

Indiana Healthcare Leadership Conference

March 22, 2015

Indianapolis, Indiana

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Understanding is the willingness to put yourself in another's shoes for the sake of appreciating that person's experience of the world. ~ Tom Rusk M.D.

*I can't understand why people are frightened of new ideas.
I'm frightened of the old ones. ~ John Cage*

A test of a people is how it behaves towards the old. It is easy to love children. Even tyrants and dictators make a point of being fond of children. But the affection and care for the old, the incurable, the helpless are true gold mines of a culture.

~ Abraham J. Heschel

Understanding Alzheimer's Disease and Dementia

Dementia is an umbrella term that describes a group of symptoms caused by changes in the brain. Dementia symptoms include forgetfulness, problems with thinking, and difficulty performing daily activities. These symptoms can be caused by several conditions. Alzheimer's disease is one of the most common conditions that cause dementia.

What are the Symptoms?

Memory

The hallmark of dementia is impairment with respect to recent events, what is often referred to as "working memory or short-term memory. Forgetting appointments, conversations, and the like typically herald the onset of dementia. New learning becomes defective whereas memories from the distant past may be intact.

Orientation

The inability to know one's place and time may also be indicative of dementia - for example, getting lost outside one's home or not knowing the month or year.

Language

Word finding difficulty is also typically seen among persons with dementia. Comprehension of spoken language may also be impaired. Rules of syntax and grammar may be impaired although speech itself may be intact.

Judgment

Reasoning skills, especially with respect to abstract tasks, are often impaired resulting in poor judgment.

Visuospatial skills

Distortions in interpreting one's environment may also be seen in dementia. Although eyesight itself may be well preserved, the brain's ability to accurately interpret what one is seeing may be impaired.

Concentration

The ability to pay attention or concentrate may also be impaired. This may be seen in difficulty with making change or balancing a checkbook.

Ability to sequence tasks

Performing any task requires the ability to put a series of steps together in the right order. Someone with dementia may forget the steps in preparing a meal or shopping for groceries.

Communication is the Foundation to Good Care

Everyone is different. Everyone we care for is at different levels and some of the suggestions may not apply or work with the person you care for. We have to be flexible and adapt to the persons changing needs.

A few things to think about before you start to communicate:

1. Make sure the person can see you well. Sit or stand directly in front of the person, and look at him or her when you speak. Avoid glaringly bright or too dark settings. Sometimes sitting at right angle instead of directly beside the person can be easier for them to see and hear you.
2. Avoid distractions. Can you ask to turn the radio volume down or turn the T.V. off?
3. Is it a new environment? Are you out at a shopping mall or a field trip or is there a special activity going on that will cause them not to pay full attention.
4. Does the person have a hearing aid or wear eyeglasses? Are they working properly?
5. How is your attitude? Are ready to be flexible, calm, patient and give full focus to the person?

Research has shown that people you communicate with will take:

7 % of our words

38 % of vocal characteristics: tone, volume, and inflection

55 % of body language & facial expressions

~ Professor Albert Mehrabian

Notes:

Non-Verbal Communication

1. Slow down

Whew! We all move to fast. Think about the pace of each individual in everything you do with him or her.

2. Eye Contact

It is very important for accurate communication, to give complete attention to the individual and to communicate with your eyes.

3. Facial Expressions

Does your face match your words? When you aren't speaking, what does your face say to those around you?

4. Body Language

Match your body language with your intent. Know that someone is always watching you.

5. Mirroring /Modeling/Cueing

Demonstrate your request by pointing, touching or beginning the task for the person. When necessary you can model/cue an activity for an individual/group. Try and show it in steps, just like when you are vocalizing instructions.

6. Approach/ Face to Face /Eye Level

Approach a person from the front. Speak and gesture face to face and try to communicate at their eye level when possible

7. Attitude

Take a breath. What you feel and what your face and body says affects others. Be aware of the attitude you send out to the world.

8. Senses

Be aware of communicating with other senses; smell, taste and touch. Massage. Smells of cooking. Music. Tasting favorite foods. Touch is very important and of when *not* to touch and when *to* touch.

9. Be Patient

Put yourself in their shoes. Take your time.

10. Laugh often

Notes:

Verbal Communication

1. Identify yourself.
Approach the person from the front and tell them who you are.
2. Address the person by name.
This is not only courteous, but also helps orient him and get his attention.
3. Use short, simple, familiar words and sentences.
Don't overwhelm him with lengthy requests or stories. Speak concisely and keep to the point. In some cases, slang words may be helpful.
4. Talk slowly and clearly.
Be aware of speed and clarity when speaking.
5. Give one-step directions.
Break tasks and instructions into clear, simple steps, giving one step at a time.
6. Repeat information or questions.
If he doesn't respond, wait a moment and ask again.
Use the same phrasing and words as before.
7. Avoid literal expression.
Directions such as, "Hop in!" may be taken literally and cause unnecessary confusion.
8. Avoid pronouns.
Instead of saying, "Here it is," try "Here is your hat."
9. Be Specific
"Go there." " Sit by her." " Put that on your head." All of those can be misunderstood. Make sure you are clear to everyone in the room.
10. Make negatives more positive.
Instead of saying, "Don't go there," try saying, "Let's go here."
11. Give visual clues.
Demonstrate your request by pointing, touching or beginning the task for the person.
12. Avoid quizzing.
Some reminiscence can be healthy, but avoid asking, "Do you remember when...?" or using statements like, "You should know who that is."
16. Write things down.
Try using written explanations for reminders, when verbal ones seem too confusing, to validate what the person says or if the person is having problems hearing you. A dry erase boards work well.

17. Try again later.
If he looks like he's not paying attention, try to communicate again a few moments later or have someone else try.
18. Treat him with dignity and respect.
Avoid talking down to him or talking as if he isn't there.
19. Validate Feelings & Empathize
Be aware of the person's facial expression and the tone of their voice. What is the content behind the words? Let them know you understand.
20. Praise Praise Praise!
21. 3 Powerful words. I Need You.

Notes:

A thought:

Make it possible for the person do what they can still do
for as long as they can still do it.

Listening Skills –It’s an Art

The goal is to understand not just the words the person is saying but the *meaning* the person is trying to get across.

1. Stop talking.
You can't listen if you are doing all the talking.
2. Be patient.
Count to 20. Take a breath.
3. Do not interrupt.
The person may need extra time to express what he or she wishes to say.
4. Show interest.
Let the person know that you care what he or she is trying to say.
Maintain eye contact, and stay near the person.
5. Double-check understanding.
Avoid assuming that the person understands you. The person may even say he or she understands what you have said but still not understand at all.
6. Use active listening skills.
Nodding the head, leaning forward, using touch, saying " Yes" " I see", repeating back what you have heard, making eye contact are some of the active listening techniques you may use.

Notes:

When you speak you are only repeating what you already know,
when you listen you may learn something new.

Reframing Behaviors into Actions & Reactions

In dementia care, the word “behavior” has become synonymous with bad things that our elders or residents do. We need to change our mindset and see these “behaviors” as purposeful actions or intentional (and normally appropriate) reactions to an action.

First lets think about our core needs as human beings and how those unmet needs may be communicated in an action or reaction to you.

Core Needs of Human Beings

Dr. Tom Kitwood suggested that people with dementia, like all people, have six psychological needs: attachment, love, comfort, identity, inclusion and occupation; and that as we care for people with dementia, we should strive to fulfill those needs everyday.

As we care for persons with dementia (or anyone for that matter), we need to consider finding ways to fulfill these needs everyday.

1. **Attachment** – We need to feel attached to another person or to a group. We want to feel *connected* to someone or something
2. **Love** – Everybody needs it. To love someone; to be loved and accepted; to love an activity, a food, a person, to love God and to feel self-love/self-respect.
3. **Comfort** – We all need to feel comfort. We need to be warm, dry and clean; to have a full stomach and not be thirsty; to have quiet when we want it; to have a sense of tenderness, closeness and bonding with others.
4. **Identity** – We need to have others know *who I am* or *who I was*. We want to be individual, to be special, to have our own identity. We want our individuality to be recognized in our food preferences, our clothing, our activities and recreation.
5. **Inclusion** – We want to feel we are a part of something; to belong to a group; to be a member; to not feel left out.
6. **Occupation** – We want to be occupied. To have something to do, to help others, to occupy us with ‘work’ that has meaning and purpose.

What if we approached everyone with these ideas in mind?

Notes:

Why May Actions and Reactions Happen?

Physical and Emotional Health

People with dementia can also have other medical problems that greatly affect behavior. Listed below are *some* of the more common physical problems to which caregivers should be alert.

1. Effects of medications.
2. Impaired vision or hearing
3. Acute illnesses (UTI, colds,)
4. Chronic illnesses (arthritis, diabetes...)
5. Dehydration.
6. Constipation
7. Depression.
8. Fatigue
9. Physical discomfort.

The Environment

1. Environment too large.
2. Excessive stimulation.
3. No orientation information or cues.
4. Poor sensory environment. Too much clutter.
5. Unstructured environment.
6. Unfamiliar environment.

The Task

1. Task too complicated.
2. Too many steps combined.
3. Task not modified for increasing impairments.
4. Task unfamiliar.

Communication

1. Behaviors are trying to communicate something to us – it is our job to figure it out.
2. Be aware of your approach – you set the tone.
3. Use your non verbal skills, body language, facial expressions, vocal characteristics
4. Respond to the emotional content
5. Be patient

Unmet Needs

See previous page

Life Story

Who is this person? What events, occupations, relationships – moments have shaped their behaviors and their communication skills. What parts of *who they were* tell you *who they are now*?

Actions and Reactions: What to do?

Sometimes there is nothing you need to do, but to be aware of the action/reaction. Other times you can prevent some actions and most of the time you need to be prepared for whatever comes your way.

What Can We Do?

1. Learn how to creatively brainstorm together as a team. You all have the answers but you need to communicate effectively with each other and be open to different techniques. Come up with a plan and let everyone in on it.
2. Keep a Journal. Communicate what has happened with everyone in an accessible space so all shifts can easily read it. Keep it in their care plan.
3. Keep offering trainings to staff about their own actions. Realize that most of what we label as a “problem” or difficult” behavior is a reaction to our actions or an attempt to communicate to us.
4. Listen to what the action is telling us. From the moment we are born we communicate to others when our needs are not being fulfilled – what might the person with dementia be communicating to you?

What would you do?

If someone walked in your own room without knocking...

If someone that you do not remember ever meeting before joins you in the bathroom and starts taking off your clothes...

If someone starts pushing your wheelchair without asking you or telling you where you are going...

If someone tells you that you live here now, but you know deep in your heart and mind that you live on a farm in Iowa...

If someone did any of these actions to you, how would you react?

We are the ones who need to change OUR actions.

Their REACTIONS are completely appropriate and accurate to how we are acting to them.

- Tom Kitwood

I Believe...

- Every person with Alzheimer's and dementia is an individual and the disease affects them each in an individual way. We must treat them individually.
- How we react to a particular behavior is what makes it challenging for *us and the person with dementia*. Get in the habit of looking at any behavior as a form of communication. What are they telling us? What do our actions say to them?
- Know the person. Know their preferences. Know their history.
- Everyone has good days and bad days - even those with dementia.
- You have to jump into their world. Accept and use their reality.
- Be Positive. No more No. Use the Yes And technique.
- You have to be patient, be flexible, and be creative. You have to be patient. That is worth repeating. Be patient. Take a deep breath. Count to 10.
- Use your sense of humor. It is universal, ageless and timeless.
- How powerful words can be. Choose your words well.
- You have to have Hope.
- 1 minute and 30 seconds can change a person's day. Whose day can you change today?
- Everyone has good days and bad days - even those with dementia.
- Let the person do what they can do for as long as they can do it.

Everyone needs purpose.

Everyone needs to have meaning in his or her life.

I used to think I love you were the 3 most important words you could say to a person. I now know that the 3 most important words are

I need you.

References, Resources & Gratitude

Here is a short list of amazing resources I have used through the years.

Websites

There are many very good web sites. Here a few. A lot of these have links to other sites.

In the Moment 1	www.in-themoment.com
In the Moment 2	www.in-themoment.net
Alzheimer's Reading Room	www.alzheimersreadingroom.com/
TimeSlips	www.timeslips.org
Alzheimer's Speaks	www.alzheimersspeaks.wordpress.com/
Memories From My Life	www.memoriesfrommylife.wordpress.com/
Truthful Kindness	http://truthfulkindness.com/
National Alzheimer's Association	www.alz.org

A Few Good Books

Sometimes Ya Gotta Laugh by Karen Stobbe

Dementia Reconsidered, The Person Comes First, Tom Kitwood

Rethinking Alzheimer's Care by Sam Fazio, Dorothy Semen, Jane Stansell

Forget Memory by Anne Basting

Dementia Beyond Drugs by Dr. Allen G. Power

Dementia Beyond Disease by Dr. Allen G. Power

Alzheimer's: From the Inside Out by Richard Taylor

Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers by Daniel Kuhn and David A. Bennett

The Best Friend's Approach & A Dignified Life: The Best Friends Approach to Alzheimer's Care, A Guide for Family Caregivers by Virginia Bell and David Troxel

Speaking Our Minds: Personal Reflections from Individuals With Alzheimer by Lisa Snyder

Finding Flow: The Psychology of Engagement With Everyday Life by Mihaly Csikszentmihalyi