

# **Progression of Loss: Providing Help that Matches Need**

# Beliefs

- People with Dementia are Doing the BEST they can
- We must learn to DANCE with our partner
- We are a KEY to make life WORTH living
- What we choose to do MATTERS
- We can change the 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?

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

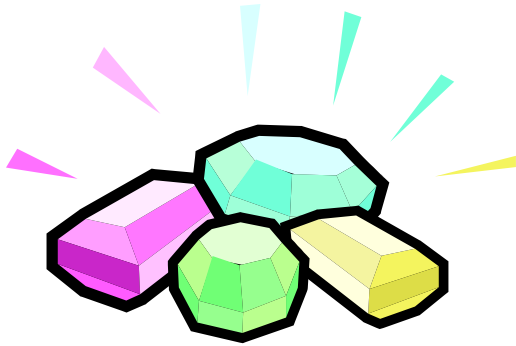
# Some Basic Skills

- 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

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

# Now for the GEMS...



Sapphires

Diamonds

Emeralds

Ambers

Rubies

Pearls



# Sapphires

Us on a good day...  
Clear & True to Themselves  
May feel 'blue' over changes  
Some are 'stars' and some are not  
They can CHOOSE



# Sapphires

- Can connect ABCs - make contracts
- May have other health issues that affect behaviors
- Recognize life experiences, achievements & values in ABCs
- Can follow written info & hold onto it
- Will still need us to work with them
- Can typically CHOOSE their behaviors





# Diamonds



Still Clear

Sharp - Can Cut

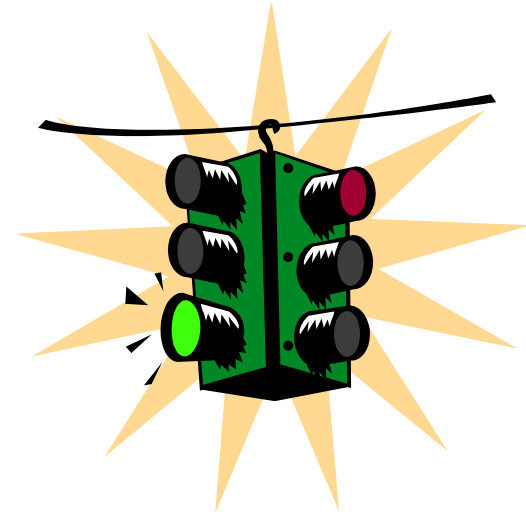
Hard - Rigid - Inflexible

Many Facets

Can Really Shine



# Emeralds



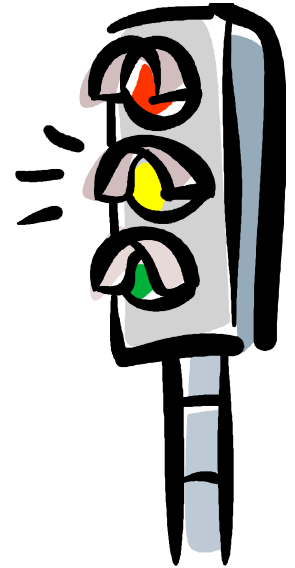
Changing color  
Not as Clear or Sharp - Vague  
Good to Go - Need to 'DO'  
Flaws are Hidden  
Time Traveling



# Ambers

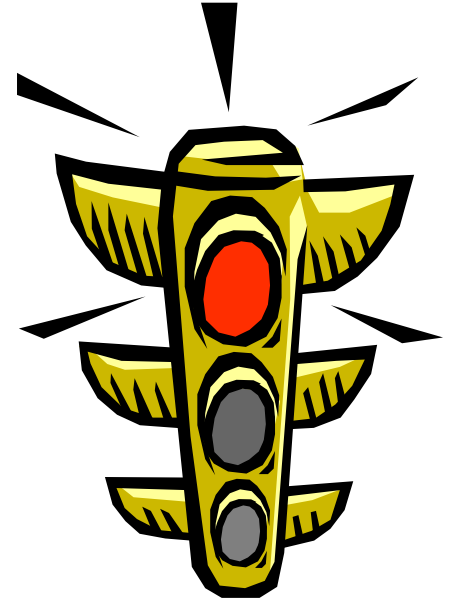
Amber Alert  
Caution!

Caught in a moment  
All about Sensation  
Explorers





# Rubies



Hidden Depths  
Red Light on Fine Motor  
Comprehension & Speech Halt  
Coordination Falter  
Wake-Sleep Patterns are Gone



# Pearls



Hidden in a Shell

Still & Quiet

Easily Lost

Beautiful - Layered

Unable to Move - Hard to Connect

Primitive Reflexes on the Outside



# Diamonds



Still Clear  
Sharp - Can Cut  
Hard - Rigid - Inflexible  
Many Facets  
Can Really Shine



# Diamonds

Are Joiners or Are Loners

Use Old Routines & Habits

Control Important 'Roles' & 'Territory'

Real? Fake? - Hard to Be Sure

# *Diamonds* - Level 5

- Uses Routines & Old Habits to function
- Can complete personal care in 'familiar place'
- Follows simple prompted schedules - mostly
- Misplaces things and can't find them
- 'Resents takeover' or bossiness
- Notices other people's mis-behavior & mistakes
- Territorial - refusals!
- Varies in lack of self-awareness



# Diamond Interests



- What they feel competent at
- What they enjoy & who they like
- What makes them feel valued
- Where they feel comfortable but stimulated
- What is familiar but intriguing
- What is logical and consistent with historic values & beliefs
- Who is in charge - the boss



# Common Diamond Issues

- **IADLs**
  - Money management
  - Transportation - Driving
  - Cooking
  - Home maintenance & safety
  - Caring for someone else
  - Pet maintenance
  - Med administration
- **Unfamiliar settings or situations**
  - Hospital stay
  - Housing change
  - Change in family
  - Change in support system
  - MD visits
  - New diagnoses
  - Traveling or vacations



# Visual Cues that Help

- Personalized room
- Way finding signs
- Highlighted schedules
- Familiar & inviting environments
- Familiar set-ups for tasks or activities
- Personal approach with a smile
- Place cards at table settings
- Wear name tags on right side



# Verbal Cues that Help

- Knock before entering
- Use Sir and Ma'am, be respectful
- Ask permission to do things in the room
- Offer positive comments
- Issue invitations not orders
- Ask for help or input
- Frame as a 'RULE' for everyone
- Acknowledge their skill, ask for their support or understanding --- a favor

# Watch how you talk...

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



# Tactile Cues that Help

- Hand shake greetings
- Return of friendly affection touches
- Responsive hugs
- Hand-under-hand comforting
- Back rubs - with permission
- Hand & foot massages - 'pampering'  
(getting used to us touching & doing)



# So What Helps?

Apologize! - "I'm SORRY!" - "I didn't mean to..."

- Friendly NOT bossy - leader to leader
- "Let's try" - temporary...
- Share responsibility not take over
- Use as many 'old habits' as possible
- Give up being 'RIGHT'
- Go with the FLOW
- Give other 'job' when taking away another



# Be Prepared for REPEATS

- For repeated questions or requests
  - Don't share so early
    - be careful about emotional information
  - Make sure you are connected to respond
  - Repeat a few of their words in a ???
  - Answer their question
  - THEN
    - Go to new words (use enthusiasm)
    - A new place
    - Add a new activity (possibly related)





# For OLD Stories

- Use "Tell me about it"
  - to accept the story
  - To reduce risk of 'paranoia-like' thinking
- Store them for the future
  - Write them down
  - Share them with others
  - You will possibly need them for supportive communication later
- Learn several - prompt for 'switch up'

# Use empathy & Go with the flow



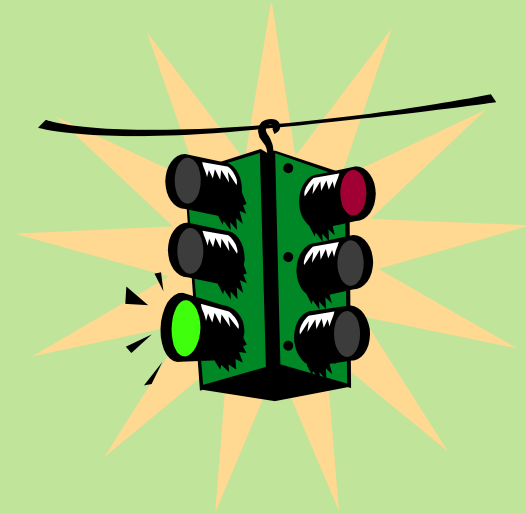


# BAD Helper Habits to BREAK

- 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



# Emeralds



Changing color  
Not as Clear or Sharp - Vague  
Good to Go - Need to 'DO'  
Flaws are Hidden  
Time Traveling



# Emeralds

Two Kinds of DOING  
Doers or Supervisors

Does What is Seen - Misses What is Not  
Must be in Control - Not able to do it Right  
Does tasks - Over and over OR Not at All



# Emerald Interests

- Doing familiar tasks
- Doing visible tasks
- Historic tasks and people and places
- Engaging with or helping others
- Finding important people or things
- Having a 'job' or 'purpose'
- Being an 'adult'
- Getting finished & doing something else



# Common Emerald Issues

- Doesn't do care routinely - thinks did
- Makes mistakes in sequence - unaware
- Repeats some care routines over & over
- Resists or refuses help
- Gets lost - can't find where to do care
- Limited awareness of 'real needs' -
  - Hunger, thirst, voiding, bathing, grooming...
- Has other 'stuff' to do...



# More Emerald Issues

- Afternoon or Evening - "Got to go home"
- Daytime - "Got to go to work"
- Looking for people/places from the past
- Losing important things - thinking others stole/took them
- Doing private things in public places
- Having emotional meltdowns
- Treating strangers like friends and visa versa





# Visual Cues that Help

- The environment
  - Overall look (friendly, fun, familiar, forgiving)
  - Surfaces to work on or do things on
  - Places to sit (paired chairs)
  - Set up Props (objects that 'say' what to do)
  - Highlighted areas (light, color contrast, clutter reduction, organized)
  - Hidden - what is NOT to be done, what is already done, what 'triggers' distress



# More Visual Cues that Help

- You
  - Facial expression
    - Friendly
    - Concerned
  - Gestures
    - Invite with gestures and your face
    - Indicate next item to use, or options
  - Offer items
    - Offer an item in correct orientation
    - Present two to pick from



# Verbal Cues that Help

- Tone of Voice
  - Friendly
  - Interested
  - Concerned
- Reduce and Focused words
  - Use preferred name for attention
  - Match words with gestures or offering
- Listen and use their words to connect



# More Verbal Cues

- When becoming distressed
  - Use PPA - Let them come to you, if possible
  - Listen - Get emotionally connected to where they are
  - Use empathic comments
  - Listen for key words
  - Go with their FLOW - don't push for the change
  - THEN Use redirection, NOT distraction



# Physical Cues that Help

- Limit this form of helping!
  - Match it with a visual & verbal cue combo
- Offer objects - don't put hands on
- Share the task -
  - Give them something to do while you do your part
- Do 'it' with/to someone else first, then approach them



# More Physical Cues

- When distressed
  - Match your touch to their preferences
  - Hand-under-Hand FIRST
  - Back rub - if interested
  - Hug - show first
  - Increase space and distance, if cued
  - BACK OFF, if it is not working



# How to Help

- Learn about "SO WHAT!"... is it worth it?
- Provide 'subtle' supervision for care
- Provide visual prompts to do
  - Gestures, objects, set-up, samples, show
- Hide visual cues to 'stop'/prevent
  - Put away, move out of range, leave
- Use the environment to cue - SHOW
- Use 'normal', humor, friendliness, support

# 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 ..."



# 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



# What NOT to DO...

- DO NOT point out errors - or focus on 'wrong'
- DO NOT offer - physical assist 1<sup>st</sup>
- DO NOT offer "Let me HELP you"
- DO NOT try to 'go back and fix it...'
- DO NOT continue arguing about 'reality'
- DO NOT treat like children...
- Do NOT react... remember to respond



# BAD Helper Habits to Break!

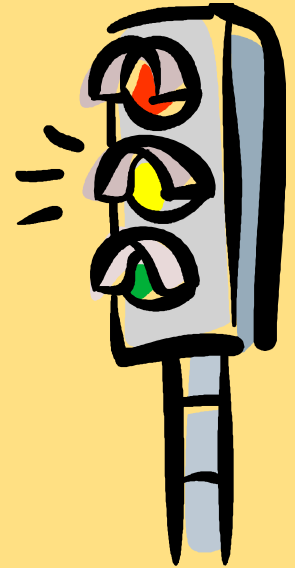
- Noticing and pointing out errors
- Telling not asking - "You need to..."
- Too little or too much - talking, showing, touching
- Trying to take over - offering "HELP"
- Putting hands on - 'fussing'
- Reality orientation or lying
- Trying to use 'distraction'



# Ambers

Amber Alert  
Caution!

Caught in a moment  
All about Sensation  
Explorers





# Ambers

Private & Quiet OR Public & Noisy

All About Sensory Tolerance & Needs

Touching - Tasting - Handling - Exploring

Attraction - Avoidance

Over-stimulated - Under-stimulated

No safety awareness

Ego-centric



## *Level 3 - Amber*

- LOTS of touching, handling, mouthing, manipulating
- Focus on fingers and mouth
- Get into things
- All about sensation....
- Invade space of others
- Do what they like
- **AVOID** what they do **NOT**



# Amber Interests

- Things to mess with (may be people)
- Places to explore
- Stuff to take, eat, handle, move...
- Visually interesting things
- People who look or sound interesting OR places that are quiet and private
- Textures, shapes, movement, colors, numbers, stacking, folding, sorting...





# Amber Issues

- Getting into stuff - taking stuff
- Bothering others
- Not able make needs known
- Not understanding what caregivers are doing
- Not liking being helped/touched/handled
- Not like showers or baths
- Repetition of sounds/words/actions



# Visual Cues that Help

- Automatic social greeting signals
- Lighted work surfaces with strong props
- Demonstrations - work along side
- Model the actions
- Do the action one time, then offer the prop
- Show one step at a time
- Show a NEW item, then cover the old



# Verbal Cues that Help

- Call name
- Use simple noun, verb, or noun + verb
  - “Cookie?”
  - “Sit down”
  - “Let’s go” (with gesture)
- Give simple positive feedback
- Listen for their words, then
  - use a few and leave a blank at the end of the sentence



# Physical Cues that Help

- Show the motion or action wanted
- Touch the body part of interest
- Position the prop for use - light touch
- Show the motion on yourself
- Use hand under hand guidance
- Offer the prop once started - encourage their use of the item

# Hand-Under-Hand Assistance



# How to Help

- Provide step-by-step guidance & help
- Give demonstration - show
- Hand-under-hand guidance after a few repetitions, uses utensils (not always well)
- Offer something to handle, manipulate, touch, gather
- Limit talking, noise, touch, other activities
- **SUBSTITUTE** don't **SUBTRACT**



# To Connect with Ambers

- Make an Emotional Connection
  - 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



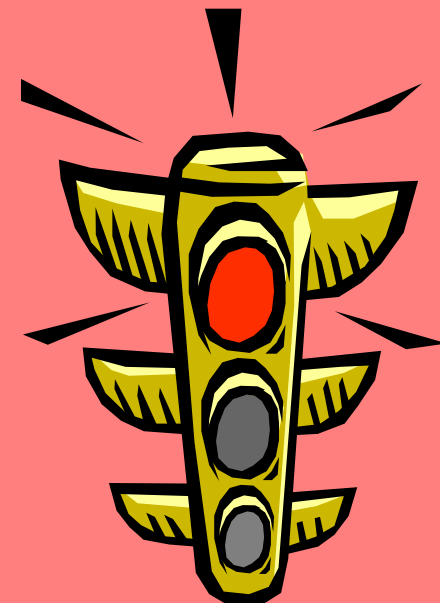
# BAD Helper Habits to Break!

- 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  
Red Light on Fine Motor  
Comprehension & Speech Halt  
Coordination Falter  
Wake-Sleep Patterns are Gone



# Rubies

Balance & coordination

Eating & drinking

Wake time & sleep time



## *Level 2 - Ruby*

- Big movements - walking, rolling, rocking
- Hand actions - not fingers
- Tends toward movement unless 'asleep'
- Follows gross demonstration & big gestures for actions
- Limited visual awareness
- Major sensory changes
- Major movement skill loses
- Fine motor skill lost - mouth & hands



# Ruby Interests

- Walking a routine path
- Going forward
- Watching others - checking them out
- Being close or having space
- Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap
- Things to chew on, suck on, grind
- Rhythmic movements and actions



# Ruby Care Issues

- Safe mobility - fatigue, wandering, & falls
- Intake - amount and safety
- Hydration - interest, amount, safety
- Rest time & place - night time waking
- Shadowing others - invading places
- Not staying - not settling for meals
- Reactions to hands on care - sensation
- Identifying & meeting needs



# More Ruby Issues

- Contractures
- Skin well being - bruises, tears, rashes
- Pressure or friction
- Infections - UTI, yeast, URI, pneumonias
- Swallowing
- Circulation



# Visual Cues that Help

- Demonstrate what you want
- Give big movements to copy
- Move slowly & with rhythm
- Present cues in central visual field about 12-18 inches out
- Hold things still - allow exploration
- Offer your hand
- Smile while offering support



# Verbal Cues that Help

- Call name to get attention - at 6' out
- Use 'song' to connect
- Give 1-3 words only
- Combine verbal direction with gesture or demo
- Give one 'action' cue at a time
- Match tone/inflection to intent
- Give positive 'Strokes' with attempts





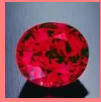
# Physical Cues that Help

- Hand-under-hand
- Touch body part to be moved or used
- Place hand/foot then gesture
- Offer comfort touch as desired before task attempt
- Back rubs -
  - Flat and slow - to calm
  - Finger tips and quick circles - to awake



# How to Help

- SLOW yourself DOWN
- Hand under hand
- Move with first - then guide
- Learn about patterns of 'needs'
- Use music and rhythms - help get or stop movement
- Use touch with care
- Combine cuing & do SLOW



# BAD Helper Habits to Break!

- Touching too quickly - startling
- Leaning in - intimate space invasion
- Talking too loudly
- 'Baby-talking'
- Not talking 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 - Layered

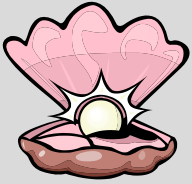
Unable to Move - Hard to Connect

Primitive Reflexes on the Outside



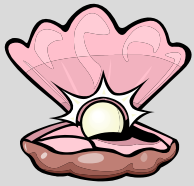
# Pearls

- The end of the journey is near
- Multiple systems are failing
- Connections between the physical and sensory world are less strong
- We are often the bridge - the connection
- Many Pearls need our permission to go -
  - They are still our moms, dads, spouses, friends
  - They will go in their own time
  - IF we don't try to change what is



# *Level 1 - Pearl*

- Immobile - can't get started
- Bed or chair bound - frequently falls to side or forward
- Has more time asleep or unaware
- Has many 'primitive' reflexes present -Startles easily
- May cry out or mumble 'constantly'
- Increases vocalizations with distress
- Difficult to calm
- Knows familiar from unfamiliar
- Touch and voice make a difference in behaviors



# Pearl Interests

- Internal cues
- Pleasant and familiar sounds & voices
- Warmth and comfort
- Soft textures
- Pleasant smells
- 'Good' tastes
- Smooth and slow movement
- Just right touch and feel



# Primitive Reflexes to Consider

- Startle reflex -
  - Sudden movement causes total body motion
- Grasp reflex-
  - touch palm - grips hard can't release
- Sucking reflex -
  - sucks on anything near mouth
- Rooting reflex -
  - Turns toward any facial touch and tries to eat





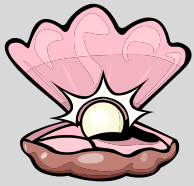
# More Reflexes

- Bite reflex
  - Any touch in mouth causes bite down
- Tongue thrust
  - Anything in mouth causes tongue to push forward and out
- Withdrawal - rebound
  - Pull away from stretch
- Gag reflex -
  - Any touch to tongue causes gag



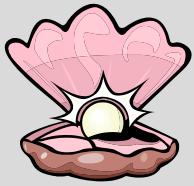
# Typical Positioning - Why?

- Constant muscle activity causes 'contractures' - shortening - can't relax
- Stronger muscles cause typical 'fetal' positioning
- Pulling against contractures is painful
- Shortened muscles cause some areas to:
  - Not get air - become 'raw' or 'irritated'
  - Rub or press against other body parts
  - Get too much pressure - can't move off



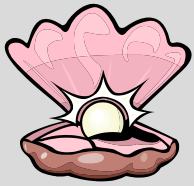
# Pearl Care Issues

- Not interacting much
- Crying out - can't make needs known
- Skin & hygiene problems
- Weight loss
- Reflexes make care challenging
- Repeated infections
- Not eating or drinking
- Not able to sit up safely



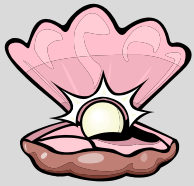
# Visual Cues to Help

- Get into supportive position
- Place your face in the central field of vision
- Make sure light comes from behind the person - into your face
- Bring up lights carefully
- Move slowly so they can follow you
- Place items to be used in central field



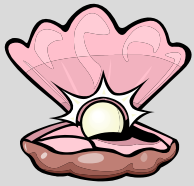
# Verbal Cues to Help

- Keep your voice deep & calm
- Put rhythm in your voice
- Tell what you are doing and what is happening while you give care
- Reflect emotions you think you see
- Offer positive comments & familiar phrases as you offer care
- Quiet down, if signaled to do so



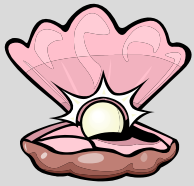
# Touch Cues to Help

- Use firm, but gentle palm pressure at joints to make contact
- Always try to maintain contact with one hand while working with the other
- Once physically connected keep it
- Use flats of fingers and palms for care
- Always use hand under hand when doing something 'intense'



# How to Help

- Hand under hand help & care - or hand on forearm, if hand/arm movement is poor
- Check for reflexes - modify help & approach to match needs
- **GO SLOW**
- Use calm, rhythmic movements & voice
- Come in from back of extremities to clean
- Stabilize with one hand & work with other



# How to Help?

- Gather all supplies for the task before getting started
- Increase warmth of the room for bathing
- Use warm towels & light weight blankets
- **GO SLOW**
- Use circular, rotational movements to relax joints for care
- Provide skin care - fragile & dry skin





# BAD Help Habits to BREAK

- Hurry - Get it done quickly
- Don't talk to - talk over or about
- Don't check for primitive reflexes prior to helping
- Use both hands to give care
- Clean from the front - use prying motions
- Focus on tasks not the relationship
- Forget to look for the Pearl