



# Dementia Alliance of North Carolina

*engage. educate. empower.*

Formerly Alzheimer's NC, Dementia Alliance of North Carolina has served local communities for over 30 years as a 501(c)(3) non-profit organization. One hundred percent of our funding stays here to improve lives of all North Carolinians impacted by dementia, engaging and empowering them through support, education and research.

## CAREGIVER SUPPORT

- Individual and family counseling at no cost
- Support groups and support group facilitator training
- Caregiver resource referral and information
- Referrals and reimbursement for respite care

## EDUCATION

- Community talks, workshops and conferences
- Seminars for family caregivers
- Training for professional groups and law enforcement

## RESEARCH

- Funding research in NC to advance innovative therapies and reduce the number of individuals impacted by dementia

## ADVOCACY

- For the rights of individuals living with dementia and their caregivers

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**DEMENTIA  
ALLIANCE**  
of North Carolina

ENGAGE. EDUCATE. EMPOWER.



# The Ten Absolutes of *Caregiving*

NEVER ARGUE **INSTEAD** Agree

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NEVER REASON **INSTEAD** Divert

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NEVER SHAME **INSTEAD** Distract

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NEVER LECTURE **INSTEAD** Reassure

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NEVER SAY "REMEMBER?" **INSTEAD** Reminisce

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NEVER SAY "I TOLD YOU..." **INSTEAD** Repeat & Regroup

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NEVER SAY "YOU CAN'T ..." **INSTEAD** Find Out What  
They CAN Do

---

NEVER COMMAND, DEMAND **INSTEAD** Ask & Model

---

NEVER CONDESCEND **INSTEAD** Encourage & Praise

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NEVER FORCE **INSTEAD** Reinforce



# Common Dementias Explained

## Overview

Dementia can be caused by a number of different conditions; it is a symptom of neurodegenerative diseases like Alzheimer's, frontotemporal dementia or corticobasal degeneration. The term "dementia" describes a progressive, degenerative decline in cognitive function that gradually impairs memory and the ability to learn, reason, make judgments, communicate and carry out daily activities. While it often includes memory loss, memory loss by itself does not mean that a person has dementia. Dementia affects more than 50 million people worldwide.

## Alzheimer's Disease (AD)

Alzheimer's disease is a progressive, degenerative brain disease that slowly erodes memory and thinking skills, and eventually even the ability to carry out simple tasks. It is the most common cause of dementia. Alzheimer's may occur in combination with vascular dementia, or other dementias.

## Frontotemporal Dementia (FTD)

Frontotemporal dementia is a group of related conditions resulting from the progressive degeneration of the temporal and frontal lobes of the brain. These areas of the brain play a significant role in decision-making, behavioral control, emotion and language. Common forms of FTD:

### Primary Progressive Aphasia (PPA)

Is caused by degeneration in the areas of the brain that control speech and language. This type of aphasia begins gradually, with speech or language symptoms that will vary depending on the brain areas affected by the disease.

### Progressive Supranuclear Palsy (PSP)

A degenerative disease of the brain leading to difficulties with walking and balance, problems with eye movements, changes in behavior, difficulty with speech and swallowing, and dementia.

### Corticobasal Degeneration

A progressive neurological disorder that affects nerve cells that control walking, balance, mobility, vision, speech and swallowing.

### Behavioral Variant FTD (bvFTD)

Involves changes in personality, behavior, judgment. Behavior and poor judgment go unnoticed by the individual. Inappropriate and impulsive behaviors are common along with apathy and loss of initiative. Memory generally not affected.

## Lewy Body Dementias

Lewy body dementias include dementia with Lewy bodies (DLB) and Parkinson's disease with dementia (PDD) and are the second most frequent cause of dementia in elderly adults. Common symptoms include problems with movement, visual hallucinations, and fluctuations in thinking skills or attention.

## Mild Cognitive Impairment

In contrast to Alzheimer's where other cognitive skills are affected, mild cognitive impairment (MCI) is defined by deficits in memory that do not significantly impact daily functioning. Memory problems may be minimal to mild and hardly noticeable to the individual.

## Vascular Dementia

Vascular dementia is a subtly progressive worsening of memory and other cognitive functions due to chronic, reduced blood flow in the brain, eventually resulting in dementia. Clinically, patients with vascular dementia may look very similar to patients with Alzheimer's, and the two diseases are very difficult to distinguish from each other. Vascular dementia may occur in with Alzheimer's disease.

(<http://memory.ucsf.edu/education/diseases>)

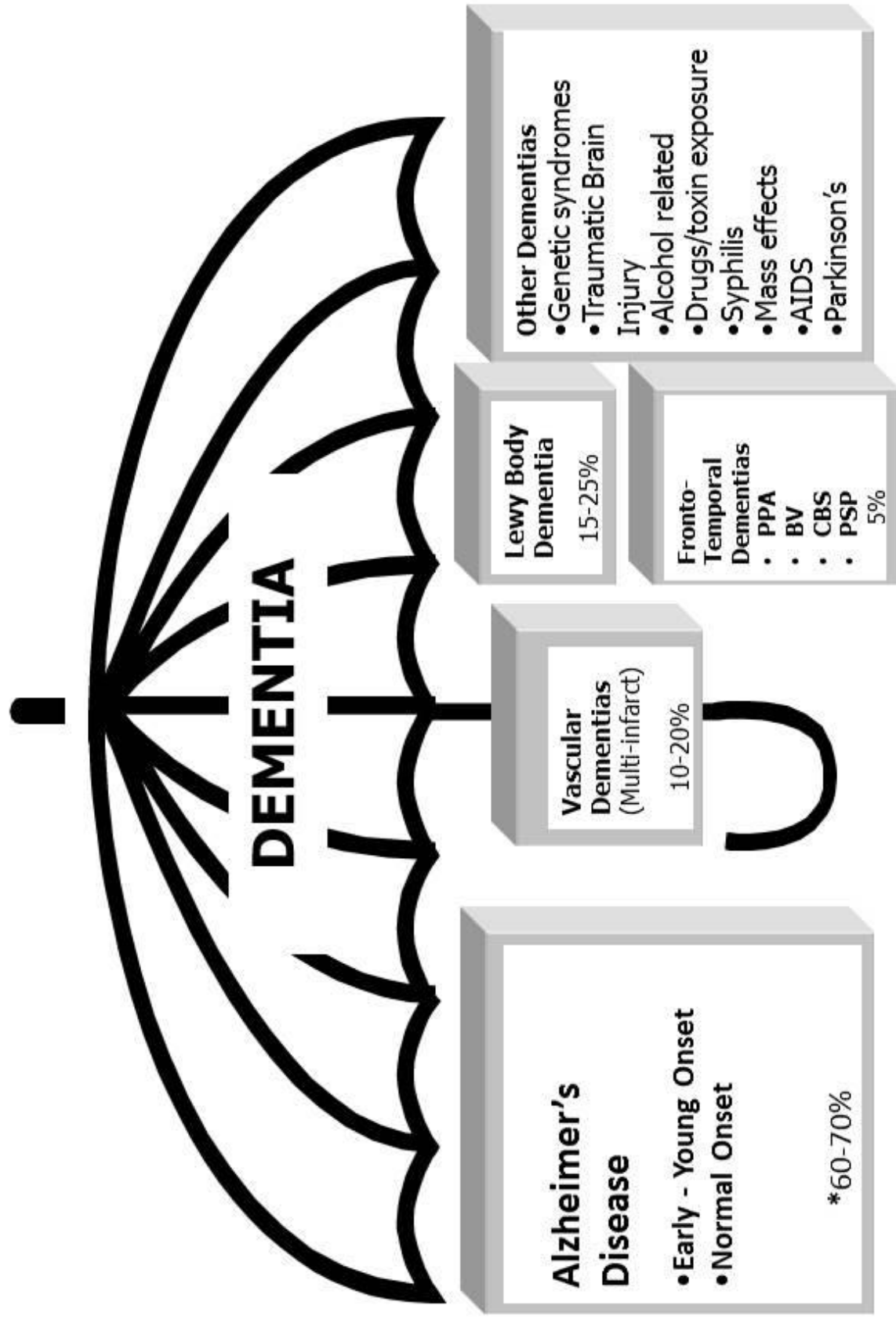


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\*Percentages from D. Kaufer, MD, UNC-CH, Carolina Alzheimers Network, Aug. 2010

# Alzheimer's Disease (AD): What Everybody NEEDS to Know

## What is Dementia?

Dementia is a non-specific term used to describe a person having changes in brain function that interfere with ability to function and do everyday activities.

The person with dementia has problems in multiple areas of brain function. These problems can include; memory, language, impulse control, ability to do things for self, personality, understanding of time, etc.

Common types of dementia include: Alzheimer's disease, vascular dementia, Lewy body dementia, frontal-temporal dementia (FTD) and mixed dementia (more than one type of dementia occurring in the same brain). Different types of dementia impact the brain in different ways, have different symptoms, cause changes in different abilities...in different orders...and at different rates.

## What is Alzheimer's Disease?

Alzheimer's disease is one type of dementia. It is a progressive and terminal disease. The changes typically occur slowly, over months and years, not hours and days.

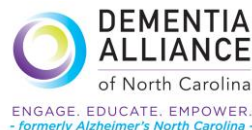
If the person has a sudden change in health status, living situation or caregiver system (for example, death of a spouse) he or she may APPEAR to change quickly. The brain has actually been changing slowly but since the person was in a routine, the person's abilities weren't being challenged and he or she was relying on OLD patterns and memories to function.

The pattern and progression of the disease is predictable BUT the experience is individual and ultimately, the person's entire life is affected by Alzheimer's disease.

## What are the early signs?

Early signs might include:

- Memory loss of recent events and information
- Confusion about place and time
- Familiar tasks become challenging
- Trouble finding words, finishing thoughts and sentences, following directions
- Decreased reasoning ability and altered judgment
- Changes in mood and personality, frequent mood swings, disinterest or withdrawal, suspicion
- Difficulty with complex mental tasks, planning, problem solving



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## How is Dementia Different from Aging and Forgetfulness?

- Aging happens to everyone. Dementia is ALWAYS a disease; it DOESN'T happen to everyone.
- With forgetfulness, new information can be stored; it may take more effort or practice, but new information can “stick”. With dementia, new information cannot be predictably retained.
- Forgetful people can use reminders, calendars, lists and to be able to DO. With most dementias, these prompts CANNOT help after the earliest stages.
- Being forgetful makes an independent life *difficult*; having dementia makes independent life *impossible*.

## What is “Normal Aging”?

Normal aging includes:

Being more forgetful

Taking longer to learn new information

Requiring more practice to learn new skills or technologies (you can do it, just have to try harder than you used to)

Having more trouble recalling people’s names (more than you used to have)

Knowing the word you want but hesitating, eventually finding the word (more often than you used to)

## Diagnosis makes a difference!

Early diagnosis is important and accurate diagnosis is critical!

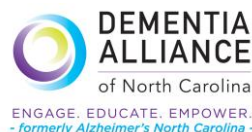
Why? Because!

1. Early treatment is more effective than waiting.
2. Early and accurate diagnosis allows for **better** planning and opportunity to **include** the person with dementia in the process. Planning makes a difference in options the person may have as the disease leads to changes in abilities and needs.

How is Alzheimer’s disease diagnosed?

Diagnosis is complicated and includes gathering lots of information, including:

1. History of the changes
2. Health history
3. Medication review
4. Physical exam (especially focusing on neurological and cardiovascular systems)
5. Laboratory studies
6. Imaging study of the brain (MRI, CT, PET)
7. Cognitive assessment (what’s working well and what’s not working well)
8. Emotional assessment
9. Other tests (ECG, EEG etc. as indicated)



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## How to Connect with the Person with Dementia:

*Approach from the FRONT respecting personal space*

*Move SLOWLY in a non-threatening manner*

*Make EYE CONTACT*

*Initiate the greeting & introduce yourself*

*Move to the SIDE and OFFER YOUR HAND*

*Wait for their response*

*Make POSITIVE STATEMENTS: "Let's try..." "Could you please help with..."*

### Remember to...

- Stay calm and be understanding
- Speak slowly using a low pitched voice
- Be patient and flexible, go with the flow
- Step into their shoes to look for a reason for each behavior
- Ask questions using fill in the blanks  
My name is xxx and you are?
- Offer simple choices instead of asking yes/no questions
- Respect personal space
- Don't argue or correct

### When the person is in distress...

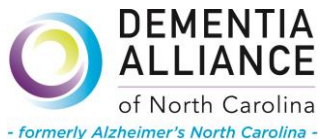
- Focus on their feelings
- Respond to the emotion, not to the action
- Ask the person to tell you more about it
- Move from talking first to then doing (go for a walk, get a cup of coffee)

### ALWAYS...

- Greet the person before moving into action
- Explain what is happening but keep it simple
- Don't take it personally
- Break the task down into single one at a time steps
- Give the person time, don't rush

### It is common for the person with dementia to...

- Say or do things that are inappropriate
- Not respond the way you expect
- Say things that don't make sense
- Use words that are close but wrong
- Have poor grooming habits or look slightly off
- Repeat themselves or not remember instructions
- Denies what you know is true
- States as true what you know is false
- Appear irritated, scared, or too personal



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# ***Caregiver Coping Strategies***

Remind yourself it is okay to cry - crying releases more than tears.

Make sure you get enough rest, even if it means having someone stay to take care of the one you care for.

Take things as they come-don't think too far ahead on things.

Breathe! Take long, slow, deep breaths... Breathing deeply releases stress.

Keep things in perspective:

- Know you cannot make life perfect for the one you care for-life is not perfect.
- Realize that things will not always work out the way you'd like them to.
- Recognize you can't do everything.
- Have someone you can trust & share your feelings with and allow them to be honest with you.
- Let things go that don't need to be held onto.
- Don't lose sight of your blessings.

Get a form of physical exercise (daily if possible).

Practice healthy eating habits.

Get the information you need to make good caregiving decisions.

Seek social support: support groups, counselors, friends, faith community.

Find time for meditation, prayer, or quiet time alone.

Participate in recreational, social activities or hobbies that are satisfying and nourishing.

Look for the positive, remember to laugh and enjoy, enjoy the moment.

Control what you can, let go of what you cannot.

Take time off from your caregiving responsibilities!

(Courtesy of: Resources for Seniors, Today's Caregiver)



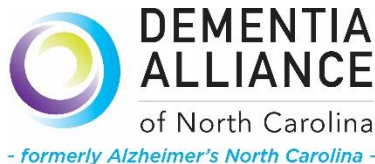
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## ***I Joined a Support Group and ...***

- ❖ Learned that I could share my challenges and learn from others who understand in a safe and confidential environment.
- ❖ Learned approaches to caregiving and creative coping strategies.
- ❖ Exchanged helpful resources.
- ❖ Was reminded to take care of myself and laughed along with others who understood while I developed my caregiver support system.
- ❖ Worked towards understanding and acceptance of the many emotions involved with dementia.
- ❖ Gained education about dementia, research, and advocacy.
- ❖ Was able to support others by sharing my own experiences.
- ❖ Learned to accept that my loved-one's ways were real and to stop correcting and reasoning.
- ❖ Became friends with others that were going through similar experiences.
- ❖ Realized it was ok if I wanted to remain quiet.
- ❖ **To find a local Support Group, visit <https://dementianc.org/family-services-support/support-groups/> or call the DA-NC office at 919.832.3732**



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# Helping with Activities of Daily Life

As dementia progresses, people gradually go from being able to do most of their personal care to needing help with everything. And as a care partner, not only do you have to assist, you also have to recognize what your person can still do so you can support their remaining skills. Doing too little or too much can be frustrating for both of you, plus many people prefer to be independent with these care tasks even though they actually need help.

Keep in mind that cues help immensely. Verbal cues can often get the ball rolling when it gets stopped. “Are you hungry?” can be a cue to start eating. “Would you like me to help you?” might be all it takes, early on, to jump-start a task. Visual cues, such as gestures, signs and demonstration help a person not understanding all of your words or needing to copy your example. Tactile cues such as touching someone’s hand or even handing them a shoe can work wonders and when you combine all three of these, seemingly lost skills can sometimes surface.

Because we are all individuals, no one approach works for anyone. And that one approach that does work won’t work all of the time. Therefore, the biggest asset to being a care partner is *patience*. Taking time and having patience during the task will result in a happier and more successful loved one – and a happier you, too!

Below are some suggestions, tips if you will, on how to make activities of daily life a bit easier to accomplish.

## DRESSING

- Clean out closets to limit choices and offer only seasonal clothing (this is often best done without your loved one).
- Offer limited appropriate choices and favorite colors.
- Lay clothes out on a light solid colored surface to provide contrast to the clothing and make it easier to see.
- Lay out clothes in the order they should be put on, underwear on top to be put on first.
- Make sure the room is warm, well-lit and private.
- Limit distractions.
- Offer clothing they can manage (buttons, zippers, Velcro, slip on).
- If a person wants to wear something frequently get duplicates.
- Choose easy care clothes in case of spills or accidents.
- Avoid tight fitting clothing, panty hose, high heels, tight socks, etc.
- Use soft music to set the tone – music they personally enjoy, more upbeat to get them going in the morning and more relaxing to help them unwind in the evening.
- Help as needed but allow them to do as much as they can. Perhaps verbal (here is your shoe) or tactile cues (touch their hand holding the shoe) can help them do something instead of you taking over.

## TOILETING

- Have patience, if you are upset they will be, too. They are doing the best they can.
- Use signs for visual cuing
- Leave lights on and doors open so the restroom and toilet are easily found. At night use motion activated lights.
- Choosing contrasting colors in the restroom can help with depth perception and finding the toilet. Colored toilet seats help show the difference between the white floor, white toilet, and white walls.
- Install grab bars for safety and a sense of security.

- Follow their schedule. It may be every 2-3 hours, but it may be shorter during some parts of the day and longer during others.
- Give privacy whenever it is safe to do so.
- Provide easy on and off clothing for success.
- For someone more advanced with their dementia, simply asking if they need the bathroom may not be enough. They may not understand what you are asking. Showing them the bathroom when you ask will be helpful.
- Issues leading to accidents might include:
  - Urinary tract infections
  - Medications
  - Dehydration
  - Constipation
- Watch for signs that might mean they have to go:
  - Pulling on clothing
  - Increased wandering, restlessness, or agitation

## MOUTHCARE

- Show them how to brush their teeth
  - Brush yours at the same time
  - Go step by step
  - Use hand under hand assistance until they can take over the task
- Follow their past routines and habits as much as possible
- Ask them to rinse with water after each meal; rinsing with mouthwash at least once a day
- Go to the dentist, they can help with cleaning and offer suggestions for other ways to make oral hygiene effective
- Use two toothbrushes, if necessary, they can hold one and you can hold one for them
- Keep in mind:
 

Mouthwash with alcohol may burn and discourage use

It may be better to brush without toothpaste than not brush, it may be better to rinse with water than do nothing at all

If he/she will not/cannot spit or rinse you may want to use toothpaste that is OK to swallow

Daily care establishes routines and habits

### Tips:

- Consider having the person sit while brushing – be sure they can still look in a mirror for cuing
- Add a rubber grip to the toothbrush to make it easier to grasp
- Try a 3-sided toothbrush – cleans all sides of teeth at one time for less actual brushing time

## BATHING

In regards to bathing, follow a regular routine and rely on habits and routines of the past, based on preferences.

### Keep in mind:

- Focus more on the person than the task
- Be flexible – you must adapt as they cannot
- Adapt the environment to make it comfortable for the person
  - Padded shower chair, warm room, cover the seat with a towel, reduce noise, try soothing music

- Use persuasion not coercion – give choices within the task, respond to requests, support remaining abilities, help the person feel in control as much as possible.
- Be prepared, have everything you need before you begin
- Stop- when the person is distressed, stop and re-assess the situation

#### Types of Bathing:

- Shower
- Bath
- Whirlpool
- Walk-in tub
- Sponge Bath

#### Equipment that might be helpful:

- Limited hand function? Bath mitt, soap on a rope
- Limited reach? Bath sponge, hand held shower head
- Limited balance or endurance? Bath chair or bench, stool, grab bars, shorter chair for shorter people (no dangling feet = better balance), slip resistance surface on shower floor
- Limited understanding of what is happening? Warm space, privacy, limited distractions, slow pace, cover for modesty (can keep on gown or boxers if need be), use hand under hand assistance to support remaining skills, start at the “edges”, wash what is most needed first, keep checking temperature, have everything you need with you, bring extra towels

#### Sample bathing:

- Know what you are going to do, what your goal is – but meet the needs of the person first
- Gather all supplies
- Give the person acceptable choices (perhaps not “Do you want to take a bath”, instead try “It’s time to get washed up, do you want to help get the towels together?”)
- Stay calm, relaxed, be gentle and respectful
- Keep the room very warm (people with dementia have trouble regulating their own body temp)
- Get the water temperature right for the person – let them test the temperature
- Be sure the foot surface is non-slip. Have grab bars. Don’t use slippery oils.
- Help them to undress in the bathing location.
- Assist or transfer them into the bathing location
- Keep the person warm (a warm, wet towel on their back or on the back of the shower chair might help)
- Help them do as much of the washing as they can, even if they are simply holding a washcloth and you are actually doing the majority of the bathing
- Start at the edges but complete the most important tasks first. Remember that areas like the feet, face and genitals may be extra sensitive
- Use hand under hand assistance to give more control and reduce resistance
- Give positive reinforcement. Praise and reassure often.
- Apologize and acknowledge the person’s concerns.
- Use distraction as needed (treats, singing)
- Help the person dry off and stay warm (pat dry instead of rubbing)
- Cover with a robe (can help with getting dry, too)
- Help them dress

#### Common issues:

- Gender of the caregiver – would the person needing help be more comfortable with someone of the same or opposite sex?
- BM while showering (get wet and have to go)
- Moving too fast
- Too cold
- Feeling exposed, scared and out of control

- Caregiver doing too many things at one time
- Pain

Ideas:

- Bathe upper body at one time and lower body at another
- Make the room comfortable, warm, inviting, no shiny floors (they look wet), no slippery rugs
- Use dry shampoo
- Get hair washed at the beauty parlor or barber shop if it is an issue at home
- Soak feet outside of the shower, when seated, as a separate and enjoyable activity
- Find ways to offer contrast in the bathroom. A white floor, white walls and a white seat make it hard to distinguish one from the next; draping a colored towel on the shower chair can be an easy fix

Myths:

- It takes a lot of water to get people clean
  - Careful washing is more important than the amount of water
- A shortened bath means someone is not doing a good job at getting someone clean
  - This is about the person taking the bath, adjusting how and when things are cleaned is good when it works better for the person being bathed
- Someone has to take a shower or bath to get clean
  - There are many ways to get clean without getting in the shower or tub
- People always feel better after a bath or shower
  - If it is forced, no one feels better after a task. They may feel attacked or fearful and may remain upset for long after the event.
- They will forget about it later so just go ahead and do what you have to do.
  - They may forget the experience but they will not forget the emotion and how they feel. They may also remember bathing as a negative experience overall, even if they don't know why.
- It takes more time to go slow and be thoughtful and gentle in your approach.
  - It actually takes more time and creates more stress if the person is resistant.

Keep in mind:

Some resistance may be due to pain. Bathing provides a lot of opportunity for painful stimulation. The person may not be able to communicate the pain to you and may simply not want to bathe.

Frequent causes of pain may include: arthritis, back pain, constipation, contractures, dental problems, headaches, diabetic nerve pain, old fracture or injury sites, infections, bruised areas.

Know the signs to watch for and learn how your person with dementia expresses themselves both verbally and non-verbally. Signs may include, but are not limited to, calling out, frowning, crying or closing eyes, wincing, hitting, pushing you away, guarding a particular body part, jerking motions, restlessness, or rapid eye blinking.

Treat pain before bathing whenever possible.



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