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I long, as does every human being, to be at home wherever I find myself. ... Maya Angelou

Dementia and Communication



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How Would You Feel If ?

1. You are feeling bored and restless at home, so you decide to go out for a walk. But you find all the doors have been locked and a stranger appears and tells you to go and sit down.
2. You are late for picking up your children from school and you are in a hurry, but the person with you won't let you go.
3. You open your door to a stranger who tells you it is time you had a bath.

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How Would You Feel If ?

4. You are trying to get dressed, but it seems someone has stitched up the sleeves in your jumper, removed some buttons from your jacket and hidden your shoes.
5. You are asleep in a chair in your home, when suddenly are woken up by a person you have never seen before trying to undress you.

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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.

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Core Needs of Human Beings

- 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.

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Core Needs of Human Beings

- 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.

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Core Needs of Human Beings

What if we approached everyone with these ideas in mind?

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Communication

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

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Communication

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?

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Communication

- 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?

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Non-Verbal Communication

We are communicating non-verbally 24 hours a day. Even when we are sleeping. We have to be able to read non-verbal communications and be aware of our non-verbal messages.

- 1. Slow down**
Whew! We all move too 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.

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Non-Verbal Communication

- 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.

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Non-Verbal Communication

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

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Non-Verbal Communication

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

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Non-Verbal Communication

You can observe a lot by watching.
~ Yogi Berra

Saying nothing... sometimes says the most.
~ Emily Dickinson

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Verbal Communication

- 1. Identify yourself.**
Approach him from the front and tell 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.

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Verbal Communication

- 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.

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Verbal Communication

- 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.

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Verbal Communication

- 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."

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Verbal Communication

- 13. 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 works well.
- 14. 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.

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Verbal Communication

- 15. Treat him with dignity and respect.**
Avoid talking down to him or talking as if he isn't there.
- 16. Validate Feelings & Empathize**
Be aware of the person's facial expression and the tone of their voice. Let them know you understand.
- 17. Praise Praise Praise!**

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Inflection

Read the message out loud. Seven times, each time putting the emphasis on a different word, thus:

- I **didn't** say he stole the money
- I **didn't** say he stole the money
- I didn't **say** he stole the money
- I didn't say **he** stole the money
- I didn't say he **stole** the money
- I didn't say he stole **the** money
- I didn't say he stole the **money**

Notice how much difference there is in the meaning as you change the emphasis on the words.

Notice how you feel as you speak each message.

Interesting?

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Verbal Communication

I guess I should warn you, if I turn out to be particularly clear, you've probably misunderstood what I said.
- Alan Greenspan

Best to take the moment present, as a present for the moment.
- Stephen Sondheim

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Listening

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.

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Listening

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.

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Listening

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.

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Listening

*I know that you believe you understand what you think I said,
but I'm not sure you realize that what you heard
is not what I meant.*
~ Robert McCloskey

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

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The gentle art of listening is a magnificent gift that we can give to others and ourselves.

When we listen to others, we show that what they have to say is worthwhile.

Therefore, we instill in them self-worth and confidence.

Even if what they have to say doesn't help us, it will help them.

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What about Behaviors ?

Learn to look at behavior as a form of communication.

What does a person's behavior communicate to us?

It may be our behavior that is a problem.

Your behavior may be the "challenging" one.

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Key Points

1. Know the Person

Getting to know each other as individuals begins to build relationship. The more we know each other the better we can work together and care for each other.

2. We are all Individuals

All of us are unique. We must acknowledge that we all have our strengths and weaknesses and a part of the web of our community – of life. When you have met one person with Alzheimer's disease you have met just one person with Alzheimer's disease.

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Key Points

3. What is your Life Story?

We all have a story to tell and a past, present and future that tells a lot about who we are, who we were and who we wish to become.

4. Take a Walk in Their Shoes

We can never truly understand what others are feeling but we can put ourselves in their shoes and imagine what it may be like. It helps us see the person and to understand how to better communicate and understand behaviors.

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Key Points

5. Words can make a difference

Words are powerful. The idea behind person-centered language is to acknowledge and respect long-term care residents as individuals. Using person-centered language, I've learned, is often as simple as reversing common phrases to put the person first and the characteristic second. "A wheelchair-bound resident," for instance, becomes "a person who uses a wheelchair for mobility," and "a feeder" becomes "someone who needs assistance with dining."

~ Karen Schoeneman, www.pioneernetwork.net

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Key Points

6. Say Yes!

Find ways to rearrange your words in a positive manner. 'Don't go that way' into 'Come this way with me.' No one likes to hear No! Learn to Say Yes!

7. Be aware of your non-verbal communication

We get messages from each other from the tone and volume of voice, posture, facial expressions and hand gestures. Not only do we need to be careful of our messages but to read those we care for when they have failing verbal communication.

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Key Points

8. Slow Down

We are all very busy. We have a lot to do in a short amount of time. But let's take a breath and slow down just a little bit. Whew, that feels better.

9. Be Present

A person with dementia may be living from moment to moment. Let's practice spontaneity, flexibility and enthusiasm to be present with them in those moments.

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Key Points

10. Respect and Empower.

Let them do what they can do for as long as they can do it.

11. Laugh. Find the Joy! Use humor.

It is the universal language. Everyone understands it. Laughter builds relationship, costs nothing and makes us feel good.

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Resources

- Sometimes Ya Gotta Laugh* by Karen Stobbe
- Rethinking Alzheimer's Care* by Sam Fazio, Dorothy Semen, Jane Stansell
- Alzheimer's: From the Inside Out* by Dr. Richard Taylor
- The Forgetting: Alzheimer's: Portrait of an Epidemic* by David Shenk
- Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers* by Daniel Kuhn, 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, David Troxel
- Speaking Our Minds: Personal Reflections from Individuals With Alzheimer* by Lisa Snyder

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Resources

Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease by Joanne Koenig Coste
Talking to Alzheimer's: Simple Ways to Connect When You Visit with a Family Member or Friend by Claudia J. Strauss
Alzheimer's: Finding the Words by Harriet Hodgson
Forget Memory by Anne Davis Basting

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References

My main reference, resource and inspiration have been my parents; Manfred and Virginia Stobbe and bringing up a close second is my daughter Grace who could teach us all a few things about being with a Grandma who happens to have Alzheimer's disease. And...
Robinson, A., Spencer, B., and White, L. *Understanding Difficult Behaviors*.
Kitwood, Tom. *Dementia Reconsidered*
Mehrabian, Albert. *Silent Messages*
Alzheimer's Association. www.alz.org
Barbara Leigh of Milwaukee Public Theatre, Richard Taylor, Anna Ortigara, Jeanne Heid-Grubman, Jim Kinsey, PHI, William Keane, Dr. William Thomas and Dorothy Seman: *various presentations*

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