expletives
PRESERVED

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Executive Control Center
Emotions
Behavior
Judgment
Reasoning
Vision Center – BIG CHANGES
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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
Progression
A Positive Framework...
seeing GEMS

Sapphires
Diamonds
Emeralds
Ambers
Rubies
Pearls

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Basics About Gems

Sapphires – True Blue – Slower BUT Fine
Diamonds – Repeats & Routines, Cutting
Emeralds – Going – Time Travel – Where?
Ambers – In the moment - Sensations
Rubies – Stop & Go – Big Moves – No Fine
Pearls – Hidden in a Shell - Immobile
Strong Positive Connectors

Sapphires – Visual Verbal Touch
Diamonds — Visual Verbal Touch
Emeralds – Visual Verbal Touch
Ambers – Visual Verbal Touch
Rubies – Visual Verbal Touch
Pearls – Visual Verbal Touch
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

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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!
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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...”
THEN – 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 SIMPLE

• WAIT!!!!
Just Having a Conversation

Connect

The more you KNOW, the better it will GO
Take it slow
Go with the Flow
To Connect...

• Use the PPA to get started
• Make a VISUAL connection
  – Look interested
• Make a VERBAL connection
  – Sound enthusiastic, keep responses short
• Make a PHYSICAL connection
  – Hold hand-under-hand, use flat open hand on forearm or knee
Connect

• ID 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 – listen actively
• Use some of their words to keep the flow going
• Remember its the FIRST TIME! – expect repeats
• Use the phrase “Tell me ABOUT …”
CONNECT

• Make an Emotional Connection
  – Later in the disease
    • Use props or objects
    • Consider PARALLEL engagement at first
      – Look at the ‘thing’, be interested, share it over....
    • Talk less, wait longer, take turns , COVER don’t confront when you aren’t getting the words, enjoy the exchange
    • Use automatic speech and social patterns to start interactions
  • Keep it short – Emphasize the VISUAL
Do’s

• Go with the FLOW
• Use SUPPORTIVE communication techniques
  – Use objects and the environment
  – Give examples
  – Use gestures and pointing
  – Acknowledge & accept emotions
  – Use empathy & Validation
  – Use familiar phrases or known interests
  – Respect ‘values’ and ‘beliefs’ – avoid the negative
DON’Ts

• Try to CONTROL the FLOW
  – Give up reality orientation and BIG lies
  – Do not correct errors
  – Offer info if asked, monitoring the emotional state

• Try to STOP the FLOW
  – Don’t reject topics
  – Don’t try to distract UNTIL you are well connected
  – Keep VISUAL cues positive
To Communicate... When DISTRESSED

First - CONNECT
Then - Use Supportive Communication
Finally – Move together to NEW
To Communicate...

Be a Detective

• Try to figure out WHAT is being communicated
  – Words
  – Thoughts
  – Actions
  – Needs
  – Beliefs

NOT a Judge

• DON’T assume or presume
• DON’T discount me because of HOW I deliver the message

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Top TEN ‘UNMET NEEDS’!

**Unmet Physical Needs**
- Hungry or Thirsty
- Tired or Over-energized
- Elimination – need to/did
- Temperature – too hot/cold
- IN PAIN!!!
  - Joints - skeleton
  - Creases or folds
  - Surface-surface contacts
  - Systems – head/heart/gut/bladder
  - Old injury/pain sites

**Unmet Emotional Needs**
- Angry
- Sad
- Lonely
- Scared
- BORED

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To Communicate & Figure It Out...

• CONNECT
  – Visually
  – Verbally
  – Physically
  – Emotionally
  – Spiritually

• HOW?
  – PPA
  – Supportive Communication

• Supportive Communication
  – Empathy
  – Validation
  – Exploration
  – Acknowledgement

• Move Forward
  – New words
  – New place
  – New Activity/Focus
Connect

• 1\textsuperscript{st} – Visually
• 2\textsuperscript{nd} – Verbally
• 3\textsuperscript{rd} – Physically

• 4\textsuperscript{th} – Emotionally
• 5\textsuperscript{th} – Spiritually
To Connect

Use the Positive Physical Approach
So... NOW

• You are connected
  – VISUALLY
  – VERBALLY
  – TACTILELY

• NEXT
  – Connect EMOTIONALLY
  – Go with THEIR FLOW
    • Don’t BLOCK - RO
    • Don’t DIRECT - Lie

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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 a OPEN PALM on Shoulder or Back
  – Offer a HUG – IF the person is Seeking more contact
Use Supportive Communication

• Repeat a few of their WORDS with a ? at the end
• LISTEN...
• Then –
  – Offer EMPATHY
    • “Sounds like…
    • “Seems like…
    • “Looks like…
• LISTEN...

• AVOID Confrontational QUESTIONS...
• Use just a FEW words
• Go SLOW
• Use EXAMPLES...
• Fill in the BLANK...
• LISTEN!!!
More Supportive Communication...

• Validate emotions
  – EARLY – “It’s really (label emotion) to have this happen” or “I’m sorry this is happening to you”
  – MIDWAY – repeat their words (with emotion)
    • LISTEN for added INFO, IDEAS, THOUGHTS
    • EXPLORE the new info BY WATCHING & LISTENING
  – LATE – CHECK OUT the WHOLE Body –
    • Face, posture, movement, gestures, touching, looking
    • Look for NEED under the words or actions
Once Connected & Communicating...

• Move FORWARD
  – ADD New Words...
  – Move to a New Place – Location
  – Add a NEW Activity

• EARLY – Redirection
  – Same subject
  – Different focus

• LATER – Distraction
  – Different subject
  – Unrelated BUT enjoyed
For ALL Communication

• If what you are trying is NOT working...
• STOP
• Back off
• THINK IT THROUGH... THEN
• Re-approach –
• Try something slightly different
What Makes Us Do What We Do?

- Our brain’s function
- Our background & personality & preferences
- What else is going on with us
- The setting – environment
- The schedule – rhythm of the day
- How others are behaving – around us and towards us
What Makes Them Do What They DO?

• SIX pieces...
  – The type & level of cognitive impairment ... NOW
  – The person & who they have been
    • Personality, preferences & history
  – Other medical conditions & sensory status & pain
  – The environment – setting, sound, sights
  – The whole day... how things fit together
  – People - How the helper helps -
    • Approach, behaviors, words, actions, & reactions
I Will Change!

(to the tune of This Little Light of Mine)

By Teepa Snow
I am gonna meet and greet
Before I start to treat
I am gonna meet and greet
Before I check your feet
I am gonna meet and greet
Before I help you eat

How I start sets us up to succeed!
No more just “Getting’ it Done”
I’m gonna DO with you
No more just “Getting’ it Done”
I’m gonna help you thru
No more just “Getting’ it Done”
We’re gonna work, we two

Cause if I do it ALL, we BOTH LOSE!
I’m gonna laugh and dance with you
Not just watch and frown
I’m gonna laugh and dance with you
Not just stand around
I’m gonna laugh and dance with you
We’ll really go to town

For the POWER of JOY I have found!