Compassionate Communication with the AD Patient

by Liz Ayres, an Alzheimer's Association volunteer and former caregiver

Don't

Don't reason.
Don't argue.
Don't confront.



Oops! You must be kidding.
You mean I can't reason????
or argue??? or remind???

Don't remind them they forget.
Don't question recent memory.
Don't take it personally!

Do

Give short, one sentence explanations.
Repeat instructions or sentences *exactly* the same way.
Allow plenty of time for comprehension.
Eliminate "but" from your vocabulary; substitute "nevertheless."



Hmmm… accept the blame?
This is gonna be tough!

Agree with them or distract them to a different subject or activity.
Accept the blame when something's wrong (even if it's fantasy).
Leave the room, if necessary, to avoid confrontations.

Respond to the feelings rather than the words.
Be patient and cheerful and reassuring. Do go with the flow.
My appeal to you: *Please elevate your level of generosity and graciousness*

Remember

They are *not* crazy or lazy. They are saying normal things, and doing normal things, *for an AD patient.* If they were doing things, or saying things, to deliberately aggravate you, *they would have a different diagnosis.*

Some days they'll seem normal, but they're *not*. Their reality is now different than yours and *you cannot change them.* You can't control the disease. You can only control *your reaction* to it.

Their disability is memory loss. They cannot remember and *can't remember that they cannot remember*. They'll ask the same question over and over *believing it's the first time they've asked.*

They do not hide things; they *protect* things by putting them in a safe place and then forgetting they've done so. Do not take "stealing" accusations personally.

They are scared all the time. Each patient reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive, or physically combative. They may even do them all at different times, or alternate between them. Anxiety may compel them to *shadow you* (follow everywhere). They can't remember your reassurances. Keep saying them.

Examples

Don't reason

Patient: "What doctor's appointment? There's nothing wrong with me."

Don't: (reason) "You've been seeing the doctor every three months for the last two years. It's written on the calendar and I told you about it yesterday and this morning."

DO: (short explanation) "It's just a regular check-up"
(accept blame) "I'm sorry if I forgot to tell you."

Don't argue

Patient: "I didn't write this check for $500. Someone at the bank is forging my signature."

Don't: (argue) "What? Don't be silly! The bank wouldn't be forging your signature."

DO: (respond to feelings) "That's a scare thought."
(reassure) "I'll make sure they don't do that."
(distract) "Would you help me fold the towels?."

Don't confront

Patient: "Nobody's going to make decisions for *me*. You can go now…and don't come back"

Don't: (confront) "I'm not going anywhere and you can't remember enough to make your own decisions."

DO: (accept blame or respond to feelings) "I'm sorry this is a tough time"
(reassure) "I love you and we're going to get through this together"
(distract) "You know what? Don has a new job. He's really excited about it."

Don't remind them they forget

Patient: "Joe hasn't called for a long time. I hope he's okay."

Don't: (remind) "Joe called yesterday and you talked to him for 15 minutes."

DO: (reassure) "Your really like talking to Joe, don't you?"
(distract) "Let's call him when we get back from our walk."

Don't ask questions of recent memory

Patient: "Hello, Susie. I see you've brought a friend with you"

Don't: (question memory) "Hi Mom, You remember Eric, don't you? …What did you do today?"

DO: (short explanation) "Hi Mom. You look wonderful! This is Eric. We work together."

Don't take it personally!

Patient: "Who are you? Where's my husband?"

Don't: (take it personally) "What do you mean – who's your husband? I am!"

DO: (go with the flow, reassure) "He'll be here for dinner"
(distract) "How about some milk and cookies? Would you like chocolate chip or oatmeal?"



Who me? Take it personally?
Of course not! Well, maaaybe…

Do repeat exactly

Patient: "I'm going to the store for a newspaper."

Don't: (repeat differently) "Please put your shoes on."
"You'll need to put your shoes on."

DO: (repeat exactly) "Please put your shoes on."
"Please put your shoes on."

Do eliminate 'but', substitute 'nevertheless'

Patient: "I'm not eating this. I hate chicken."

Don't: (say 'but') "I know chicken's not your favorite food, but it's what we're having for dinner."

DO: (say 'nevertheless') "I know chicken's not your favorite food, (smile) *nevertheless* I'd appreciate it if you'd eat a little bit."