Stages of Alzheimer's Disease

Experts have documented common patterns of symptom progression that occur in many individuals with Alzheimer's disease and developed several methods of "staging" based on these patterns. Progression of symptoms corresponds in a general way to the underlying nerve cell degeneration that takes place in Alzheimer's disease.

Nerve cell damage typically begins with cells involved in learning and memory and gradually spreads to cells that control other aspects of thinking, judgment and behavior. The damage eventually affects cells that control and coordinate movement.

Staging systems provide useful frames of reference for understanding how the disease may unfold and for making future plans. But it is important to note that all stages are artificial benchmarks in a continuous process that can vary greatly from one person to another. Not everyone will experience every symptom and symptoms may occur at different times in different individuals. People with Alzheimer's die an average of four to six years after diagnosis, but the duration of the disease can vary from three to 20 years.

The framework for this fact sheet is a system that outlines key symptoms characterizing seven stages ranging from unimpaired function to very severe cognitive decline. This framework is based on a system developed by Barry Reisberg, M.D., Clinical Director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

Within this framework, we have noted which stages correspond to the widely used concepts of mild, moderate, moderately severe and severe Alzheimer's disease. We have also noted which stages fall within the more general divisions of early-stage, mid-stage and late-stage categories.

Stage 1: No cognitive impairment
Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Stage 2: Very mild decline
Individuals at this stage feel as if they have memory lapses, forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

Stage 3: Mild cognitive decline
Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people

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- Performance issues in social and work settings noticeable to others
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

Stage 4: Moderate cognitive decline
(Mild or early-stage Alzheimer's disease)

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent events
- Impaired ability to perform challenging mental arithmetic. For example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

Stage 5: Moderately severe cognitive decline
(Moderate or mid-stage Alzheimer's disease)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

Stage 6: Severe cognitive decline
(Moderately severe or mid-stage Alzheimer's disease)

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet

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- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

Stage 7: Very severe cognitive decline

(Severe or late-stage Alzheimer's disease)

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

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Look At Me

My body may look wrinkled;
Spots are on my skin from age,
But I could tell you stories. . .
That would fill page upon page.

I no longer do a day's work,
Though I've done more than my share.
I cannot walk a fast pace. . .
Or get easily from my chair.

My hands and fingers may be stiff,
My back a little bent.
My taste buds have diminished. . .
And it's hard to smell a scent.

My eyes are poor; my hearing's gone;
My hair has turned to gray.
I cannot do the things I'd like. . .
To occupy my day.

I do not want your pity.
Please don't take away my pride.
All I need is understanding. . .
And a good friend by my side.

Some may think I'm worthless.
They may judge by what they see,
But they're more blind than I am. . .
They're not really seeing **me**!

Inside this worn out body
Is a child with many fears.
I stumble, fall, and hurt myself. . .
I even cry real tears!

I wish I could turn back the hands
Of time and start anew,
But that would be a miracle. . .
Not planned for me or you.

I still have many feelings;
How I love a tender touch.
A hug. . .a smile. . .a kind word. . .
To me, they mean so much.

The next time that you see me,
Please don't turn the other way,
For you possess the power. . .
To give meaning to my day!

I may be old, my mind half gone;
It seems life is unfair.
Is it too much to ask for. . .
Some tender loving care?

Someday, you'll walk in my shoes;
There'll be things you, too, can't do.
Today, you see these things in me. . .
But, soon, it will be **you!**

By Pat VanWinkle, Social Worker
Ainsworth, NE
February 22, 1994

The city dude and the country spouse lived together in a cute little house that had an animal theme for each room, including a living room with horses, a bedroom of birds, cows for the kitchen, and lambs in the nursery for their new baby girl.

Following are some possible answers and solutions to the exercises at the end of the Communicating session. These aren't the only answers that will work. Encourage participants to think creatively.

Exercise 1.

What can Becky do to encourage Lucille to get dressed?

Find a reason, from Lucille's perspective, for her to get dressed.

Give her limited choices of what to wear.

What are things she definitely shouldn't do or say?

Don't try to reason with her, and don't keep repeating the things that her daughter said to her.

Don't make her feel bad, embarrassed or guilty for not being dressed.

What could Emma do differently that might make a difference?

Lucille has moderate Alzheimer's disease. Let her pick out her own clothes, within limits.

Don't rush her. Emma was the one who was late. That's not Lucille's problem.

What's likely to happen if Emma returns and Lucille is still in her pajamas and robe?

In Lucille's world, probably not much. Lucille may not care whether she's dressed or not.

From Emma's perspective, several things are possible.

> She may be angry with you, because you didn't do your job.
> She may be upset, especially if her mother is napping.
> If she voices her displeasure in front of Lucille, it may upset Lucille and trigger unwanted behaviors.
> She may see it as one more reason to place Lucille in a long-term care setting.

Exercise 2.

What is Kathy's first responsibility?

To make sure Tom is safe, while allowing him the most freedom possible.

What are some of the things she can do or say to convince Tom to go back to his house?

An excuse that makes sense to him:

> “You don’t have to work today.”
> “It’s Saturday.”
> “I’m headed that way, too. Mind if I walk with you?” (Re-direct as you walk.)

Engage him in conversation about where he’s going and why. Gently guide him back to the house as you talk, preferably without it looking like you’ve turned around.

“I know you’re busy, but I could really use some help with….”

What might Kathy say that would not help the situation?

“You don’t work anymore.”

Anything that would make Tom feel dependent and not needed.

“If we don’t go back to the house, I’ll really be in trouble with your (wife, daughter, etc).

“You can’t go anywhere by yourself. You have to have someone with you.”

What are some things Tom’s family could do to reduce his wandering and keep him safer, and how should Kathy communicate those ideas to the family?

Alert the neighbors to the situation and ways to manage it.

Enroll him in Safe Return.

Install some kind of alert system – anything from an elaborate system to bells on the doorknob to child-proof doorknob covers.

Give Tom things to do around the house to make him feel useful.

Exercise 3.

What can Jenny do to make Carol feel more comfortable in public?

Stay away from large gatherings. Try places with smaller groups.

Make sure Carol knows they’re “in this together” without being condescending.

See what works for Carol, and don’t put her in an uncomfortable situation.

Do you think Carol could get involved in a political campaign again?

Yes, in small group meetings where she can analyze, offer opinions, and suggest strategies. She may also be able to help with mailings, where everyone is pitching in, so it doesn’t feel demeaning.

What are some things Jenny should not try to do for Carol?

Carol should probably not attend large rallies or fundraising dinners.

Jenny should encourage Carol but not insist that she participate in any particular way. She has to let Carol determine how she'll be involved.

What decisions can Jenny make on her own, and when should she consult with Mark?

There should be certain guidelines set up when a person is hired. As long as what she's doing is within those guidelines, she should be okay, but still keep Mark informed about what they're doing.

Anything outside those guidelines should be discussed with him. (Example: It was decided that Jenny would go with Carol to meetings, as long as Carol was comfortable with where they were going. Carol, though, has heard about a national political figure who's coming to speak, and she really wants to hear her. There will be a large, enthusiastic crowd. Jenny would love to take Carol, but she's not sure how she'll handle it.)

Making the Most of Your Time and Theirs:
Connecting to a Person with Late Stage Alzheimer's Disease

When late-stage Alzheimer's disease reduces a person's ability to communicate through words, it might seem useless to try to make a connection with that person. However, those with late-stage Alzheimer's can still experience the world through senses, such as touch, smell, sound and sight, and their capacity to feel frightened or at peace, loved or lonely, and sad or secure remains. The most helpful interventions for individuals with late stage Alzheimer's disease are those which ease discomfort and **provide meaningful connections**, like the following:

Tap into his or her senses*.* Think about this person's personal history. Was she a gardener? Perhaps she'd enjoy the smell of fresh cut flowers or herbs. Does he love animals? He might find pleasure in stroking a dog or cat (if he doesn't have a pet, maybe you can find a relative or neighbor with a pet you can trust). If she enjoys the outdoors, she might enjoy bird watching. If he likes music, he may enjoy sounds that represent a cultural or spiritual tradition or a happy time in his life. The key is to find a way to tap into that person's senses, using his or her unique qualities.

Use touch. Simply holding a person's hand or providing a gentle massage can communicate reassurance and caring to a person with late-stage Alzheimer's. Hold hands; give a gentle massage to the hands, legs, or feet; give a kiss; or brush her hair.

Speak in a soothing tone*.* Even if the care receiver can no longer understand what you're saying, speaking in a gentle, soothing tone of voice can provide comfort and a feeling of safety. Similarly, the rhythm of reading to him can be relaxing, even if he doesn't understand what you're reading. Sometimes, it does not matter what you say but, rather, how you say it. Speak gently and with affection.

Protect bony areas. Protect elbows, knees, hips and other bony areas with pillows or pads. If you use moisturizer on the person's skin, apply it gently over bony areas; do not massage the lotion into these areas. Change the person's position at least every two hours to relieve pressure and improve skin moisture. Use pillows to support arms and legs.

Prevent contractures. Limb contractures or "freezing" of the joints can occur when a person is confined to a chair or bed. To maintain the person's range of motion in the joints, carefully and slowly move his or her arms and legs two to three times a day. Perform these exercises when the person's skin and muscles are warm, such as immediately after bathing. A physical therapist can show you the proper technique for range of motion exercises.

Play music and videos. Choose music the care receiver enjoyed when he was a young adult or something from his ethnic or spiritual background. Videos can also be relaxing to the person with Alzheimer's disease. Select one with scenes of nature and soft, calming sounds or one that appeals to his likes and interests.

Reminisce and share. Ask the family to fill a box with photographs and items that represent the person's interests, favorite activities, or past work or military history. Have the person take out an item (or you take it out for her if she can't) and share the significance of that item. If the person with Alzheimer's can no longer communicate verbally, ask the family to briefly describe the significance of each item, so that you can be her memory when you are looking at the items together. An example might be a family photograph from a favorite vacation, a recipe card with a traditional family dish, or a military medal and why the person received it. You can describe the items in simple terms. You could say, "I know that the person(s) in the picture loves you and wanted me to give you a big hug." Hugs are just great. They'll know you care. The act of hugging may bring a smile to her face.

Spend time outdoors, if possible. It may be beneficial to reduce anxiety and depression and encourage healthy sleep patterns. Even for those with late stage Alzheimer's – maybe *especially* for them – being outside and feeling the warmth of the sun or a cool breeze may have a very positive effect on that person's day.

Respect and nurture spirituality. For many people, being part of a faith community is an important component of their identity. Tapping into spiritual traditions which have been a significant part of the person's life can provide comfort, continuity and a sense of self. Familiar rituals, symbols and music, or reading familiar scripture passages can trigger memories and connect with a person at a deeply emotional level when cognitive abilities have been severely impaired.

It is important to view activities of daily living (ADLs), such as bathing, dressing and feeding, not as boring jobs to get done, but as occasions to help the person have as much fun as possible and to have a sense of being loved and cared for.

Try a compliment. You might get her to smile. For example, "You have the softest skin, Mary. You must always use good lotion." Or "I love to comb your hair. It is so pretty and soft." Additionally, if the person is able to do even a small part of a task or participate in any way, it is important that it is recognized and complimented.

The most important thing is to make your time together as pleasant and meaningful as possible and to treat this person with dignity and respect.

Adapted from articles by
Carrie Hill, PhD, for About.com
and alzact.today.com

Results of Stress

Cognitive

- Memory problems
- Indecisiveness
- Inability to concentrate
- Trouble thinking clearly
- Poor judgment
- Seeing only the negative
- Anxious or racing thoughts
- Constant worrying
- Loss of objectivity
- Fearful anticipation

Emotional

- Moodiness
- Agitation
- Restlessness
- Short temper
- Irritability, impatience
- Inability to relax
- Feeling tense and “on edge”
- Feeling overwhelmed
- Sense of loneliness
- Depression or general unhappiness

Physical

- Headaches or backaches
- Muscle tension & stiffness
- Diarrhea or constipation
- Nausea, dizziness
- Insomnia
- Chest pain, rapid heartbeat
- Weight gain or loss
- Skin breakouts (hives, eczema)
- Loss of sex drive
- Frequent colds

Behavioral

- Eating more or less
- Sleeping too much or too little
- Isolating yourself from others
- Procrastination, neglecting responsibilities
- Using alcohol, cigarettes or drugs to relax
- Nervous habits
- Teeth grinding or jaw clenching
- Overdoing activities
- Overreacting to unexpected problems
- Picking fights with others

Caregiver Fatigue Timeline

We know that caregiving takes its toll on individuals and families. The following timeline gives you an idea of when and how that happens, when you should seek help, and what can happen if you don't get any help. If you are a long-time caregiver, it may also explain some of your unexpected, out-of-character responses to people and situations. Please keep in mind that all caregivers are different, and physical and emotional responses to the stresses of caregiving may vary widely.

1 – 18 Months

- Anxious to provide the best possible care for loved one
- Manages the person with dementia
- Maintains house, garden, car, etc.
- Attends to family relations
- Keeps up appearances
- Helps the person with dementia through social situations
- Remains optimistic, caring, supportive
- Operates as "superwoman" or "superman"
- Attends to personal care

At 21 Months

- Begins to take medication, usually for sleep and/or headaches
- Becoming more and more difficult to keep on top of things
- Some help from family is still available

24 – 32 Months

- Emotional and physical resources drained
- Less and less contact with personal doctor, dentist, minister, friends
- Experiences feelings of powerlessness
- Caregiving consumes the whole day and night
- Outside help dwindles away

At 32 Months

- Stress becomes harder to conceal
- May begin to take tranquilizers
- Begins using medication for musculoskeletal pain
- Sleep is continually disturbed
- Becomes irritable more easily
- Has less and less contact with others

By 38 Months

- Feels unhealthy
- Finds it hard to get up
- Never feels rested
- May have hypertension and/or colitis
- Has symptoms of chronic fatigue
- Loses the will to care for herself/himself
- Is unable to manage the household
- Rarely socializes with others
- Feels helpless, guilty, a failure

After 50 Months

- Is in a chronic state of fatigue and "unwellness"
- Is often unable to ask for help or access resources for information and assistance
- Is isolated

Source: Family Caregiver Support Project,
Northwest Regional Council/Area
Agency on Aging, Bellingham, WA

Distributed by the WV Bureau of Senior Services
304-558-3317

Suggested Answers to Working with Families Scenarios

Keep in mind that there is almost always more than one right answer. Encourage creative thinking, and give everyone a chance to express their thoughts.

Scenario 1: The Long-Distance Daughter

How would you, as the worker, deal with Jenna?

Recognize that Jenna, the daughter, is probably dealing with several emotions, including guilt, anger and sadness. Give her the opportunity to talk about her mother. Ask questions that will help you get to know her mother better and, at the same time, will allow her to reminisce a little about happier times with her mom. If Jenna has specific complaints, suggest that she talk with the provider and give her the contact information.

If Jenna's actions seem to be upsetting to her mother, get Margaret involved in something she likes to do, to take the focus away from her daughter's screaming and crying. Better still, get her out of the room, and do something together that is calming to her (take a walk, sit on the porch, have a cup of coffee, etc.)

As a staff person at the senior center, what would you do or say if Jenna called you?

Let her talk. Listen to all her objections and complaints about the care her mother is receiving. Take notes. Explain what you can. If there are complaints that could be legitimate, tell her you'll check them out and get back to her. Then do it. If there's information she needs, see that she gets it. As long as her mother is receiving services, Jenna is going to be around. The more she knows and the more open the communication is, the better chance you'll have of eventually making her a "partner" in getting the best possible care for her mom.

How could you help Jenna understand the situation better, and what could you do to avoid future confrontations?

Show her a record of the activities you've done with her mother, and explain why you chose those activities. You may want to show her the personal history form, so that she can see your interest in getting to know her mother and what she likes and doesn't like.

For the future, ask if you can keep in touch periodically, to let Jenna know how her mother is doing. Relate some of the highlights of your time with her mother, and do your best to answer her questions (or accusations) objectively and honestly. (Someone has to remain calm and objective, and it probably won't be Jenna.)

Scenario 2: The Large, Protective Family

Who should deal with the family, and how?

The social worker or outreach worker may need to schedule a family meeting, with as many family members as possible in attendance. They probably don't realize they're giving conflicting suggestions or that they're upsetting Harry. Ask them to be specific about who should be giving instructions to the worker, and which family members can get Harry to do what.

What can you do to keep Harry from getting so upset?

If you learn the children's and grandchildren's names, you can be Harry's "memory" when you're there. You can say something like, "Look, Harry, your son, Jeff, is here. It looks like he just came from his job at the plant."

How can you turn their concern for their dad/granddad into a positive for both the family members and Harry?

Explain to family members how upset Harry gets when he can't remember who they are and that the things they suggest only make him more agitated and withdrawn. Recommend a photo album, with captions, of all those who might stop by. It's something Harry can use to help him put names with familiar faces. It may also serve as a way to help him open up and reminisce about events and people in his past.

Scenario 3: The Worn-Out Husband

How can you convince Mr. Nelson that caring for his wife is taking a toll on his own health? What can you do to help him deal with the guilt he feels?

Tell him how concerned you are and the changes you've observed in his appearance or his health. Show him information about caregiver fatigue and stress and what it can do to a person (Ex: Caregiver Fatigue Timeline). He probably feels that no one can care for his wife the way he does, and he's probably right. Acknowledge that. At the same time, let him know that you will do your best to see that she is well cared for while he is gone. You may have to say that several times before he is comfortable leaving, even for a short time.

Make sure Mr. Nelson understands that getting a break is good for his wife, as well as for him. When he is rested and refreshed, he can better provide for both their needs.

Should you get anyone else involved? If so, whom?

If Mr. Nelson's physical and emotional decline continues, that should be reported to a supervisor. He may need services separate from his wife. Additionally, a nurse, social worker, or other professional may need to convince him to see his doctor for a physical. Above all, he needs to be able to talk with the person who makes him feel the best about himself, whoever that person is.

Blessed in Aging

By Esther Mary Walker

Blessed are they who understand
My faltering step and shaking hand.

Blessed, who know my ears today
Must strain to hear the things they say.

Blessed are those who seem to know
My eyes are dim, and my mind is slow.

Blessed are those who looked away
When I spilled tea that weary day.

Blessed are they who, with cheery smile,
Stopped to chat for a little while.

Blessed are they who know the way
To bring back memories of yesterday.

Blessed are they who make it known
That I am loved, respected and not alone.

And blessed are they who will ease the days
Of my journey home, in loving ways.

Alzheimer’s Hero

By Valerie Stephenson

You entered my world extending your hand,
Reaching for the “me” that I had lost.
You helped me remember who I am
With kind and gentle reminders
Of the memories composing my life.

You took the time to know me
Beyond the intricacies of my disease –
You helped me find my way, each day,
Easing my fears,
Helping me feel that I still belong.

You overlooked my daily confusion,
Understanding the rage, giving me comfort.
You walked along with me, not for me,
Helping me face the day
With a sense of dignity and a semblance of pride.

My memory fades,
But I know when someone cares.
And I know when I look into your eyes
That you are my hero.
For you are faithful, you are strong,
And you respect the best of who I am.
And I know that your belief and steadfastness
Have allowed me to rediscover
That strength and courage
Of the hero that lies within me.