Meeting the Spiritual Needs When Someone Has Dementia: Noticing the Changes & What to Do?

How Can We HELP?

- Noticing it
- Getting help
- Helping out
- Being there
- Still being there
- Ending it
- Finding Joy
Who are the Players?

• The person with dementia
• Family members in the ‘loop’
• Family members NOT in the ‘loop’
• Peers in the ‘loop’ or faith community
• Other members with dementia
• Members of a faith community or support system
• Leaders of the system

Typical Problems

• Knowing “Normal” from Dementia
• General lack of knowledge & awareness of ‘dementia’, Alzheimer’s, and senility
• Opening up conversations about ‘it’ – 1:1 or in the Faith Community or in the support system
• Addressing changing abilities of support system/community members
• Preserving relationships during the illness – for both the person with dementia and their care partners
• Rejection of faith & faith community or support system by person & family
More typical problems

- Family dynamics – each person is at a different place or has different ideas
- Lack of family involvement – family not around – faith community is surrogate family
- Acceptable behavior problems – the person is not acting the way others believe they should or they used to
- Mis-communication problems – due to changes in memory, language, and judgment info is messed up
- Territoriality – anger and frustration about who should do what – who should lead, follow, & get out of the way!
- Withdrawal from Community – lost sheep…

Why should we be worried about DEMENTIA in our Communities & Support Networks?
A Few Facts…

• Aging is the greatest risk factor
  – 10% at age 65 TO 50% at age 85
• Early signs are subtle & inconsistent
• Doctors only catch it 20% in early stages
• It’s a relatively new condition
• There are many different types
• It affects EVERYTHING!

What is it NOT…

• NORMAL Aging
  • Slower to think
  • Slower to do
  • Hesitates more
  • More likely to ‘look before you leap’
  • Know the person but not the name
  • Pause to find words
  • Reminded of the past
  • HARDER

• NOT Normal Aging
  • Can’t think the same
  • Can’t do like before
  • Can’t get started
  • Can’t seem to move on
  • Doesn’t think it out at all
  • Can’t place the person
  • Words won’t come – even later
  • Confused about past versus now
  • VERY DIFFERENT
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 mis-understanding
• 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 form normal patterns of activities and interests

What Could It Be?

• Another medical condition
• Medication side-effect
• Hearing loss or vision loss
• Depression
• Acute illness
• Severe but unrecognized pain
• Other things…
What Should the Doctor Do?

- A thorough physical & medical history
- Blood work
- A neurological exam
- A good history from the person and the family of the ‘problem’
- A complete medication review
- A CAT scan or MRI or PET scan
- Neuropsychological testing – screening for cognitive changes
- FOLLOW-UP and counseling or at least a referral

What Should We Do If We Suspect Something Might Be Happening?

- Work Out Legal Support – Financial PoA
- Work Out Health Care Support – HC-PoA
- Check with Your Doctor – Raise Your Concern
- Consider a Neuropsychological Assessment
- Consider Seeing a Specialist – geriatrician, neurologist, gero-psychiatrist
What Makes Dementia Different than Other Conditions?

• Forgetfulness and dementia – look similar
• Not consistent – good days/bad days or moments
• Gradually gets worse – takes time to notice
• Motor skills are OK – correct sequencing & quality control are gone
• Self-awareness is usually limited – can’t see it
• Self-monitoring is not possible – can’t change
• Social skills are often preserved - covering

Progression & Typical AT-RISK Behaviors

• Early
  – Way-finding problems
  – Need to get ‘home’, to ‘work’, to ‘familiar’
  – Can’t remember new info on location, time, activity
  – Most not aware of impairments
  – Gets frustrated with limits set by others
  – May still drive or can get independent transport
  – Poor time awareness
  – Repeats the familiar – over & over & over
Progression & Typical AT-RISK Behaviors

• **Middle**
  - Goes back in time – hours or days or years
  - Gets stuck on ‘important things to do’
  - Can still think and watch others for inattention or information – picks up on others’ reactions
  - Fluctuates in ability during 24 hrs
  - Wake-sleep disturbances
  - Will agree– won’t remember it or mean it
  - Acts and speaks impulsively or not at all

• **Late**
  - Follows/shadows selected people - constant
  - Can’t verbally communicate – can’t make needs or wants known – physical needs are huge
  - May seek others out OR avoid them completely
  - Follows visual cues – doors/cars/windows
  - No self-protection – wandering is a possibility
  - Can’t use fingers or mouth well
  - Worsening mobility skills
  - No day-night or seasonal awareness
  - Can’t meet own needs (food/drink/care)
The person’s brain is dying

Brain Atrophy
PET and Aging

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

ADEAR, 2003

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

Normal  Early Alzheimer’s  Late Alzheimer’s  Child

G. Small, UCLA School of Medicine
Alzheimer’s Disease
- Early onset
- Normal onset

Vascular (Multi-infarct) Dementia

Lewy Body Dementia

Fronto-Temporal Lobe Dementias

Other Dementias
- Metabolic
- Drugs/toxic
- White matter disease
- Mass effects
- Depression
- Infections
- Parkinson’s

Loss of Memory
Memories

- Losses
  - Where & when you are
  - What is going on
  - Where you want to go
  - What you want to do

- Preserved abilities
  - Confabulation!
  - Emotional memories
  - Motor memories

Understanding
Issues of Understanding

- **Losses**
  - Can’t interpret information
  - Can’t make sense of words
  - Gets off target

- **Preserved abilities**
  - picks up on facial expression
  - picks up on tone of voice

Language & Movement & Sensory Changes
Sensory Changes

• Losses
  – Awareness of body and position
  – Ability to locate and express pain
  – Awareness of feeling in most of body

• Preserved Abilities
  – 4 areas can be sensitive
  – Any of these areas can be hypersensitive
  – Need for sensation can become extreme

Self-Care Changes

• Losses
  – initiation & termination
  – tool manipulation
  – sequencing

• Preserved Abilities
  – motions and actions
  – the doing part
  – cued activity
Language Issues

- **Losses**
  - Can’t find the right words
  - Not able to say what you mean
  - Can’t make needs known

- **Preserved abilities**
  - automatic speech
  - singing
  - swearing
  - turn taking

Emotional & Impulse Control

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[Image of brain scans: Normal vs. Alzheimer's]
Issues of Impulses & Emotions

- 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

What Can You Do to Help?

- Recognize what the problem might be
- Be willing to try something different
- Use a Positive Physical Approach in Interactions
- Use Positive Communication Skills
- Consider Project Lifesaver
- Contact the Alzheimer’s Association or Society for more information
Positive Physical Approach

• Come from the FRONT
  – Make sure they are aware of you, before you get close or touch (knock, call out)

• GO SLOW
  one second - one step OR let them come to you

• Get to the SIDE
  – Use supportive stance NOT confrontational
  – Provides visual and physical ‘out’ for the person

Positive Physical Approach

• Get LOW
  – Sit down or get down to the person’s level
  – Reduce intimidation without invading space

• Offer your HAND
  – Greet the person as a ‘friend’ rather than as a ‘threat’
  – It also provides safety for you from ‘striking out and connects you to the person (prevents wandering or leaving)
Positive Physical Approach

• Introduce yourself by name
  – Making sure the person ‘knows you’
  – Also cues them for the next step…
• WAIT for a response… (count to 10)
  – Let’s you know if they processed
  – Let’s them know you are listening
  – Use your non-verbal skills while you are waiting

Positive Physical Approach

• Come from the front & offer your hand
• Go slow
• Get to the side
• Get low
• Introduce yourself
• WAIT for a response…
• Then talk
Positive Communication

• Get the person to DO something
• Have a conversation
• Deal with distress

Get the Person to DO something

• Introduce self and get name…
  – “Hi, I’m ____ , and you are????
  – This helps you get connected & see if info is correct without stressing the person

• Offer simple, short info about situation
  – “It sounds like you are _____ (give an emotion you think the person may be experiencing). PAUSE
  – “I want to ask you a few questions to help….”
  – This gives orienting info about what is happening and sets the interaction up
Get the Person to DO something

• Provide simple choices
  – “Did you call us or did your daughter call?”
  – Helps you determine if the person is able recall situation and accurately select choices

• Ask for help
  – “Could you help me …”
  – Providing help is frequently almost automatic and gets things going

Get the Person to DO something

• Ask to TRY
  – “Could you give it a try?…”
  – Safer to ‘try’ something than to ‘be sure’

• Break tasks down in steps
  – “Lean forward, reach back, sit down…”
  – Use words, gesture, then demonstrate
Having a Conversation

• Use the positive physical approach
• Introduce self
• Ask something about origins…
  – Where are you from?
  – What kind of work did you do?
  – Who is in your family?
• Use some of their words in your responses

Having a Conversation

• REALIZE!!!!
  – They will not be 100% accurate in recent recall of information
BUT!!!!
  – They do have emotional memories
  – They may remember OLD stuff well – out of sequence and situation
  – They will make specifics up to fit their feelings
Having a Conversation

• Confirm understanding through head movement opposite of correct response
  – “Am I wearing a blue shirt? While you move your head in the incorrect direction
• Consider using a second officer to get info from significant other – other space
  – Helps to keep the person busy and occupied while more info is gathered

Dealing with Distress

• Use the approach
• Make a visual and physical connection
• Make an emotional connection
• VALIDATE – offer support for what is ‘true’
• Use some of their words
• THEN –
  – Use redirection – same topic with new direction
  – Use distraction – different topic with action
• Move to a new location or activity
How Will the Condition Progress?

• Easy – Early, Middle, Late
• Then
• LEVELS – 5-1

Levels & Help

Levels

- Diamond
  - Uses old habits
  - Seeks rigid
  - Easily frustrated with others
  - Does the familiar

- Emerald
  - Works on tasks
  - Not see = not do
  - Looks for things to do
  - Asks questions
  - Errors & skips in doing
  - Set up
  - Simple words
  - Pictures
  - Objects
  - Watch you do
  - Hand under hand guide - selected parts

- Amber
  - Manipulates things
  - Investigates places and things
  - Repeats familiar actions
  - Trouble with tools
  - Demo
  - Gestures
  - Single step verbal cues
  - Hand-under-hand assist

- Ruby
  - Walks a lot
  - Big body movements
  - Little use of fingers
  - Can’t sit still or can’t get going
  - Gross demo
  - Hand under hand assist
  - Take movement breaks
  - Let go & return

- Pearl
  - Reflexes get stronger
  - Controlled movement stops
  - More internal
  - Sometimes aware
  - Touch
  - Smooth slow voice and hands
  - Familiar sounds, smells, contact
  - H-U-H help

Typical Behaviors

- Diamond
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What Can & Does the **Diamond** Person Do?

- Seeks authority figures for help
- Follows simple directional signs
- Follows prompted schedules
- Follows familiar routes to get around
- Looks for places, people, activities that are desired BUT gets lost easily
- Becomes easily frustrated when things don’t go well or others won’t ‘behave right’
- Will look and sound ‘normal’ most of the time

Spiritual Strengths

- Rituals
- Routines
- Continued participation with less *independent* responsibility
Typical Issues

• Repeats
• Territoriality
• Lack of boundaries
• Arguments and disagreements
• Mistakes about times, places, activities
• Difficulty with roles
• Problems with change

How Can We Help?

• Acknowledgement & expectations
• Use of old routines and rituals
• Share roles and responsibilities
• “I’m sorry that happened”
• “I’m sorry, this is hard!”
• “I’m sorry I made you….”
What Can & Does the *Emerald* Person Do?

- Asks questions over and over
- Picks up on visual information more than verbal
- Elopes - Goes back to old work & home habits
- Elopes – To get away from current rules/situation
- Has some problems with hygiene, personal care, care of others or pets, can’t be alone
- Becomes upset if unable to figure out what should or needs to be done

Spiritual Strengths

- Rhythms and rituals
- Music and prayer
- Place of worship
- Comfort in worship – short and sweet
Common Issues

• Talking during sermon
• Difficulty with ‘behavior’ during activities
• Language or behavior changes
• Embarrassment about behaviors
• Private behaviors in public places

Help?

• PPA
• Short and sweet
• ‘Children sermon’ format
• Make strong VISUAL cues
• Keep words ‘friendly and familiar’
• Pick up on cues – respond
• Celebrate moments of joy
What Can & Does the *Amber* Person Do?

- Follows demonstrations and hand-under-hand guidance after a few repetitions, uses utensils (not always well)
- Likes to handle, manipulate, touch, gather, place things
- Will not respect others’ space or belongings
- Goes to places or activities that are interesting visually, tactiley, auditorily
- Leaves places or activities that are TOO busy or crowded

Spiritual Strengths

- Favorite sensory experiences still enjoyed:
  - Sights
  - Sounds
  - Textures and movements
  - Smells
  - Tastes
Common Issues

• Sensory Intolerance
• Sensory Needs
• Mix with other Gems
• Space issues

Help?

• Meet their needs and preferences
• Become a detective NOT a judge
• Celebrate moments
What Can & Does the Ruby Person Do?

- Walks/wheels around a majority of the time when awake
- May carry objects or rub/clap/pat with hands
- Tends toward movement unless 'asleep'
- Uses hands poorly, not spontaneously, inconsistently
- Follows gross demonstration & big gestures for actions
- Limited awareness of others - may invade personal space
- Gets stuck in 'tight' places
- Leaves during 'unpleasant' experiences

Spiritual Strengths

- Songs and prayers
- Celebration in moments
- Quiet and still in moments
- Individualized abilities and needs
- OLD, OLD comforts still comfort
Common Issues

• Can’t be still
• Can’t get going
• Not able to ‘participate’ or understand
• Calling out or moving around – making noise

Help?

• ACCEPT
• CONNECT & SLOW DOWN
• CELEBRATE
What Can & Does the *Pearl* Person Do?

- Is bed or chair bound
- 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

Spiritual Strengths

- Soul still there
- Hidden spirit with only moments of connection
Common Issues

• Leaving Us
• Very limited words or movements
• Little interaction
• Not hungry or thirsty

Help?

• Offer to be there
• Offer to let the person go
• Celebrate their life and time with us
• Sing, pray, be SILENT
• Connect and then let go
• LISTEN to them….
In Summary…

So… What will they do?

• They will confabulate – part of the disease… but it isn’t ‘traditional lying’
• They will agree to do something – then will NOT remember at all about it – and argue with you
• They will NOT be able to control impulses
• They will behave differently with you than with family (early on)
• They may try to avoid you and hide more during busy or unpleasant situations
...What will they do?

- They think they can and should be able to do things the way they ALWAYS have
- They do NOT see errors or problems
- They may miss key words, but act like they are ‘getting it’
- They will ask you the same thing over and over
- They do ‘get lost’ easily – even on familiar routes

...What will they do?

- They can sometimes do things no one expects them to be able to do
- They will blame others for problems
- They will call you (or the authorities) to help them with problems – even when they are wrong
- They will follow others – getting lost in public places
What ELSE???

- If you are suspicious … consider a confidential conversation with a leader or family member
- Learn more about these conditions
- Consider an In-Service for all church members
- Share info about those with dementia with others in the community
- Think about being proactive – rather then reactive, especially with wandering and elopement risks, domestic abuse and neglect, driving, & fraud

Finally…

- Don’t give up or turn away
- Don’t ignore
- Don’t judge
- Help both the person with dementia & their care partner(s) – may need different help and support
- DO Love and Pray and Connect!