

# Alzheimer's: Straight Talk Begins with Compassion

Monica Vest Wheeler

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Dear Doctor,

Don't forget that you work for the patient and family. I need straight talk with compassion.

Sincerely,

The caregiver

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## What your doctor can tell you:

- Alzheimer's is a fatal disease. There is no cure.
  - Alzheimer's is now the sixth leading cause of death.
  - The brain is being destroyed, and there is no easy or single path of destruction.
  - No two patients are alike.
  - There are some medications that can possibly slow the progression.
  - Resources are available in your community.
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"The doctors are not living with our people, and they don't understand our everyday life."

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## Questions your doctor should answer:

- What's the diagnosis? What does it mean?
  - How can you be sure? Do we need more tests?
  - Where can we get more information?
  - How do we go about getting a second opinion?
  - What stage are we in? What does that mean?
  - What is the prognosis?
  - What are our medication options? Pros and cons?
  - What about the side effects of the medication(s)?
  - What can I do to minimize the side effects?
  - What about alternative medicines?
  - Will this be covered by insurance?
  - What signs, symptoms or other problems should we look for?
  - What information do you have at your office on support groups for my family?
  - How often do we need to come in to see you?
  - Do we need a referral for another physician?
  - If you were in our place, what would you do?
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"Do I understand all topics brought up during this appointment? Tell the doctor, 'Let me make sure I understand ...' "

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## Questions your doctor can't answer:

- How rapidly will they decline?
  - How will they be affected?
  - Will their personality change?
  - How long will they know me?
  - How long can they live independently?
  - Do they understand what's happening to them?
  - Will the medicine work and for how long?
  - How long will they live?
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"Tell me what to do. Help me be the caregiver."

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## What a caregiver must do to survive "the system":

- Speak up!
  - Ask why something is being done.
  - Ask why something isn't being done.
  - Question the number of medications.
  - Request a week's trial of a new medicine instead of a full month's worth to see how the person responds. It will save a lot of money and medicine.
  - Do your homework.
  - You are THE advocate for this person.
  - Question the insurance company for exact details on what is and is not covered and get it in writing.
  - You are a customer.
  - Refuse to be transferred again and again on the phone.
  - Don't be rude. Don't accept rudeness.
  - Be realistic on how much the person on the phone can do for you. Ask to talk to their boss if you don't get the answers you need, and keep going up the ladder if necessary.
  - Step on toes if you have to, and if they're wearing steel-toed shoes, step a little harder.
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Dear Insurance Company,  
Don't forget that I'm your customer. That's how you make money. I need straight talk with compassion.

Sincerely,

The caregiver

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# Don't let Alzheimer's destroy your family along with your loved one

## What family and friends need to understand:

- Alzheimer's is a disease of the brain.
- There is no cure. It is a terminal illness.
- Alzheimer's is not contagious.
- It destroys brain cells that control thinking, behavior and physical activity.
- Show nay-sayers the official diagnosis.
- When nobody believes you early on, it's because the person with Alzheimer's is putting on an award-winning performance for the rest of the world.
- At some point, this individual will require fulltime caregiving.
- One person, YOU, can't do it all.
- Family members and friends need to help.
- Alzheimer's is generally a long-term disease, requiring years of care.
- There is no shame and no blame in Alzheimer's.

## What family and friends need to do:

- Just listen and don't offer advice unless asked.
- Don't barge in and tell the caregiver what to do.
- Out-of-town relatives need to create ways to keep in contact and not rely on the caregiver to initiate contact every time.
- Offer to fulfill specific tasks such as cleaning the gutters, picking up groceries, sitting with the person who has Alzheimer's so the caregiver can get out and take a well-deserved break.

## What YOU need to do:

- Determine your limits: emotionally, physically and financially.
- What is your point of "self-preservation," when you have to put your needs above the person with Alzheimer's?
- You need to talk to someone when you're stressed. That act of communication is good medicine for you.
- Social isolation is a horrible side effect of Alzheimer's. You need to stay connected with the "outside world" if you're a fulltime caregiver.

- Join a support group of caregivers.
- Learn not to say "nothing" when someone asks how they can help.
- Understand that some people are simply "clueless." Many don't know what to say or do when there is a long-term illness like Alzheimer's, something between "life and death."
- Make a reverse gift list or "here's how I can help you" list. Think of everything you do in your everyday life and make that the foundation of your list.
- If you're uncomfortable asking someone directly for help, confide in someone you can trust to do the asking for you.
- Don't make decisions for other people by not asking them to help. Don't assume they're too busy. They may be waiting to be asked and are too shy to speak up otherwise.
- Learn that some people will let you down.
- Use humor to generate support.
- Know when to give out-of-town family a break and when to knock some sense into them.
- When you're angered by relatives who claim to know everything, it's okay to say, "You don't know! You aren't here!" And you're right. However, do learn to listen to suggestions that are realistic.
- NEVER promise the individual with Alzheimer's that you'll never send them a nursing home. That's a promise that may be impossible to keep. Reassure them that, "I'll do my very best to keep you safe." And that is the truth.
- Forgive yourself now and then for the day you want to send this person away and never see them again. Guilt is part of the Alzheimer's package. Learn to accept that you will NEVER be a perfect caregiver. Neither will anyone else. You will make mistakes and second-guess yourself. It's part of being human.

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**You have an obligation to educate this world about Alzheimer's. Take care of yourself so you do can that. Your loved one is counting on you.**

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## Monica Vest Wheeler

Author, Alzheimer's, Dementia & Memory Loss: Straight Talk for Families & Friends, part of the Help Me Cope & Survive series

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