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Dementia Talk

**Why do they do that...
and what can I do about it?**

Why are dementia behaviors so difficult?

Because they are losing the capacity to change their behavior.

Dementia is a progressive, irreversible brain disease.

It robs people of the brain functions that are the building blocks for problem-solving



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Dementia can rob a person of

- **language**
- **memory**
- **logic and reason**
- **sense of time and place**
- **doing complex tasks**
- **being able to move about safely**
- **managing emotions and impulses**



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It's not that they don't *want* to cooperate with us —
it's that they *can't*.

People with Alzheimer's
can't change the way it makes them
act any more than a cancer patient can
keep the cancer cells from spreading.

- Brandyn Shoemaker



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It's so hard because...

Our usual ways don't work

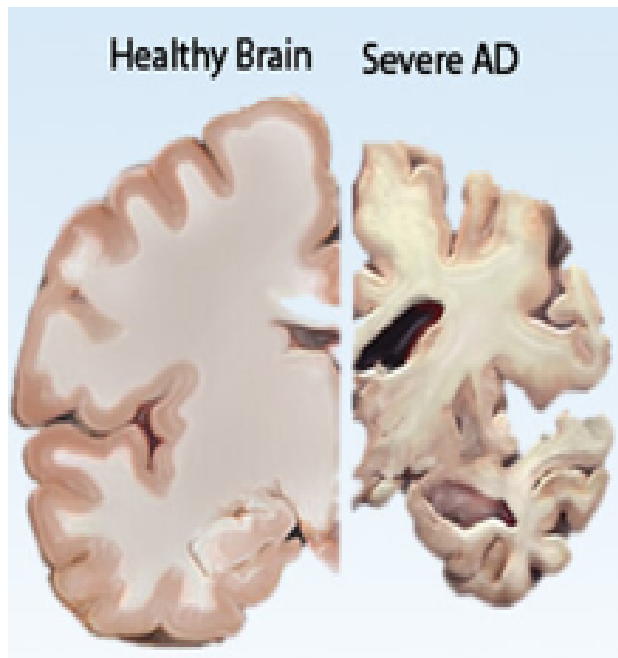
- **Rewards and punishments...**don't work
- **Using your authority....**doesn't work
- **Logic and reason...**don't work
- **Using your relationship...**doesn't work



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**If something needs to be changed,
then we must be the changers.**



**The dementia person cannot ‘get with
the program.’**

But we can to get with *their* program.

We can enter *their* world.

We can go with *their* flow.



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It's so hard because...

Dementia care takes a big emotional toll

We grieve the lost parts of our loved one.

We grieve the changed parts of ourselves.


We grieve life as we knew it.

We are tired. We lose patience.



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A close-up photograph of a hand holding a pen, poised to write on a document. The background is dark and out of focus, emphasizing the hand and the pen. The text is overlaid on this image in a white, handwritten-style font.

You can miss someone who died,
you can miss someone who moved away,
but the worst is when you
miss someone you see everyday.

TeenagerLyrics.blogspot.com



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Change your game plan to be more effective

Focus on their **comfort**

Try to anticipate and meet their comfort needs – *before they get uncomfortable.*

Stop trying to fix the behavior.

Look to ease the **distress**
that may be causing the behavior.



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Strategy #1

Create a comforting and safe setting

- Make frequent offers of food and fluids
- Room temperature not too hot or cold
- Lighting not too bright or too dark
- Not too noisy or overstimulating and not too sterile



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Strategy #1 continued

Create a comforting and safe setting

- Opportunities for person to make choices and be in control when possible.
- Meaningful activities
- Opportunity to toilet – *before incontinent episode*



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We communicate comfort through...

- Our **words** – speak slowly and simply. No lengthy explanations or instructions. One step at a time.
- Our **tone of voice** – calm, kind, and direct manner.
- Our **movements** – *slow pace*. Approach the person from the front. Make eye contact. Give them space. Ask/tell before touching.



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We also communicate comfort through...

- Our **attention** – be watchful and observant about what is going on in a setting. Look for signs that the person is comfortable or uncomfortable, content or distressed. Step in **early** to meet comfort needs.
- Showing **interest** in them *before there is a problem*.



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Strategy #2

Try to match their unique natural rhythms

When persons are allowed to eat, sleep, move, and interact in alignment with their natural preferences and rhythms, they get to feel more in control, and more respected.

There are fewer **battles**.

They tend to be **calmer**.



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Healthy Brain

Severe AD



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Strategy #3

Focus on what gives comfort and pleasure to this unique person

- **What makes them feel right with their world?**
- **What can we do that lights up the parts of their brain that still work?**
- **What clues we can get from their past?**
- **What seems to make them happy these days?**



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Help them find moments of pleasure

To love a person is
to learn the song
that is in their
heart and sing it to
them when they have
forgotten.

- Thomas Chandler

Music Puzzles Cooking
Trains, planes or automobiles
Manicures Dancing Hand rubs
Folding laundry Holding a doll
Gardening Taking a walk
Holding hands Puppies Hugs
Wearing lipstick Playing cards
Watching baseball Singing
Jokes Eating ice cream Crafts
Pretending they are 'on the job'



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How to **respond** to difficult behaviors

- Respond to the **distress** – focus on the feelings rather than the behavior
- Communicate calm, concern, and **reassurance**. Speak slowly and simply.
- Move slowly. Don't invade their physical space when possible.
- Scan the environment for possible sources of the distress...then address the problem.



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How to **respond** to difficult behaviors

- Don't argue, lecture, or try to reason with them.
- Don't confront them. **DO redirect** them. Shift their focus. Offer alternatives.
- Step away. Circle back. Restart.
- Check your own priorities. How much does this matter? Should I let it go?



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How to **respond** to difficult behaviors

Could this be a sign of physical pain or infection/illness? Blood sugar? Possible fracture?

**Is this behavior unusual for the person?
Did they change suddenly?**

If so, seek medical evaluation.



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Social Problems

- Verbal outbursts or insults
- Colorful language
- Removal of clothes in public
- Socially inappropriate behaviors
- Sexually inappropriate behaviors



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Social Problems: Why do they do that?

- Dementia can take away a person's social 'filter'.
- It often damages the parts of the brain that control impulses and inhibitions.
- When a person loses language, memory, comprehension, and a sense of time and place, they can easily become 'out of sync' with others in social situations.



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What can I do aboutverbal outbursts?

- **Prevention:** Watch for early signs of distress. Try to address needs for quiet, food, rest, fewer people, more activity, etc.
- Remember that these behaviors are beyond their control. Don't get caught up arguing the facts, or debating accusations. Logic and reason probably won't help you.



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What can I do aboutverbal outbursts?

- React by staying calm and reassuring.
- Validate your loved one's feelings.
- Try to distract them or redirect their attention to another activity.



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What can I do aboutverbal outbursts?

If you are out in public, and you are concerned about reaction of others....you may want to use the Alzheimer's Association cards that say:

Thank you for your patience.

My companion has Alzheimer's disease.

This lets you explain/apologize without embarrassing your loved one.



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What can I do about removal of clothes in public?

- **Prevention:** Replace existing clothing with garments that are hard to remove without help.
- Pay attention to warning signals, such as zipper-tugging or button-fumbling.
- Keep an extra sweater on hand to throw around the person in case you're too late ...



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What can I do about removal of clothes in public?

- Make sure you've identified the right issue. They may be pulling down pants because they have an urgent need to use the bathroom.
- Keep calm. If you shout or scold, you risk agitating the person.
- Remember that this behavior is beyond their control. Shaming is futile at best, and hurtful to your loved one at worst.



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What can I do about sexually inappropriate behaviors?

- **Prevention:** Create space between your loved one and other people so they can't reach out.
- Give them something to do with their hands.
- Be on the lookout for what triggers this behavior.



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What can I do about sexually inappropriate behaviors?

- *If it's possible, switching to a female or male caregiver may solve the problem.*
- If this becomes a consistent problem, and other efforts have failed, ask a doctor about medications.



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Aggression

Hitting

Pinching

Hair-pulling

Shouting

Biting

Scratching

Threatening

Swearing



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Aggression: Why do they do that?

- People with dementia can feel cornered or trapped when approached. They can feel threatened or violated when being handled by others.
- Sudden aggression might indicate pain, infection or illness.
- Something or someone in the environment is triggering distress in the person – and they are unable to identify or express what they need.
- They are losing the capacity to control aggressive impulses.



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What can I do about....Aggression

Prevention measures:

- Look for early signs of distress and discomfort – before the person acts with aggression.
- Be especially careful to approach person from the front, make eye contact, greet, ask permission to touch, and **move slowly**.
- Create physical space between this person and other people.



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What can I do about....Aggression

Maintain – or try to get back to – a calm manner and voice.

Look for unmet basic needs or discomforts...and address those needs.

Redirect. Engage in activities that they enjoy.

Do not try to overpower or shout down the person.

Seek help. Get a doctor to assess for pain, infections, other medical problems.

If it is a persistent problem that doesn't resolve with usual comfort measures, consider medications.



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Agitation

Restlessness

Pacing

Emotional upset

Anxiety and sense of urgency

Repetitive questions



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Agitation: Why do they do that?

- They may have lost a reliable sense of time and place. They can't remember what just happened, and they can't anticipate what will happen next. **The people, places and events that used to be familiar may now be unfamiliar and scary.**
- Their mind may have returned to an earlier stage of their lives, so they are preoccupied with carrying out activities from that era.
- As they lose the ability to express themselves, act on their own behalf, and regulate emotions and impulses, they get more easily frustrated. **Agitation can be a response to their inability to identify, understand, and take care of their own comfort needs.**



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What can I do about....Agitation

Simplify their surroundings. Communicate calm. Slow down. Offer reassurance.

Find out what is agitating them. If they can tell you, ask. Otherwise look for clues. Look for patterns.

Don't just tell them to sit down. Don't explain that they are wrong. Don't try to bring them back to 'reality.'



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What can I do about....Agitation

- **Join them** – validate their emotions. Take an interest in their ‘problem.’ Try to help them experience some measure of **control and independence**.
- **Redirect them** – to another activity or conversation.
- **Engage them in physical activity** – take a short walk with them.



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Bath Wars

Why do they do that?

- They no longer understand the “why” of bathing. They don’t recognize the need.
- Bathing involves many steps. They can’t sequence the actions.
- Bathing is physically invasive. It involves taking off their clothes, adjusting to water and air temperature changes, getting into a tub or shower, and having other people to touch them and ‘invade their space.’ They have lost their privacy.



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What can I do about....Bath Wars

- Before you take on the bath, address *other* comfort needs. Is the setting too noisy? Do they have to go to the bathroom? Are they tired, hungry, thirsty? If they are already experiencing distress.... it's not a good time for a bath.
- Is there a part of bathing routine that this person used to enjoy? A certain scent? Shower vs bath? Warm towels? Big bathrobe? If so, work those into the routine.
- Is there a part of the bathing routine that this person especially hates? Try to change that part. Ex: if they hate getting their head wet, try using a dry shampoo.



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What can I do about....**Bath Wars**

- **If they say, “I don’t need a bath,” don’t argue or try to convince.**
- **Go step by step. It may help if you don’t announce that it’s time for their bath. Instead, say we are going to the bathroom. Let’s get your shirt off. Let me help you sit down on this shower chair. Can I wash your hands with this warm cloth?**
- **Respect and encourage their autonomy. Let them make simple choices. Give them a washcloth. Let them do as much as they can. Sometimes they can complete a task if you start it for them.**



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What can I do about....Bath Wars

- Consider their wish for autonomy when choosing type of clothing. They may be able to dress themselves if they have tube socks, slide in shoes, no button-shirts, and elastic waist pants. If they can do it by themselves, let them. If they just need a little help, give a little help. When you see the first signs of frustration, move in to help.
- Remember, the goal of a bath or shower is to get someone clean and help them feel refreshed. This can be done and needs to be done in many ways. See your booklet for ideas.



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Be flexible!

Do they really need baths as frequently as you think?

Caregiver Moment #12

Arguing for 30 minutes to get your loved one to wear matching socks...

Then realizing you went out with your own shirt on backwards.

visit eldercareissues.blogspot.com for more caregiving articles and graphics.



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Last but not least....

Take care of the caregiver

Caring for a loved one with dementia can be stressful, lonely, and exhausting.

There is too much to do. *You need to take breaks.*

It's hard to know *how* to do it. *You need to find some fellow travelers to learn, discuss, share.*

Relationships change (family, friends, neighbors, faith community, and coworkers). *You need support.*



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Take care of the caregiver

Don't ignore your needs.

**Self-care is not a luxury...
it's a necessity.**

Reach out...take a class, join a support group, speak with a counselor, get respite care, and find your own ways to keep up your hope, spirits and strength.



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