

BE SUPPORTED

The ABCs of Dementia



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You don't have to take
this journey alone.



1-800-733-1476
Monday through Friday 8 a.m.-5 p.m.

The ABCs of Dementia



When a spouse, parent or other relative develops dementia, it is a frightening time for the whole family. We believe that by providing individuals, families and caregivers with key information and support, they can live well with dementia. These ABCs of dementia will help you understand the overall disease of dementia, as well as characteristics of specific forms of the disease.

Dementia

- Is NOT a part of normal aging! It is a disease!
- Is more than forgetfulness – which is part of normal aging
- Makes independent life impossible
- Is an umbrella term that includes many cognitive loss conditions
- Includes some reversible conditions – should be checked out carefully

Alzheimer's Disease

- Is the most common type of dementia
- Is caused by damage to the nerves in the brain and their eventual death
- Has an expected progression with individual variations – one to two years
- Will get worse over time – we cannot stop it
- Is a terminal disease – there is no known cure at this time

Vascular Dementia (Multi-Infarct)

- Is caused by damage to the blood supply to the nerves in the brain
- Is spotty and not predictable
- May not change in severity for long periods, then have sudden changes

Lewy Body Dementia

- Problems with movement – falls and stiffness
- Visual hallucinations and nightmares
- Fluctuations in performance – day-to-day

Frontal-Temporal Dementias

- Problem behaviors – poor impulse control
- Difficulty with word finding
- Rapid changes in feelings and behaviors

Symptoms Common to Most Dementias – Over time...

- It affects a person's entire life as it causes the brain to shrink and stop working
- It steals memories – the most recent first, but eventually almost all
- It steals your ability to use language – leaves you with some skills
- It steals your ability to understand what others mean and say
- It steals your reasoning and logic
- It robs you of relationships
- It makes even the familiar seem odd and scary
- It steals you of your ability to care for yourself and move around safely
- It robs you of impulse control – takes away emotional and mood control

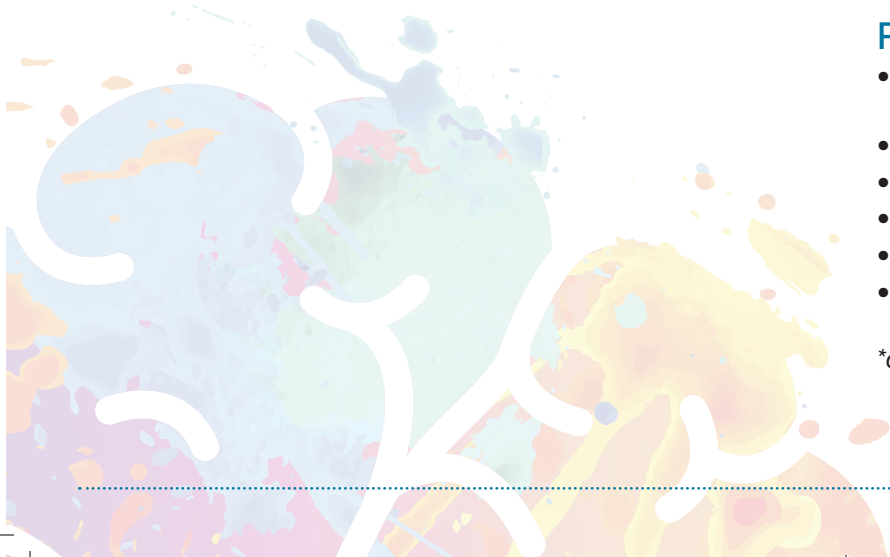
Drug Treatment for Alzheimer's

- Drugs to improve chemicals in the brain so nerve activity might happen
- Drugs to treat depression
- Drugs to control distressing hallucinations, severe paranoia, or unprovoked violence
- No vaccines or cures...yet
- No way to stop the disease...yet

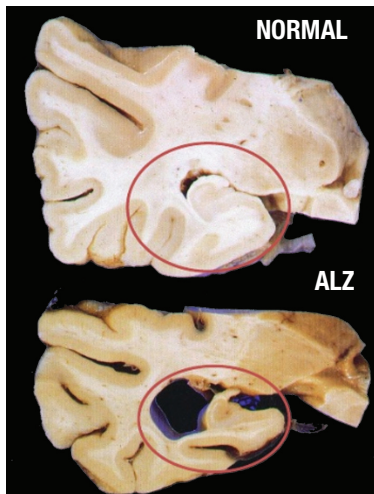
Prevention

- Have a good family history for staying alert and “with it” – genetics do play a part
- Eat healthy and moderately (heart smart)
- Exercise your body – 100 minutes/week*
- Exercise your brain – challenge yourself
- Eat fish once a week
- Control your blood pressure, sugar and weight

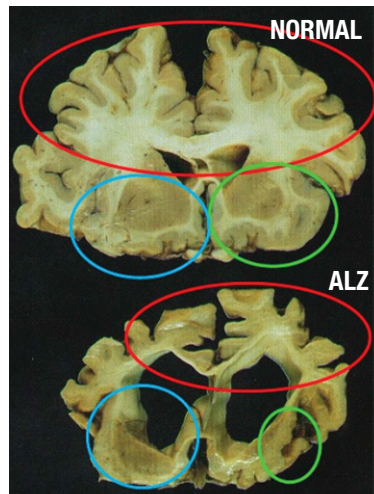
**consult your doctor*



Brain Images: Normal Vs Alzheimer's Disease



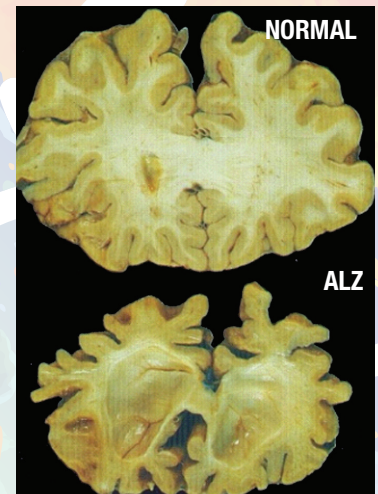
The ability to remember information



The ability to use words and language



The ability to understand what is being said



The ability to control your impulses, temper, & moods

Be Positive. It makes a difference in communicating with people living with dementia.

It is important to respond in a way that is not hurtful or offensive when caring for a loved one experiencing changes in cognition and abilities. With practice, common reactions to the person living with dementia can become thoughtful responses that improve quality of life for everyone involved. Keep in mind that the person with this disease is doing the best they can. If something isn't working, it's the caregiver's responsibility to change their approach and to discover what can be done differently to deal with the situation. Also, be aware of the environment surrounding a person living with dementia and make changes as needed.

A POSITIVE APPROACH

ALWAYS

- Come from the front
- Go SLOW
- Get to the side
- Get low – sit down
- Offer your hand
- Use the person's preferred name
- Wait for a response – before you start talking or doing!

WAYS OF HELPING

Visual cues

- Make eye contact and smile
- Use simple written schedules and notes as reminders early on
- Label areas and items with simple words to prompt
- Use pictures to remind about what is hidden
- Use props to focus or provide choices
- Use gestures and pointing
- Use demonstration – show what you want and mean by doing it yourself

Verbal Cues

- Use the person's preferred name
- Keep information simple and short – “Here's your tea.”
- Say what's going on – “It's time for lunch.”
- Offer simple choices – “Do you want tea or coffee?”
- Ask for help – “Could you help me, please?”
- Ask to try – “Would you like to give it a try?”
- Break requests into smaller steps – “Stand up.”
- ALWAYS give positive feedback and praise – “Yes! Good!”

Tactile – touching cues

- Shake hands to start
- Offer a hug or hand holding if distressed
- Touch for attention during tasks
- Guide movement – lead through once
- Do the hard parts – have them do the easier ones
- Hand-under-hand assistance

BE POSITIVE

Be Mindful. Your Actions Make a Difference.

Caring for a loved one with dementia can be challenging and frustrating. However, by being aware of your own behaviors and reactions, while interacting with your loved one, you have the power to create a better outcome for everyone involved.

REALIZE ...

It takes two to Tango... or TANGLE

By managing your own behavior, actions, words and reactions, you can change the outcome of an interaction.

Being “right” doesn’t necessarily translate into a good outcome for you both.

Deciding to change your approach and behavior WILL REQUIRE you to stay alert and make choices... it is WORK!

It’s the relationship that is MOST critical, NOT the outcome of the encounter.

As part of the disease, people with dementia tend to develop atypical patterns of speech, behavior and routines. These people will also have skills and abilities that are lost while others are preserved.

Typically Lost – can’t use	Preserved – can or may use
MEMORY SKILLS	
<ul style="list-style-type: none"> • Immediate recall • Short-term memory • Clarity of time and place • Depth of categorical information • Relationships and specifics 	<ul style="list-style-type: none"> • Long-ago memories • Emotional memories • Confabulation • Procedural memories • Awareness of familiar versus unfamiliar
UNDERSTANDING SKILLS	
<ul style="list-style-type: none"> • Interpretation of abstract meaning • Early – misses ¼ of words • Later – misses ½ of words • Subtle emotions, unspoken agreements • At the end – most words 	<ul style="list-style-type: none"> • “Gets” the concrete message • Picks out familiar or meaningful words • Covers well that they may not fully understand • Facial expressions that are consistent with the message being sent
LANGUAGE USE SKILLS	
<ul style="list-style-type: none"> • Specific word finding • Descriptive abilities • Reading for content • Content of speech • Spoken communication • Words • Meaningful “yes” and “no” • Socially acceptable expressions of emotion • Verbal communication of needs and desires 	<ul style="list-style-type: none"> • Desire to communicate • Ability to use hands or actions to describe • Reading aloud • Rhythm of speech • Para-verbal communication (how you say it) • Music and song • Automatic speech • Swearing, sex words, socially unacceptable words • Non-verbal communication of needs and desires
EMOTIONAL AND IMPULSE CONTROL SKILLS	
<ul style="list-style-type: none"> • Ability to “demand” respect • Ability to limit or control emotions • Ability to control impulsive speech • Ability to control impulsive actions • Don’t act out when “pushed” • Ability to keep private thoughts and actions in private places 	<ul style="list-style-type: none"> • Desire to be respected • Ability to feel emotions and have needs • Say what is on your mind – with errors • Do what you want to do • Sometimes, feel badly after emotion/impulse has passed • Sometimes, behaving differently in public if cues are strong
MOTOR SKILLS AND SENSORY PROCESSING	
<ul style="list-style-type: none"> • Early on, very little change as far as skills go • As disease progresses, problems initiating getting started • Later, parts of tasks get left out/skipped • Misinterprets sensory information • Organized scanning is lost • Visual field is restricted • May become hypersensitive OR hyposensitive to touch, sound, light... 	<ul style="list-style-type: none"> • The movement patterns associated with pieces of tasks • Gross motor skills last longer than fine motor • Can often do the mechanics – BUT not safely or well • Looks for stuff – seeks out things • Mouth (lips, tongue), fingers and palms, soles of feet, and genitalia or “private body parts”

Be Observant.

As dementia progresses, identify the below level your loved one is exhibiting and how that affects him or her.

Understanding the behaviors and abilities at each level of the disease will help you better care for and communicate with your loved one living with dementia. They can't help what is happening to them, their brain is going through changes that affect cognition levels, social skills, language and more.

LEVEL 1: Early Loss – Running on Routine – Repeating Stories

- Some word problems and loss of reasoning skill
- Easily frustrated by changes in plans and routines
- Seeks reassurance but resents take over
- Still does well with personal care and activities
- Tends to over- or underestimate skills
- Seeks out authority figures when upset or frustrated
- Points out others' errors, but doesn't notice own behavior
- Many have some awareness – “Just not right” – might blame others or self
- Can't remember new rules, locations, plans, discussions, facts

LEVEL 2: Moderate Loss – Just Get It Done! – Wanting a Purpose and a Mission

- Gets tasks done, but quality is getting to be a problem
- Leaves out steps or makes errors and WON'T go back and fix it
- Can help with lots of things – needs some guidance as they go
- Likes models and samples – uses others' actions to figure out what to do
- Asks “what/where/when” LOTS
- Can do personal care tasks with supervision and prompts – often refuses help
- Still very social BUT content is limited and confusing at times
- May try to “elope”/leave to get to an older familiar time or situation OR get away from fighting
- Can't remember what happened AND can misremember it – goes back in time periodically

LEVEL 3: Middle Loss – See It – Touch It – Take It – Taste It – Hunting and Gathering

- Touches and handles almost anything that is visible
- Does not recognize others' ownership – takes things, invades space, gets too close
- Can still walk around and go places – “gets into things”
- Language is poor and comprehension very limited – does take turns
- Responds to tone of voice, body language, and facial expression
- Loses the ability to use tools and utensils during this level
- Does things because they feel good, look good, taste good – refuses if they don't
- Stops doing what isn't interesting anymore
- Can often imitate you some – But not always aware of you as a person

LEVEL 4: Severe Loss – Gross Automatic Action – Constant GO or Down and Out

- Paces, walks, rocks, sings, hums, claps, pats, rubs
- Frequently ignores people and small objects
- Doesn't stay down long in any one place
- Often not interested in/aware of food – significant weight loss expected at this level
- Can grossly imitate big movements and actions
- Generally enjoys rhythm and motion – music and dance
- Doesn't use individual fingers or tools (more eating with hands)
- Either moves toward people and activity (feels like a shadow) or leaves busy, noisy places (ghost)
- Chewing or swallowing problems are common – soft, ground, puree food may be needed
- May not talk much at all, understands demonstration better than gestures or words

LEVEL 5: Profound Loss – Stuck in Glue – Immobile and Reflective

- Generally bed or chair bound – can't move much on own
- Muscles are often stiff and contracted making positioning difficult – primitive reflexes (involuntary motor responses) reappear
- Poor swallowing and eating
- Still aware of movement and touch
- Often sensitive to voice and noise – startles easily to sounds, touch, movement...
- Difficulty with temperature regulation
- Limited responsiveness at times
- Moves face and lips a lot, may babble or repeatedly moan or yell
- Give care in slow, rhythmic movements and use the flats of fingers to open palms
- Keep your voice deep, slow, rhythmic and easy as you talk and give care

BE OBSERVANT

Be Patient. Communication takes time and skills when talking with people with dementia.

The following information will help you build communication skills to better communicate with your loved one who is living with dementia. Your behaviors and methods of communicating have a direct impact on creating a positive interaction.

First – ALWAYS use the positive physical approach

Then – Pay attention to the THREE ways you communicate: HOW you speak, WHAT you say, and HOW you respond.

1) HOW you speak

- TONE of voice (friendly not bossy or critical)
- PITCH of voice (deeper is better)
- SPEED of speech (slow and easy, not pressured or fast)

2) WHAT you say: THREE basic reasons to talk to someone

One: To get someone to DO something (Five approaches to try)

- Give a short direct message about what is happening
- Give simple choices about what the person can do
- Ask the person to help you do something
- Ask if the person will give it a try
- Break down the task – give it one step at a time
- ** Only ask “Are you ready to...” if you are willing to come back and ask again later if they initially respond they are not**

Two: Just to have a friendly conversation

- Go slow – Go with the flow
- Acknowledge emotions – “sounds like/seems like/ I can see you are...”
- Use familiar words or phrases (what the person uses)
- Know who the person has been as a person – what they value
- Use familiar objects, pictures, actions to help and direct
- Be prepared to have the same conversation over and over
- Look interested and friendly
- Be prepared for some emotional outbursts
- DON'T argue – BUT don't let the person get into dangerous situations

REMEMBER the person is doing the BEST that they can AND go with the FLOW

Three: Deal with the person's distress or frustration/anger

- Try to figure out what the person really *needs* or *wants*. Use phrases like “It sounds like...” “It looks like...” “It seems like...” “You're feeling...”
- Use *empathy*, but not *forced* empathy or lying
- Once the person is listening and responding to you:
 - Redirect their attention and actions to something that is ok, or distract them with other things or activities you know they likes or value

Always BE CAREFUL about personal space and touch with the person, especially when they are distressed or being forceful.

3) How you RESPOND to the person

- Use positive, friendly approval or praise (short, specific and sincere)
- Offer your thanks and appreciation for their efforts
- Laugh with them and appreciate attempts at humor and friendliness
- Shake hands to start and end an interaction
- Use touch (hugging, hand holding, comforting) ONLY if the person wants it

Key points about WHO the person IS

- Preferred name
- Introvert or extrovert
- Planner or a doer
- Follower or a leader
- “Detail” or “big picture” person
- Work history – favorite and most hated jobs or parts of jobs
- Family relationships and history – feelings about various family members
- Social history – memberships and relationships to friends and groups
- Leisure background – favorite activities and beliefs about fun, games, and free time
- Previous daily routines and schedules
- Personal care habits and preferences
- Religious and spiritual needs and beliefs
- Values and interests
- Favorite topics, foods, places
- Favorite music and songs – dislike of music or songs
- Hot buttons and stressors
- Behavior under stress
- What things help with stress?
- Handedness
- Level of cognitive impairment

BE PATIENT

Be Mindful. Physical actions make a difference.

Caregivers can improve their ability to approach, connect and provide care to people living with dementia through the positive physical approach. By using the approach, you can build a better connection with your loved one that enables safety, comfortability and happiness.

A Positive Physical Approach for Someone with Dementia

1. Knock on door or table to get attention if the person is not looking at you and get permission to enter or approach.
2. Wave and smile. Look friendly and give the person a visual cue; make eye contact.
3. Call the person by name OR at least say "Hi;" pause your approach or let the person come to you, if they like to be in control.
4. Move your hand out from a wave to a greeting handshake position.
5. Approach the person from the front; come within 45 degrees of center.
6. Move slowly, one step per second, stand tall, and don't crouch down or lean in as you approach the person.
7. Move toward the right side of the person and offer your hand. Give the person time to look at your hand and reach for it if they are doing something else. Offer, don't force.
8. Stand to the side of the person at arm's length. Respect personal space and be supportive, not confrontational.
9. Shake hands with the person. Make eye contact while shaking.
10. Slide your hand from a shake position to hand-under-hand position for safety, connection and function.
11. Give your name and greet the person, for example, "I'm (name), It's good to see you!"
12. Get to the person's level to talk; sit, squat, or kneel if the person is seated and stand beside the person if they are standing.
13. NOW, deliver your message...

Approaching when the person is DISTRESSED!

TWO CHANGES

1. Look concerned, not too happy, if the person is upset
2. Let the person move toward you, keeping your body turned to the side (supportive = not confrontational)
3. After greeting, try one of two options
 - a. "Sounds like you are (provide an emotion or feeling that seems to be true)?"
 - b. Repeat the person's words to you. If she said, "Where's my mom?" you would say, "You're looking for your mom (pause)...tell me about your mom." If the person says, "I want to go home!" you would say, "You want to go home...tell me about your home."

BASIC CARD CUES – WITH Dementia

- Knock – Announce self
- Wave and Smile
- Move Slowly
- Move from the front to the side
- Greet with a handshake and your name
- Slide into hand-under-hand hold
- Get to the person's level
- Be friendly – make a nice comment or smile
- Give your message – simple, short and friendly

BE MINDFUL

Personal Data Collection: Helping patients tell their stories

Areas to Explore	What Did You Find Out?
Preferred Name:	Preferred Hand:
Living Situations and History (where are you from today and originally, who do and did you live with, what type of places did you live in [house, apartment, etc.]	
Marriage History and Status (who's involved, has been involved, and how do you feel about them?)	
Family History and Membership (who's who and how do you feel about them? Think about several generations...)	
Work History (What jobs have you had in your life? How did you feel about them? What jobs would you have loved to do, but never did?)	
Leisure History (What do you and did you do for fun and in your spare time? How do you feel about 'having fun'? What would you like to do if you had the money? Time? Skill?)	
Spiritual History (What religion do you and did you follow, how involved are you and were you, and how important is it to you? How do you feel about other religions?)	
Personal Care Practices and History (eating habits, sleeping habits, grooming habits, bathing habits, etc.)	
Time Use History (schedules and routines...When do you and when would you like to do things?)	
Important Life Events (What were some things that were very important to you or that happened to you? Do others know about these events?)	
Hot Buttons (What are things/activities/topics/actions that really tend to upset you?)	
Chill Pills (What are things/activities/topics/actions/people that really help calm you down?)	

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