

# When a Friend is Diagnosed with Alzheimer's—

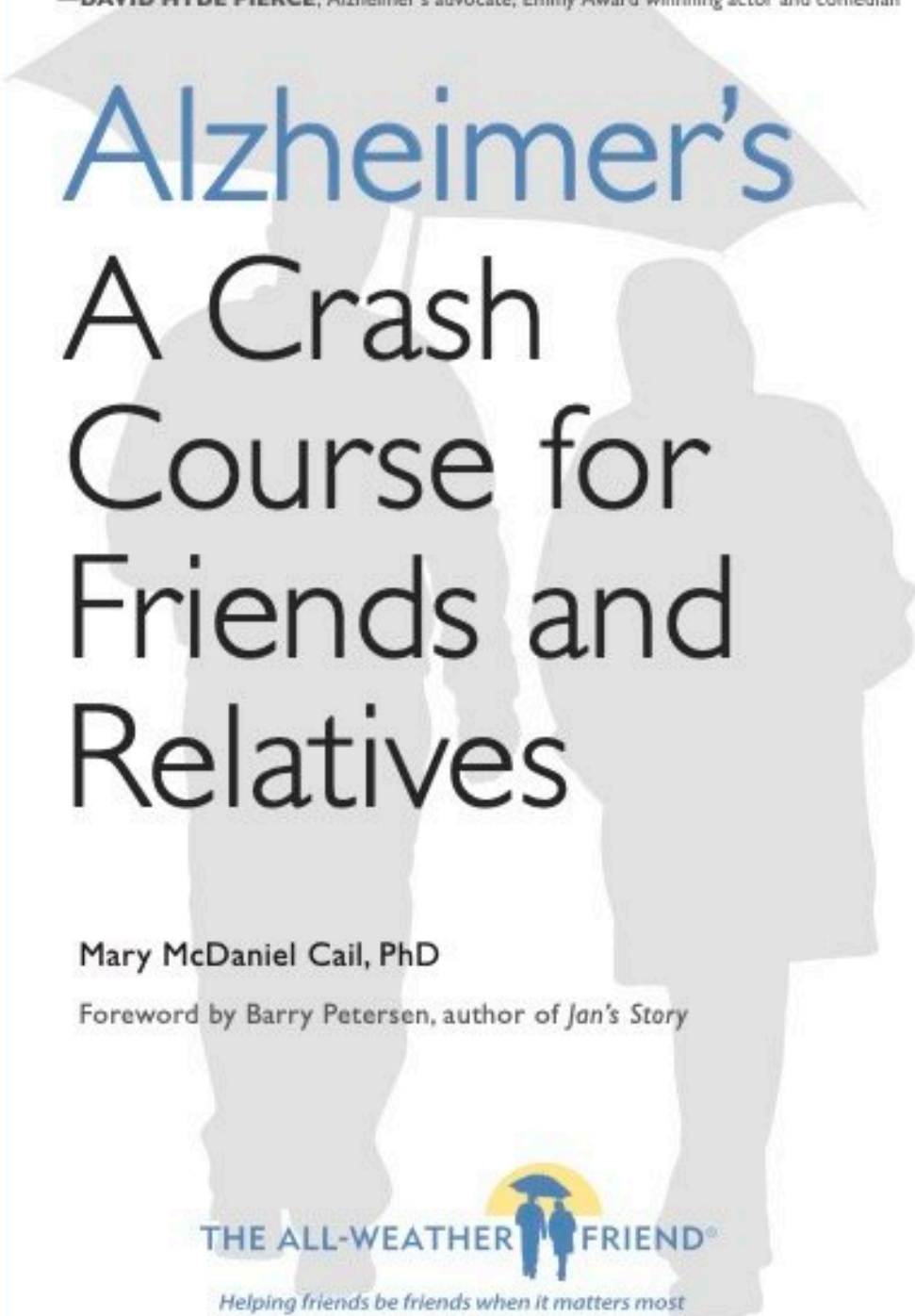
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## Ways to Help



"This fine, compassionate book, full of humor and practical advice, is more than a guide to coping with Alzheimer's—it's a reminder of what it is to be human, and what it is to be a friend."

—**DAVID HYDE PIERCE**, Alzheimer's advocate, Emmy Award winning actor and comedian



# Alzheimer's

## A Crash Course for Friends and Relatives

Mary McDaniel Cail, PhD

Foreword by Barry Petersen, author of *Jan's Story*

THE ALL-WEATHER FRIEND®  
Helping friends be friends when it matters most

## **From *Alzheimer's: A Crash Course for Friends and Relatives* by Mary Cail**

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# Acknowledge the Difficulty

## THINK ABOUT THIS...

1. Early-stage Alzheimer's (AD) can go on for about 7 years. During the early stage, the symptoms are mild and sometimes may not be noticeable.
2. Alzheimer's is progressive. There is no cure. The friendship will change, but it will not change all at once. You can adapt.
3. Your friend needs you: Don't vanish. Let the relationship evolve as needed.
4. For information about AD, check out the Alzheimer's Association website: [www.alz.org](http://www.alz.org).

People in the early stage of AD can seem okay to friends and relatives. Although problems may not be obvious to others, a diagnosis usually comes after struggles in everyday life: managing finances, remembering dates and conversations, following directions, keeping track of valued items, staying on schedule.

Some people with early or mild AD have bouts of anxiety when they leave home. Some have trouble with hand-eye coordination, depth perception and balance. The symptoms are not necessarily consistent between people.

But no matter what: A diagnosis with Alzheimer's is frightening and traumatic, so here are some things to **avoid** saying:

- "I forget things. Everyone does. It's all right." This remark may seem supportive, but it minimizes the frustration of serious memory loss, which impacts almost every activity of the day.
- "You need to get out more and try harder. Fight the disease." Loss of initiative, like short term memory loss, can be one of the early symptoms. It isn't a lack of effort; it's a part of a neurological condition. Your friend cannot help it.
- "Be positive. Keep doing what you've been doing." Depression and discouragement are unavoidable at times *because* it's not possible to carry on as before.

•“What just you said was [witty, clever, sharp, or insightful]. You’re back to your old self!” A person in the early stage may have the sense of shifting on a day-to-day basis between the reliable brain of the past and the unpredictable brain of the present. There is no going back to the “old self.” Remember, though, that your friend is the same person as always in the most important ways and will be for some time—possibly a number of years. This is especially true as physicians diagnose the disease earlier, before symptoms have even started.

•“But you’re so smart. How could you have Alzheimer’s?” Since the onset of AD is gradual, there are still many areas of cognitive strength early in the disease. Instead of downplaying, giving advice or questioning your friend’s diagnosis, empathize with the feelings that would arise naturally from coping on a daily basis with it:

“This must be frustrating. How can I help?”

“I’m not going anywhere. I’ll be here for you. We’ll figure this out together.”



# Help with Words

## THINK ABOUT THIS...

1. One of the first symptoms of AD is trouble with language. The difficulty can involve word finding, reading, putting thoughts into words and understanding what others are saying.
2. The nonverbal component of communication is just as important as the words. Pay attention to signals that your friend is becoming frustrated or confused and slow things down.
3. Some days, communication skills will be stronger than on other days. We all experience fluctuations in how well we think due to sleep, stress and many other variables, but it's worse for a person with AD.

Subtle problems with spoken language begin early in AD and become more noticeable as the disease goes on. Words can no longer be brought to mind with ease and assembled into sentences at the spur of the moment. People describe a sensation that the words are there, but mired in a kind of “molasses of the mind,” as one person in early AD put it.

If you understand, filling in the missing words is not necessary. No one likes to be cut off or have sentences finished by an impatient listener. When your friend is fumbling for words and has asked for help, make suggestions. People in early AD tend to substitute descriptions and homonyms for words they can't recall, which makes the guesswork easier.

**Friend:** I can't find my... the things you use in cold weather. What are they?

**You:** A jacket and scarf?

**Friend:** No, glasses. I mean sleeves. The things for your hands.

**You:** Gloves? Did you wear gloves today?

**Friend:** Yes! Gloves. I can't find my gloves.

Words may be replaced, maddeningly and uncontrollably, with nonsensical substitutions, like *fat* or *fun* for the word *fine*. While the outcome may be humorous—malapropisms are usually funny—remember to laugh with (not at) your friend *if she laughs*. Take the mistakes in stride. Here's an example:

**You:** Were you able to get the books off the top shelf?

**Friend:** No, and I was on my hind legs.

**You:** Hind legs? Do you mean you were on a stepladder?

**Friend:** I can't believe I said that. I'm always saying things I don't mean. I'm not sure who I am anymore. Crazy words come out of my mouth.

**You:** You're my good friend. Do you want me to help you out, or does it bug you?



## Take Care of Trust

### THINK ABOUT THIS...

1. We learn to trust friends over time. We count on our friends to behave in predictable ways. We know our friends. AD changes a friend's ability to be as consistent with feelings and behaviors.
2. Trust has to be redefined. Adopt a bigger view of trust: *You* can be trusted to see your friend through this illness, because he or she would have done the same for you. Trust is based on a commitment to be present and to accept the realities of the disease.

As one person in a relationship loses the ability to initiate, communicate and respond as usual, established patterns re-evolve, either consciously or by default. The old rules no longer apply, since those heartfelt talks in which expectations and feelings are made explicit may not be remembered by both of the people involved. This change doesn't make trust less important. When his confidence has been shaken to the core, your friend needs, more than ever, the reassurance of his loved ones' continued belief in him as a competent person, capable of contributing and talking openly about his condition.

A person in the early stage may be aware that important relationships have begun to take on an altogether different, less intimate dynamic. A man in early AD, visiting friends a thousand miles from his home, described to me in clear terms how much he wanted to ask his wife *Why haven't we had sex since my diagnosis?* He wanted to ask his son *Why haven't you called me 'Dad' since my diagnosis?* But he wasn't able to speak frankly with the people he loves. He feared that if he tried, the words would not come out right, and he couldn't face the prospect of the jumbled, hurtful exchange that might take place. Instead of addressing delicate issues, he brooded in silent resentment as his wife and son talked in hushed tones about him, presuming he would not hear, understand or care. Talking with me, he had no trouble expressing himself, but he had nothing to lose with me—I was someone he'd never see again—and he felt less pressure.

It requires patience and flexibility to keep trust in a relationship when one member of the pair must adapt to involuntary

changes in the other. Think of this analogy: If you had to build a house at a place prone to earthquakes, you would make the design basic and close to the ground, not a big complicated structure on stilts. Speak explicitly and without elaboration, realizing relationship discussions can't move nimbly around the emotional map, the way they may have in the past. Here are two examples; the first doesn't work, the second does:

**Friend:** It bothers me when you talk about me when I'm standing nearby, like I can't hear you. I'm not deaf.

**You:** This is hard for me, too. It's inconvenient when you forget we've made plans. I don't see why you can remember some things and not what we've decided to do together.

**Friend:** I can't make myself remember what I want to. Why don't you call and remind me before you leave your house?



**Friend:** It bothers me when you talk about me when I'm standing nearby, like I can't hear you. I'm not deaf.

**You:** I'm sorry. I didn't know I was doing that

**Friend:** People are treating me like I don't have opinions or anything worthwhile to say. I do, and I can talk for myself.

**You:** I'll be sure to talk directly to you from now on. But as

long as we're bringing up complaints, I have a problem, too.

**Friend:** With what?

**You:** When you forget our plans, it throws off my schedule.

Can you write yourself a note, or should I call before I come?

**Friend:** It's better to call. I'm having trouble writing now.



## Lend a Hand, Subtly

### THINK ABOUT THIS....

1. No matter what happens in life, people want feel respected. Early Alzheimer's doesn't change the need for respect from others. Help when it's appropriate, but think of your friend's sense of pride and try not to be obvious about it.
2. Sometimes people with AD feel they're being treated as though they can no longer do things for themselves. Give your friend the benefit of the doubt whenever you can. Be aware, though, of the potential for sudden problems to crop up with short term memory, directions, language and, at times, emotions.

Have you ever had to ask for help paying a bill, while people stood in line behind you at the cash register? Forgotten whether or not you've ordered at a restaurant? Had trouble finding your way back to the table?

Drawing a mental blank in the midst of everyday activities is an early sign of AD. As mentioned, these setbacks fluctuate in the beginning. Some days, a person in the early stage can manage independently, and over-attentiveness from a companion may be irritating. It would be to most of us. People resent being smothered, mothered or treated as if inept.

Rather than assuming your friend will always want help, decide together on a way she can easily tell you her needs from one time to the next. This may be accomplished by assigning this meaning to the question, *How are you today?*:

**"Fine,"** meaning: "I'm having a pretty good day. If I need your help, I'll ask for it."

**"Not the best,"** meaning: "I'm frustrated. Help me out and don't take what I say or do personally. This is one of the bad days."

Think how you would feel, if you were trying to make sense of the language, especially when rapidly or impatiently spoken, that you've used your whole life. It would be embarrassing to ask repeatedly for clarification or to be uncertain how to respond. Anticipate greater frustration on the difficult days and discreetly offer help:

- "I'm having the Greek salad, or here's pasta with chicken. Do either of those sound good to you?"
- "I'll figure out the bill. Why don't we split it evenly, since we ordered about the same amount?"
- "I'm going downstairs to wash my hands. Would you like to come, too?"
- "This shopping center is crowded. Do you want to go to a quieter place?"



## Make Adjustments

### THINK ABOUT THIS...

1. You can change. Your friend with AD really cannot alter the course or the problems of the disease. It will be up to you and the others in your social network to make changes that allow him to continue to be active socially.
2. Instead of thinking of your friendship as though it's a bank, based on a balance between giving and receiving, think of it more like sailing together on an open sea. You can't anticipate what the weather and waves will do, but you keep sailing because you're taking the journey together.

With a loved one in the early stage of Alzheimer's, forgotten plans, one-sided conversations, and outbursts of sudden anger or frustration are part of a journey, always worthwhile in its larger contexts of humanity, compassion and commitment, if challenging from the standpoint of convenience. In working out the changes in the relationship:

**Remain in touch.** You can help by continuing to include your friend in activities he would normally enjoy and in which he can safely participate.

**Be flexible:** You may have to cancel plans at the last minute. He cannot override his state of mind. You'd make the same concession for someone with an upset stomach or a migraine headache. Think in advance of an alternative for the time you've set aside: "It's okay if you don't feel like going, John. I can either stay for a visit, or I have errands I can run." The concepts of date, day of the week and hour of the day become hazy. Always call a short while ahead with a reminder of plans you've made and tell the caregiver, too. Build in extra time. Hurrying is never a good idea.

**Support strengths.** Faith, humor, optimism, perseverance, and courage are among the character traits of many people with mild AD and caregivers alike. Acknowledge and encourage these strengths, without reproaching your friend when they aren't clearly in evidence on a given day. "Cheer up!" "Don't let it get the best of you," "Be brave," and other such exhortations tend to raise hackles when coming from a person who doesn't face the same set of trying circumstances. Along

with the unwelcome changes, there can still be joy, and the depth of love and commitment often present in caregiving and other relationships is gratifying to all involved. When your friend seems down, try saying your own version of the Bill Withers classic, *Lean on Me*.

"I'll be here for you; you'd do the same for me."

"You're my friend. I'm here to stay."

"Thinking of the future is hard, but I'm with you now, and I will be then."



## Be Careful with Questions

### THINK ABOUT THIS...

1. Alzheimer's disease begins in and around the hippocampus, a structure in the medial temporal lobe of the brain which controls our ability to take in and store new information. A person in the early stage of Alzheimer's will be able to remember some things and not others. She won't be able to predict or control her memory.
2. While asking questions about the recent past may put your friend on the spot, state-of-being questions are usually safe: *Are you enjoying your summer? What do you plan to do when you retire? Would you like a cup of coffee?*

*What did you think of the program last night? Did you make it out to the polls on Tuesday? What have you been up to lately?*

We use questions about our daily lives as keys to open the door to conversation without thinking twice. A working hippocampus enables the storage of memories that form the answers to such questions, sifting out volumes of unimportant detail like a coarse screen. Scientists first learned the role of the hippocampus in an experimental operation with a disastrous outcome. In 1953, Yale-trained neurosurgeon William Beecher Scoville used a metal straw to remove much of the hippocampus and medial temporal lobe from the brain of a young man suffering from epilepsy. The man, Henry Molaison, known in medical annals by the initials HM, while largely relieved of seizures, lost the ability to remember anything from one minute to the next. He could only retrieve memories stored before the surgery. Scoville, horrified by the result, ensured through wide publicity that such an operation would never be repeated. He had done to Molaison in minutes what Alzheimer's disease does over the course of years.

In early AD, the hippocampus is breaking down gradually. Although not a consequence of normal aging, it occurs in some ways like the subtle relinquishments which are a part of ordinary experience: A man doesn't brush a thick head of hair one day and have a sunburned bald spot the next; we move up the ranks of reading glasses slowly; fine wrinkles at forty become a deep crisscrossing map by the mid-sixties. The hippocampus is destroyed by AD, but unlike changes so disconcertingly re-

vealed in every pass by a mirror, we cannot accurately gauge how fast this is happening, and the process is more complicated than the loss of hair or skin tone. To be safe, replace questions about the recent past with statements to which your friend can respond without trying to remember.

**Instead of:** “How was your weekend?”

**Try:** “Saturday I went to the farmers market and bought tomatoes.”

**Instead of:** “What did you do at the beach last week?”

**Try:** “While you were away, Evan drove the car for the first time. Melanie said she was scared to death.”

**Instead of:** “Did you go to the fitness center on Thursday?”

**Try:** “I see you have a new pair of walking shoes.”



## Keep Eye Contact

### THINK ABOUT THIS...

1. Early Alzheimer's disease makes taking part in conversations with more than one person or in group activities more of a challenge. People with AD sometimes feel self-conscious and stay silent, but while this response is self-protective, it also leads to feeling left out. The conversation or activity swirls at a fast pace, and it's hard to think and react quickly enough to participate.
2. There are many nonverbal ways to help a friend feel his presence is valued and that he's being kept in the loop—without calling attention to his problems. For example, you can subtly slow things down a bit by taking more time yourself to think.

Intermittent, lingering eye contact is an almost foolproof way to make a friend feel included, but people abandon this courtesy when caught up in awkwardness, uncertainty or, less diplomatically, in petty egotism. Years back, I had to spend evenings, thankfully not often, with a tedious older physician whose eyes darted around in disinterest when we spoke with each other. Charming to my husband, he treated me like a child or a decorative potted tree, one which annoyingly obscured his view of the rest of the room. People with early AD feel they've become invisible if this kind of encounter becomes common, and frequently it does.

Eye contact is particularly important in groups. Because conversation between several people requires timing and quick thinking, we can unintentionally exclude someone who has trouble with these skills. Now and then, it may not matter. Repeated many times, being left out results in the sense that people no longer value what you have to say, and you've been nudged to the sidelines.

Make a point of looking a friend with AD in the eye and speaking directly to him, the way you would anyone else, especially when you are with others. Avoid, however, the knitted brow and prolonged blank stare in the event of a conversational misfire or lost train of thought. Glance up or sideways, and help your friend get back on track: "Hmm.... We were talking about annoying neighbors, and you were telling me about Mrs. Huckstep's yappy little poodle."