Using a Positive Approach to Dementia Care
PET and Aging:

PET Scan of 20-Year-Old Brain  
PET Scan of 80-Year-Old Brain

ADEAR, 2003

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

**Something Goes Wrong with Our Brains**

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
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

The person’s brain is dying

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 – can’t be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually
Caring for Someone Living with Dementia:

What Works Best?

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

Beliefs:

People living with dementia are doing the best they can
We must learn to dance with our partner
What we choose to do matters
We are a key to making life worth living
We must be willing to change ourselves
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 and try again

The Basics for Success:
- Be a Detective, not a Judge
- Look, listen, offer, think
- Use your Approach as a screening tool
- Match your help to remaining abilities

Some Basic Skills:
1. Positive Physical Approach™
2. Hand-under-Hand® for connection and assistance
3. Supportive Communication
4. Consistent and skill-sensitive cues
   - Visual, verbal, physical
5. Open and willing heart, head and hands
Getting The Person to Do Something:

Form a relationship first, then work on task attempt!

1. Positive Physical Approach™:
   - Pause at edge of public space (6 feet)
   - Gesture and greet by name
   - Offer your hand and make eye contact
   - Approach slowly within visual range
   - Shake hands and then maintain Hand-under-Hand®
   - Move to the side
   - Get to eye level and 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!
2. Hand-under-Hand®:
Protects aging, thin, fragile, forearm skin

3. Supportive Communication
• Repeat a few of their words with a question at the end
• Avoid confrontational questions
• Use just a few words
• Go slow
• Use examples
• Fill in the blanks
• Listen, then offer empathy:
  “Sounds like...” or “Seems like...” or “Looks like...”

4. Ways of Cueing and Helping:
- Sight or Visual cues
- Verbal or Auditory cues
- Touch or Tactile cues
To Connect:
- Use the Positive Physical Approach™ to get started
- Make a Visual Connection:
  - Look interested and friendly
- Make a Verbal Connection:
  - Sound enthusiastic, keep responses short
- Make a Physical Connection:
  - Hold Hand-under-Hand®, or use flat open hand on forearm or knee

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.”

Connecting Emotionally:
- Identify 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…”
To Communicate:
Just Having a Conversation
- The more you know, the better it will go
- Take it slow and go with the flow
- Later in the disease:
  - Use props or objects
  - Consider parallel engagement at first: look at the 'thing,' be interested, share it
  - Talk less, wait longer, take turns
  - Cover, don’t confront when you aren’t getting their words and just enjoy the exchange
  - Use automatic speech and social patterns to start interactions
  - Keep words short and emphasize the visual

Then, Get it Going!
- Give Simple and short information
- Offer concrete choices
- Ask for help
- Ask the person just to try
- Break the task down to single steps at a time

Give Simple Information:
- Use Visual Cue (gesture/point) combined with a Verbal Cue:
  - “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 information
- Limit your words and keep it simple
- Wait!!!!
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

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
  - Inside systems: head, chest, gut, output
  - Creases or folds of skin
  - Surfaces that contact other surfaces

Unmet Emotional Needs:
- Angry
- Sad
- Lonely
- Scared
- Bored

For All Communication:

If what you are trying is not working:
- Stop!
- Back off
- Think it through, then:
  - Re-approach
  - Try something slightly different
Use empathy and go with the flow!

Do:
- Go with the flow
- Use supportive communication techniques
- Use objects and the environment
- Give examples
- Use gestures and pointing
- Acknowledge and accept emotions
- Use empathy and validation
- Use familiar phrases or known interests
- Respect values and beliefs and avoid the negative
- Offer info if asked, monitoring the emotional state

Don’t:
- Try to control the flow
- Use reality orientation and big lies
- Correct errors
- Try to stop the flow
- Reject topics
- Try to distract until you are well-connected
- Use negative visual cues
The GEMS®

Sapphires
Diamonds
Emeralds
Ambers
Rubies
Pearls

Until we begin to see the beauty and value in what the person is at this point in time, we will never care for them as we should.

Why Use GEMS®?
- 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 us to get beyond the words dementia and Alzheimer’s
- 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

**How to Help Diamonds:**

- Apologize: “I’m sorry!” or “I didn’t mean to…”
- Be friendly, not bossy: leader to leader
- Make it temporary with “Let’s try…”
- Share responsibility, not take over
- Use as many ‘old habits’ as possible
- Give up being ‘right’
- Go with the flow
- Give another ‘job’ when taking one away

**Bad Helper Habits to Break:**

- Saying “Don’t you remember?”
- Not recognizing or accepting differences
- Trying to force changes in roles or responsibilities
- Trying to take over completely
- Taking responsibility for saying “No”
- Accepting things at face value
- Arguing with them
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

How to Help Emeralds:
- Think about “So what?!” … is it worth it?
- Provide subtle supervision for care
- Provide visual prompts: gestures, objects, set-up, samples, show
- Hide visual cues to stop/prevent issues: put away, move out of range, leave
- Use the environment to cue
- Use normal humor, friendliness, support

Bad Helper Habits to Break!
- Noticing and pointing out errors
- Telling, not asking: “You need to…”
- Trying to take over, offering “Let me help you”
- Putting hands on, ‘fussing’
- Reality orientation, arguing, or lying
- Trying to use ‘distraction’
- Trying to go back and ‘fix’ something
- Treating them like a child
- Reacting instead of responding
- Rejecting topics of conversation
- Not going with the flow!
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

How to Help Ambers:

- Provide step-by-step guidance and help
- Give demonstration, show
- Use Hand-under-Hand guidance: may be able to do themselves after a few repetitions
- Offer something to handle, manipulate, touch, gather
- Limit talking, noise, touch, other activities
- Substitute, don’t subtract

Bad Helper Habits to Break!

- Talking too much, showing too little
- Keep on pushing
- Doing for, not with
- Stripping the environment
- Leaving too much in the environment
- Getting in intimate space
- Over or under stimulating
- Getting loud and forceful
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

How to Help Rubies:

- Slow down!
- Hand-under-Hand® assistance
- Move with first, then guide
- Learn about patterns of needs
- Use music and rhythms to help get or stop movement
- Use touch with care
- Use cueing

Bad Helper Habits to Break!

- Touching too quickly, startling them
- Leaning in: intimate space invasion
- Talking too loudly
- ‘Baby-talking’
- Not talking to them at all
- Not showing by demonstrating
- Trying to understand what is said by being confrontational
**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

**How to Help Pearls:**
- Hand-under-Hand® assistance, or hand on forearm if hand/arm movement is poor
- Check for reflexes, modify help and approach to match needs
- Go slow!
- Use calm, rhythmic movements and voice
- Come in from back of extremities to clean
- Stabilize with one hand and work with other
- Gather all supplies for the task before getting started
- Increase warmth of the room, use warm towels and lightweight blankets
- Use circular, rotational movements to relax joints for care
- Provide skin care for their fragile and dry skin

**Bad Helper Habits to Break!**
- Hurrying to get it done quickly
- Don’t talk to – talk over or about
- Don’t check for primitive reflexes prior to helping
- Not using both hands to give care
- Cleaning from the front using prying motions
- Focusing on tasks, not the relationship
- Forgetting to look for the Pearl
What you leave behind is not what is engraved in stone monuments, but what is woven into the lives of others.