

# **Alzheimer's Support Network's**

## **Practical Alzheimer's Staging Tool (PAST) ©**

The Alzheimer's Support Network's Practical Alzheimer's Staging Tool (PAST) for family care partners aims to provide a straightforward, accessible framework for family care partners to understand the progression of Alzheimer's disease. This tool is designed not for clinical diagnosis but to help care partners recognize the progression of cognitive impairment, focusing on the skills and abilities that are lost as well as those retained at each stage. It uses the level of support needed and the capacity to perform Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs) as a framework. The stages of PAST are mapped over the Reisberg (1983) Global Deterioration Scale (GDS) as this is one of the most widely used Alzheimer's staging tools.

Expanding on the Practical Alzheimer's Staging Tool for family care partners (PAST) by incorporating the 6 A's of Alzheimer's—Apraxia, Aphasia, Amnesia, Anomia, Agnosia, and Anosognosia—offers a more comprehensive understanding of what individuals and their care partners might expect. This approach not only helps in recognizing the progression of cognitive impairment but also guides care partners on how to adapt care strategies to address these challenges.

### **Descriptions of Concepts**

#### **The 6 A's of Alzheimer's - Brief Definitions**

- Apraxia: Difficulty with motor tasks.
- Aphasia: Difficulty with language.
- Amnesia: Memory loss.
- Anomia: Difficulty naming objects.
- Agnosia: Difficulty recognizing objects.
- Anosognosia: Lack of awareness of illness.

## Amnesia

- Brief: Memory loss.
- Detailed: Amnesia refers to a loss of memories, such as facts, information, and experiences. In Alzheimer's, it primarily affects short-term memory in the early stages, meaning the person may forget recent conversations, events, or newly learned information, while long-term memory—memories stored from a more distant past—remains intact until the later stages of the disease.

## Apraxia

- Brief: Difficulty with motor tasks.
- Detailed: Apraxia refers to a motor disorder caused by damage to the brain where the individual has trouble with motor planning to perform tasks or movements when asked, despite understanding the request and having the willingness to perform the task. For instance, a person with apraxia may have difficulty using tools or performing daily activities, such as brushing their teeth or dressing, even though they are physically capable.

## Aphasia

- Brief: Difficulty with language.
- Detailed: Aphasia is a condition characterized by impaired ability to comprehend or formulate language because of damage to specific brain regions. In Alzheimer's disease, this can manifest as difficulty in speaking, reading, and writing, ranging from struggling to find the right words to complete inability to communicate verbally. It affects both the expression and understanding of language.

## Anomia

- Brief: Difficulty naming objects.
- Detailed: Anomia is a form of aphasia where the person has trouble recalling the names of everyday objects. Individuals with Alzheimer's might be able to describe how an object is used without being able to name it, reflecting a disruption in the linguistic process despite retained knowledge of the object's purpose and characteristics.

## Agnosia

- Brief: Difficulty recognizing objects.
- Detailed: Agnosia is the inability to recognize or make sense of incoming information despite intact sensory capabilities. In the context of Alzheimer's, it can manifest as difficulty recognizing familiar faces (prosopagnosia), objects, sounds, shapes, or smells, impacting the person's ability to interact with their environment effectively.

## Anosognosia

- Brief: Lack of awareness of illness.
- Detailed: Anosognosia is a condition in which a person with a certain disability seems unaware of the existence of their disability. Within Alzheimer's disease, it refers to the lack of insight or awareness that they have a memory or cognitive problem, which can lead to significant challenges in managing the disease, as the individual may resist treatment or assistance.

## IADLs & ADLs

Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs) are two categories of skills used to assess an individual's ability to live independently and perform day-to-day tasks. ADLs refer to basic self-care tasks, while IADLs are more complex skills required for living independently in the community.

### IADLs (Instrumental Activities of Daily Living)

IADLs involve more complex skills than ADLs and are necessary for living independently in a community:

Managing Finances: The ability to budget, manage banking transactions, and pay bills.

- *Example:* Keeping track of and paying monthly bills on time.

Managing Transportation: The capability to travel independently, whether by driving oneself or organizing other means of transport.

- *Example:* Driving a car or using public transportation.

Shopping: The ability to make appropriate food and clothing purchase decisions.

- *Example:* Planning and buying groceries for the week.

Preparing Meals: The capability to plan and prepare meals.

- *Example:* Cooking a meal from scratch or heating pre-prepared food safely.

Managing Medications: The ability to obtain medications and take them as prescribed.

- *Example:* Organizing daily medications and taking them at the correct times.

Housekeeping and Maintenance: The capability to maintain a clean living space and perform minor repairs.

- *Example:* Doing laundry, cleaning living spaces, and changing light bulbs.

Using Communication Devices: The ability to use devices such as telephones, computers, or tablets to communicate.

- *Example:* Making a phone call or sending an email.

Managing Home Health Services: Understanding and organizing the use of additional services for health care at home.

- *Example:* Arranging for home nursing visits or physical therapy as needed.

## ADLs (Activities of Daily Living)

ADLs are the fundamental skills needed for basic physical self-care and include:

Bathing and Showering: The ability to clean oneself and perform grooming activities like shaving and brushing teeth.

- *Example:* Being able to get in and out of the shower or bath.

Dressing: The capability to make appropriate clothing decisions and physically dress and undress oneself.

- *Example:* Choosing clothing appropriate for the weather and managing zippers and buttons.

Feeding: The ability to feed oneself, though not necessarily the capability to prepare food.

- *Example:* Being able to use utensils to eat a meal.

Functional Mobility: The ability to move oneself from one position to another, including getting in and out of a bed or chair and walking.

- *Example:* Walking to the bathroom or getting out of bed without assistance.

Personal Hygiene: The ability to maintain personal cleanliness and grooming.

- *Example:* Brushing one's hair and teeth.

Toileting: The capability to get to and from the toilet, using it appropriately, and cleaning oneself.

- *Example:* Going to the bathroom independently and managing clothing.

# Practical Alzheimer's Staging Tool (PAST)

## PAST Stages

### 1. Living Independently *[Global Deterioration Scale (GDS): No Cognitive Decline (Normal Function)]*

- **Cognitive Impairment: None**
- **IADL / ADL Status:** IADLs and ADLs: Fully independent in personal care, housekeeping, money management, transportation, and medication management.
- **Retained Abilities:** Individuals have full cognitive and physical function, engaging in complex decision-making, problem-solving, and social activities without impairment. They maintain their hobbies, work, and social relationships as before.
- **Compromised Capabilities:** At this stage, individuals are generally not experiencing noticeable symptoms of cognitive decline that impact daily living. There may be very subtle changes, but these are usually not apparent. Minor forgetfulness (Amnesia) may begin, such as misplacing items or forgetting names, which is often attributed to normal aging rather than the onset of Alzheimer's.
- **Memory Changes:** At this stage, individuals may experience very mild memory lapses that do not significantly interfere with daily activities.
- **Language Changes:** No noticeable language impairments. Individuals communicate and understand language as they always have, without signs of aphasia or anomia. Individuals have full comprehension of both spoken and written language. They are able to engage in complex conversations, understand detailed instructions, and comprehend written materials without difficulty.
- **Attention Deficits:** Generally, no noticeable deficits in attention at this stage. Individuals are able to focus on tasks, follow conversations, and engage in activities without evident difficulty.
- **Apathy:** Individuals at this stage usually do not exhibit apathy related to Alzheimer's disease. They remain active and engaged in their interests and social activities.
- **Altered Perceptions:** No altered perceptions are noted at this stage. Individuals have a clear understanding of their environment and do not experience perceptual disturbances.
- **Altered Perceptions:** No altered perceptions are noted at this stage. Individuals have a clear understanding of their environment and do not experience perceptual disturbances.
- **Agnosia:** Non-existent. Individuals have no difficulty recognizing familiar objects, people, or their environment. Cognitive functions are intact, allowing for normal sensory processing and recognition.

- **Apraxia:** Non-existent. Individuals are fully capable of performing tasks and movements without difficulty, as cognitive and motor functions are not impaired by Alzheimer's disease at this stage.
- **Anosognosia:** Non-existent. At this stage, individuals are fully aware of their cognitive abilities and have no noticeable deficits that would trigger a lack of insight into their condition.
- **Brain Changes:** At this very early stage, microscopic changes in the brain may begin with the accumulation of amyloid-beta plaques and tau protein tangles in brain areas critical to memory and cognitive functions. However, these changes are not yet sufficient to cause symptoms of memory loss or cognitive impairment that are noticeable.
- **Care Partner Challenges:** At this stage, there might not be noticeable symptoms that significantly impact daily life. The challenge for care partners is often related to detecting early signs of cognitive decline and encouraging their loved ones to seek medical evaluation for subtle symptoms.
- **Most Common Challenges for Care Partners:** care is not required.
- **Living Setting:** Own home or independent living.
- **Support Needed:** none.
- **Alzheimer's Support Network Services:** volunteer, support for friends/family members. Educational programs. No support services are needed for self.

## 2. Living with Reminders *[GDS: Very Mild Cognitive Decline (Age-Associated Memory Impairment)]*

- Cognitive Impairment: **Mild Cognitive Impairment (MCI)**
- **IADL / ADL Status:** IADLs: May need reminders for complex tasks like managing finances or planning complex events. ADLs: Independent.
- **Retained Abilities:** Planning and executing complex tasks, managing finances, remembering appointments or medication schedules. Minor forgetfulness, such as misplacing objects or forgetting names or appointments may occur and require occasional reminders. Though they may experience minor forgetfulness, individuals can still manage their personal care, household tasks, and most daily activities independently. They continue to participate in social and recreational activities, maintaining their interpersonal skills.
- **Compromised Capabilities:**
  - *Mild disorientation in unfamiliar environments.* Occasional forgetfulness becomes more apparent than in Stage 1, with individuals sometimes misplacing items or forgetting recent conversations, appointments, or names they used to recall easily. These lapses in memory are often sporadic and can be managed with simple organizational tools or reminders.
  - Mild difficulty with concentration or task management may be observed, especially in situations requiring multitasking or rapid shifts in focus. Individuals

might find themselves overwhelmed or making minor errors in tasks that require sustained attention or complex thought, which were previously handled with ease.

- There might be a subtle decrease in initiative or motivation for tasks that require planning or effort, noticeable mainly by those close to the individual. This change is often not severe enough to impact work performance or social engagements significantly but may manifest in reduced interest in hobbies or activities that require significant mental engagement.
- An increased reliance on notes, calendars, and digital reminders may start to be necessary to compensate for these minor lapses in memory and concentration, helping individuals maintain their independence and manage their daily routines effectively.
- **Memory Changes (Amnesia):** Individuals begin to have noticeable memory difficulties, especially with recent events or conversations. They might forget important dates or appointments, misplace items more frequently, and have trouble recalling information that was just presented. The need for reminders, notes, or electronic aids to help with memory becomes more apparent. Noticeable memory lapses, difficulty remembering recent events or conversations. Anosognosia: The individual may not recognize these memory lapses as a problem, attributing them to aging.
- **Language Changes:**
  - **Aphasia (Speaking):** Very minimal, if present at all. Individuals might occasionally struggle to find the right word, but these instances are not severe and do not significantly impact communication.
  - **Anomia (Naming):** Very minimal. Occasional difficulty finding the right word may occur, but it's often attributed to normal aging or momentary lapses, not significantly impacting daily communication
  - **Comprehension:** Comprehension remains largely intact. Minor difficulties may arise, such as occasionally needing to reread sentences for full understanding or asking for repetition in conversations, but these are not significantly disruptive.
- **Attention Deficits:**
  - Minor difficulties in concentrating on more complex tasks may begin to appear.
  - Individuals might start to find it challenging to multitask or may become easily distracted during activities that require sustained attention.
- **Apathy:** is generally minimal or not apparent at this stage. While there might be occasional moments of disinterest, these are not consistent or significantly impactful on daily life.
- **Altered Perceptions:** Still minimal to none. If any changes in perception occur, they are typically very mild and not significantly impactful, often attributed to normal aging rather than cognitive decline.
- **Agnosia:** Still non-existent or very minimal. Any occasional difficulty in recognition is usually not due to agnosia but may be attributed to normal forgetfulness or distractions.

- **Apraxia:** Still non-existent or very minimal. Any observed clumsiness or difficulty with complex tasks is usually not severe enough to be considered apraxia and is often attributed to normal aging or other non-neurodegenerative causes.
- **Anosognosia:** Minimal to none. Individuals may recognize and sometimes express concern about minor memory lapses or cognitive changes, but these are often attributed to normal aging rather than recognized as symptoms of Alzheimer's disease.
- **Brain Changes:** The accumulation of amyloid plaques and tau tangles continues, primarily affecting the hippocampus, which is crucial for forming new memories. Neurodegeneration is still relatively limited, allowing most individuals to function normally in daily life despite beginning to experience minor memory lapses.
- **Care Partner Challenges:** As individuals start to forget minor details, such as appointments or where they placed items, care partners might need to implement strategies like setting reminders or creating lists. The challenge lies in balancing assistance with the individual's desire for independence, and addressing any denial or resistance to acknowledging the cognitive changes. **Repetitive Actions (Repetitive Questions):** Individuals may start to ask the same questions more frequently, as they begin to experience minor memory lapses.
- **Living Setting:** Own home, possibly with some technological aids or reminder systems in place.
- **Support Needed:** Occasional check-ins and reminders, especially for safety considerations and complex tasks.
- **Alzheimer's Support Network Services:** Kindred Spirits Early Stage Discussion Group. Specialized educational workshops. Naples Unites Passion & Purpose Program. Educational Programs. Family Support & Guidance.

### 3. Living with Supervision [GDS: Mild Cognitive Decline (Mild Cognitive Impairment)]

- Cognitive Impairment: **Early Stage Alzheimer's**
- **IADL / ADL Status:** Navigating new locations, managing medications without assistance, or handling unexpected situations independently.
- **Retained Abilities:** Still able to perform personal care with supervision, but might need help with more complex ADLs and IADLs like driving, managing medications, or dealing with finances. While they may need reminders for certain tasks, individuals can still engage in simple hobbies and social interactions. They often retain the ability to follow familiar routines and enjoy stories, music, and other entertainment that does not demand short-term memory.
- **Compromised Capabilities:**
  - *Increased forgetfulness, including difficulty retaining new information.*
  - *Beginning challenges with complex tasks, such as managing finances or planning events.*

- *Mild disorientation in unfamiliar environments.*
- **Memory Changes (Amnesia):** Short-term memory loss becomes more pronounced. Individuals may repeat questions, forget recent conversations entirely, and show noticeable gaps in memory regarding personal history or current events. They might also struggle to remember plans or activities scheduled for the same day and require supervision to ensure safety and assistance with decision-making.
- **Language Changes:**
  - **Aphasia (Speaking):** Mild symptoms may begin to appear. This includes occasional difficulty finding the right word (anomia) and possibly slight difficulty following complex conversations or instructions. However, the ability to communicate effectively in familiar situations generally remains intact.
  - **Anomia (Naming):** Mild. Individuals may start to experience noticeable, though relatively infrequent, challenges in finding the correct words for objects, leading to pauses or substitutions in conversation. They might describe an object instead of naming it ("the thing you sit on" for "chair"). They might substitute descriptions for the actual names ("that thing for writing" instead of "pen"). Conversations can still be managed, but the effort to recall specific words is evident.
  - **Comprehension:** Mild difficulties in comprehension begin to emerge, especially in understanding complex or abstract language. May need more time to process spoken instructions or detailed information. Subtleties of language, such as sarcasm or implicit meanings, may start to be missed.
- **Attention Deficits:**
  - Noticeable difficulties in maintaining attention on tasks, leading to unfinished projects or activities.
  - May have trouble following complex conversations or TV programs, resulting in the need for repeated information.
  - Increased distractibility and potential difficulty in shifting attention from one task to another.
- **Apathy:**
  - Early signs of apathy may emerge, such as decreased interest in hobbies or social activities.
  - Individuals might begin to show a preference for more passive activities, like watching television, over more engaging or complex tasks.
- **Altered Perceptions:**
  - Some individuals may begin to experience mild misinterpretations of their environment or situations, but these are not typically marked by significant hallucinations or delusions.
- **Agnosia:** Minimal. There might be initial signs of difficulty in recognizing complex or less frequently encountered objects, but these instances are generally rare and do not significantly impact daily life.

- **Apraxia:** Minimal to mild. Individuals may begin to show slight difficulties with more complex daily tasks that require a series of steps, such as cooking or managing finances, but true apraxia is generally not observed until later stages.
- **Anosognosia:** Mild. As cognitive changes become more noticeable, individuals may start to show signs of anosognosia by downplaying their memory problems or rationalizing their difficulties as normal aging. They may be resistant to suggestions that they seek medical evaluation.
- **Brain Changes:** Neurodegeneration begins to spread more widely, affecting areas involved in language, reasoning, and spatial orientation. This leads to more noticeable memory deficits and cognitive impairments. Synaptic connections between neurons start to degrade, affecting the brain's ability to process and recall information.
- **Care Partner Challenges:** Increased forgetfulness and potential safety issues, like forgetting to turn off appliances, require more active supervision. Care partners may face the challenge of providing constant oversight without infringing too much on the individual's sense of autonomy. They might also begin managing medication regimens and assisting with financial management, which can be complex and time-consuming.
  - **Shadowing:** This action may begin to emerge as individuals seek reassurance and comfort by staying very close to their care partners, following them around the home.
  - **Repetitive Actions (Repetitive Questions):** This action becomes more noticeable, with individuals asking the same questions repeatedly due to short-term memory loss.
- **Living Setting:** Own home or a senior living community that does not necessarily provide medical services but offers a safer environment.
- **Support Needed:** Regular supervision, especially for safety and complex tasks; daily check-ins recommended.
- **Alzheimer's Support Network Services:** Kindred Spirits Early Stage Discussion Group. Specialized educational workshops. Naples Unites Passion & Purpose Program. Family Support & Guidance.

#### 4. Transitional Support Needed *[GDS: Moderate Cognitive Decline (Mild Alzheimer's Disease)]*

- Cognitive Impairment: **End Early / Transition to Middle Stage**
- **IADL / ADL Status:** Difficulty with independent decision-making in finances, driving, or managing household tasks. IADLs: Significant assistance required with finances, transportation, and medication management. Driving is usually no longer safe. ADLs: Assistance may be needed with dressing and maintaining personal hygiene.
- **Retained Abilities:** Despite needing assistance with planning and complex tasks, individuals can still perform basic ADLs with some support. They may enjoy simplified

versions of their previous hobbies and engage in conversations about familiar topics, relying on long-term memory.

- **Compromised Capabilities:**

- *Significant memory loss, affecting knowledge of recent events and personal history.*
- *Difficulty with some activities of daily living (ADLs), necessitating assistance.*
- *Challenges in executing complex tasks, leading to impaired judgment and decision-making.*
- *Decreased awareness of safety, increasing the risk of accidents.*

- **Memory Changes (Amnesia):** At this stage, significant memory loss affects both recent and some long-term memories. Individuals might forget major life events, have difficulty recognizing close friends and family, and become increasingly confused about past and present. The ability to learn new information severely declines, and retaining information about one's own personal history becomes challenging.

- **Language Changes:**

- **Aphasia (Speaking):** Moderate aphasia becomes more noticeable. Individuals might have significant trouble finding words, leading to frequent pauses and substitutions in conversation. They may also begin to exhibit difficulties in understanding complex sentences or expressing themselves clearly, impacting their ability to engage in more in-depth discussions. They might use vague language or generic terms ("thing," "that place") more frequently.
- **Anomia (Naming):** Moderate. Word-finding difficulties become more frequent, affecting the fluidity of conversations. Individuals may struggle to recall names of familiar objects or people, leading to increased use of nonspecific language ("that thing," "whatchamacallit"). Difficulty naming objects might become pronounced, making conversations more challenging and sometimes leading to frustration or withdrawal from social interactions.
- **Comprehension:** Moderate difficulties with language comprehension become evident. Individuals may require simplified explanations and may struggle with following the gist of conversations involving abstract concepts or when information is presented rapidly. Understanding of complex written material (e.g., legal documents, dense narrative texts) is impaired, necessitating more straightforward, concise language.

- **Attention Deficits:**

- Significant challenges in focusing on tasks, even those previously enjoyed or found easy.
- Difficulty in engaging in social activities or conversations for extended periods due to decreased attention span.
- May exhibit restlessness or frequently change activities without completing any.

- **Apathy:**
  - Noticeable increase in apathy, with individuals often showing diminished initiative to start or participate in activities.
  - Reduced involvement in social interactions and a tendency to withdraw from previously enjoyed engagements.
- **Altered Perceptions:**
  - Increased likelihood of experiencing misinterpretations, particularly in low-light conditions or unfamiliar settings.
  - May have unfounded suspicions or mild paranoid thoughts, but full-blown delusions are less common at this stage.
- **Agnosia:** Mild. Individuals may begin to show noticeable difficulties with object recognition, such as mistaking one household item for another. However, recognition of familiar people and common objects used daily often remains intact.
- **Apraxia:** Mild to moderate. Signs of apraxia become more evident as individuals may struggle with tasks that involve sequencing or precise movements, such as dressing (buttoning shirts, tying shoelaces) or using household appliances correctly. There might be difficulty in initiating the steps required for a task, even though the task itself is familiar.
- **Anosognosia:** Moderate. With the progression of cognitive decline, individuals often have a reduced awareness of their memory and cognitive impairments. They may not recognize the need for assistance in daily tasks or deny that their condition is worsening, leading to challenges in caregiving and decision-making.
- **Brain Changes:** Significant atrophy begins in the regions of the brain involved in memory, cognitive function, and executive functioning. The spread of tau tangles to the frontal and temporal lobes affects emotional regulation, judgment, and language skills. The brain's ability to compensate for lost connections diminishes, leading to more apparent and impactful symptoms.
- **Care Partner Challenges:** As individuals experience more significant memory and cognitive difficulties, they may need help with a broader range of activities, including personal care. Care partners face the challenge of increasing care responsibilities, including the emotional difficulty of witnessing their loved one's decline and managing their own stress and potential care partner burnout.
  - **Rummaging/Hoarding:** These actions can start in this stage as individuals may begin to rummage through drawers or closets and hoard items, possibly in an attempt to exert control over their environment or from a misplaced sense of security.
  - **Wandering:** The risk of wandering may increase as confusion and memory loss worsen, leading to disorientation even in familiar settings.
- **Living Setting:** Assisted living or beginning to consider a move to a more supportive environment.
- **Support Needed:** Daily support with IADLs and some ADLs; consideration for regular in-home care or part-time assistance.

- **Alzheimer's Support Network Services:** Specialized educational workshops. Brain Fitness Program. Naples Unites Passion & Purpose Program. Ladies & Gentlemen's Club. Family Support & Guidance.

## 5. Living with Daily Supports *[GDS: Moderately Severe Cognitive Decline (Moderate Alzheimer's Disease)]*

- Cognitive Impairment: **Middle Stage**
- **IADL / ADL Status:** unable to perform most if not all IADLs without assistance. ADLs: Needs assistance with most personal care activities.
- **Retained Abilities:** Individuals can often still participate in basic personal care activities with guidance, such as dressing (when laid out for them) and eating. They may recognize family members and close friends and respond to emotional cues, enjoying music, pets, and other sensory experiences.
- **Compromised Capabilities:**
  - Major difficulties with memory, including significant portions of one's personal history.
  - Increased need for assistance with ADLs, including personal hygiene and dressing.
  - Difficulty recognizing familiar people and places.
- **Memory Changes (Amnesia):** Memory loss is severe, with individuals often unable to recall critical personal information, such as their address, phone number, or close family members' names. They may not recognize familiar environments and can confuse past life events with current reality. Consistent daily support becomes necessary as individuals can no longer manage their day-to-day lives due to profound memory impairments.
- **Language Changes:**
  - **Aphasia (Speaking):** Conversational abilities decline significantly. Individuals might rely on familiar phrases, repeat the same stories or questions, and have difficulty understanding others. Major difficulties in communication; may speak in gibberish or be unable to find words. Understanding others becomes significantly impaired, requiring simple and direct communication from caregivers.
  - **Anomia (Naming):** Moderate to severe. The ability to name common objects and express thoughts coherently is significantly impaired. Conversations may be marked by frequent pauses, incorrect word use, or reliance on very basic vocabulary. This stage shows a marked decline in the ability to engage in complex conversations.
  - **Comprehension:** Significant impairment in comprehending both spoken and written language. Conversations need to be direct and simple for the individual to understand, and they may frequently require repetition or rephrasing of

information. Reading comprehension is markedly reduced, making it difficult to understand even simple written content without assistance.

- **Attention Deficits:**
  - Marked difficulty in concentrating on almost any task.
  - May not be able to follow short conversations or simple instructions, impacting their ability to participate in daily activities.
  - Increased likelihood of being easily distracted by external stimuli, making focused activities challenging.
- **Apathy:**
  - Apathy becomes more pronounced. Individuals may require encouragement and assistance to engage in basic daily activities and personal care.
  - There is a significant decrease in expressing preferences or making choices, reflecting a deeper level of disinterest in their surroundings.
- **Altered Perceptions:**
  - Misinterpretations and illusions may become more common, such as mistaking reflections in mirrors or patterns on carpets for objects, animals, or people.
  - There might be occasional hallucinations, but these are typically not pervasive.
- **Agnosia:** Moderate. There is an increased difficulty in recognizing objects and their uses, which can affect the ability to perform tasks independently. Individuals might struggle with identifying or using common items correctly, such as confusing a toothbrush with a comb.
- **Apraxia:** Moderate to severe. Individuals require assistance with many ADLs due to increased difficulty coordinating movements for tasks. This includes challenges with personal grooming, eating (using utensils becomes harder), and dressing. The ability to independently perform tasks that require fine motor skills is significantly compromised.
- **Anosognosia:** Moderate to severe. At this stage, individuals frequently have significant anosognosia, showing little awareness of their cognitive deficits and the extent of their dependence on others for daily activities. This lack of insight can complicate efforts to provide care, as they may not understand why assistance is necessary.
- **Brain Changes:** By this stage, widespread atrophy is observed in the cerebral cortex, leading to severe cognitive and functional impairments. The hippocampus is further degraded, significantly affecting long-term memory. The extensive loss of neuronal connections severely impacts the individual's ability to perform daily tasks independently.
- **Care Partner Challenges:** With the need for assistance in basic ADLs, such as dressing and bathing, care partners must devote considerable time to direct care, which can be physically demanding. Managing changes to emotions, attitudes, and ability to communicate becomes more challenging. Care partners may need to seek additional help or consider adult day stay care, in-home care services, or assisted living with levels of support or memory care which introduces financial and logistical challenges.
  - **Wandering:** Wandering can become more pronounced due to increased disorientation and confusion. Care partners need to implement safety measures to prevent the individual from getting lost.

- **Shadowing:** May intensify as individuals become more dependent on their care partners for emotional support and guidance.
- **Living Setting:** Assisted living with a focus on memory care or increased in-home care.
- **Support Needed:** Comprehensive daily support for both IADLs and ADLs; structured environment. Adult day stay programs.
- **Alzheimer's Support Network Service:** Brain Fitness Program. Naples Unites Passion & Purpose Program. Ladies & Gentlemen's Club. Family Support & Guidance.

## 6. Extensive Care Required *[GDS: Severe Cognitive Decline (Moderately Severe Alzheimer's Disease)]*

- Cognitive Impairment: **Late Middle Stage**
- **IADL / ADL Status:** IADLs and ADLs: Requires full-time assistance with all activities. Communicating needs or discomfort; mobility becomes increasingly limited.
- **Retained Abilities:** Limited; comfort can still be provided through sensory experiences like touch, taste, and sound. Communication may be limited, but individuals can usually express basic needs and preferences in some form, whether verbal or non-verbal. They may show recognition of familiar people and respond positively to touch, taste, and smell, finding comfort in familiar and simple routines.
- **Compromised Capabilities:**
  - Severe memory loss, with individuals often unable to recall significant life details or recognize close family members.
  - Substantial assistance is required with all ADLs, including eating, toileting, and mobility.
  - Potential for incontinence.
  - Pronounced changes in personality and behavior, including possible agitation or aggression.
- **Memory Changes (Amnesia):** In this stage, individuals may lose almost all ability to remember new information and struggle significantly with long-term memory. They might not recognize their spouse or children and have little recall of their personal history. Memory lapses are profound and pervasive, requiring specialized memory care and constant supervision to navigate daily life.
- **Language Changes:**
  - **Aphasia (Speaking):** Very severe aphasia is prevalent, with individuals often unable to form coherent sentences or understand more than basic commands or phrases. Individuals may speak in jumbled or incoherent sentences or may revert to speaking in a first language if bilingual. Speech may be reduced to repeating simple words or phrases, and comprehension of spoken language is significantly limited. Non-verbal communication becomes a crucial mode of interaction.
  - **Anomia (Naming):** Severe. Individuals often cannot recall the names of even everyday objects and familiar people, making verbal communication highly

challenging. They might rely heavily on gestures or non-verbal sounds to communicate needs or responses, as specific words are hard to retrieve.

- **Comprehension:** Severe challenges in understanding language. Individuals may only grasp very basic instructions or familiar phrases. Comprehension of written language is typically lost, and spoken language comprehension is limited to very familiar or routine expressions. Non-verbal cues become increasingly important for communication as verbal understanding diminishes.
- **Attention Deficits:**
  - Severe impairment in the ability to focus, making engagement in any structured activity difficult.
  - Attention may be extremely fleeting, with individuals quickly losing interest in or forgetting what they were doing.
  - May exhibit behaviors indicative of an inability to process and respond to information in a focused manner.
- **Apathy:**
  - Apathy is marked and pervasive, with individuals showing little to no interest in interacting with others or their environment.
  - Engagement in activities, even those designed to meet their cognitive level, is minimal unless highly structured and facilitated by caregivers.
- **Altered Perceptions:**
  - Hallucinations (seeing, hearing, or feeling things that aren't there) and delusions (fixed, false beliefs) may become more pronounced and frequent.
  - Individuals might misinterpret the actions of others, leading to accusations or fear, and may require careful reassurance and management.
- **Agnosia:** Severe. At this stage, agnosia becomes more pronounced, extending to difficulties in recognizing familiar faces (prosopagnosia) and understanding the purpose of everyday objects. This can lead to frustration and challenges in communication and daily activities, as individuals may not recognize even their close family members or know how to use simple items. **May not recognize myself in the mirror.**
- **Apraxia:** Severe. Apraxia is prominent, with individuals often unable to perform simple tasks without direct assistance. This could include inability to properly use objects (misusing a toothbrush, for instance), difficulty with walking or changing positions, and needing help with nearly all aspects of personal care.
- **Anosognosia:** Severe. Anosognosia is typically profound, with individuals often completely unaware of their condition and limitations. They may express unrealistic abilities or desires, such as wanting to engage in tasks or activities they are no longer capable of safely performing.
- **Brain Changes:** The neurodegenerative process involves almost all parts of the brain, with severe atrophy in the cerebral cortex and hippocampus. Communication between different parts of the brain is drastically reduced, leading to profound memory loss, difficulties in communication, and significant changes in personality and behavior.
- **Care Partner Challenges:** This stage may require around-the-clock care due to significant memory loss, confusion, and potential for wandering. Care partners face the difficult

decision of whether to continue home care or transition their loved one to a memory care community. Emotional challenges include dealing with the grief of seeing their loved one's personality and memories fade.

- **Rummaging/Hoarding:** These actions may continue or escalate as individuals try to make sense of their surroundings or cling to familiar objects for comfort.
- **Wandering:** Continues to be a significant concern, with a higher risk of safety issues as individuals may no longer recognize their environment or the need to return home.
- **Repetitive Actions (Repetitive Questions):** Repetitive questioning can be a significant feature of this stage, reflecting profound memory impairment and anxiety.
- **Living Setting:** Memory care community or full-time home care to ensure safety and meet care needs.
- **Support Needed:** Constant supervision and assistance, specialized care for dementia.
- **Alzheimer's Support Network:** Keeping Connected Wellbeing visits. Family Support & Guidance.

## 7. Total Care Required [Very Severe Cognitive Decline (Severe Alzheimer's Disease)]

- Cognitive Impairment: **Late Stage**
- **IADL / ADL Status:** IADLs and ADLs: Complete dependence for personal care, with significant cognitive decline. Engaging with the environment in a meaningful way; basic functions such as swallowing may become impaired.
- **Retained Abilities:** Basic reflexes; some may retain the ability to respond to tone of voice or physical touch. Physical Responses: While cognitive skills are significantly diminished, reflexive responses such as smiling or turning towards a familiar voice may remain. Sensory Appreciation: The ability to enjoy certain sensory inputs, like the feel of a soft blanket, favorite music, or the taste of preferred foods, can persist, providing comfort and moments of connection.
- **Compromised Capabilities:**
  - *Near-total loss of speech and ability to communicate needs effectively.*
  - *Complete dependence on care partners for ADLs, with mobility severely restricted.*
  - *Difficulty swallowing and potential for nutrition and hydration issues.*
  - *Vulnerability to infections, such as pneumonia.*
- **Memory Changes (Amnesia):** Memory function continues to decline until individuals may only have fleeting moments of recognition or remembrance. They may occasionally utter familiar words or phrases but generally are unable to communicate or recall any

significant details of their personal history or identity. At this point, care focuses on comfort and quality of life, as memory and cognitive abilities are minimal.

- **Language Changes:**

- **Aphasia (Speaking):** Profound. At this stage, verbal communication may be virtually non-existent. Individuals may no longer be able to speak or understand language in any meaningful way. Communication is primarily through non-verbal means, such as facial expressions, gestures, or vocal sounds, with caregivers needing to interpret these cues to understand the individual's needs and emotions.
- **Anomia (Naming):** Profound. Verbal communication may be reduced to very simple words or phrases, if present at all. The ability to name objects, people, or express specific needs through language is essentially lost, requiring caregivers to interpret non-verbal cues and provide anticipatory care.
- **Comprehension:** Profound difficulty with language comprehension. Verbal communication may not be meaningful, and the individual's response to spoken language is often based more on tone of voice and emotional context rather than the specific words or sentences. Written language is no longer comprehensible. Communication relies almost entirely on non-verbal cues, physical comfort, and environmental familiarity.

- **Attention Deficits:**

- At this stage, the capacity for focused attention is profoundly compromised.
- Individuals may show very brief moments of apparent attention to stimuli (e.g., responding to loud noises or direct touch) but are generally unable to engage with their environment in a meaningful way.
- The ability to purposefully shift or maintain attention on specific tasks, people, or conversations is essentially lost.

- **Apathy:**

- At this final stage, apathy is profound, with individuals often appearing indifferent to most stimuli.
- Responses to the environment, social interactions, and activities are minimal. Engagement is largely non-existent, requiring continuous and tailored efforts from caregivers to ensure comfort and quality of life.

- **Altered Perceptions:**

- While cognitive function is significantly diminished, some individuals may still experience hallucinations or delusions.
- The capacity to communicate these experiences verbally decreases, so altered perceptions may be inferred from non-verbal cues, such as reactions to unseen stimuli or agitation without an apparent cause

- **Agnosia:** Profound. The ability to recognize most objects, people, and their environment is significantly impaired or lost. Sensory information like sounds or smells may not be processed meaningfully. Interaction with the environment becomes highly limited, relying on basic sensory experiences and reflexive responses rather than recognition.

- **Apraxia:** Profound. At this stage, the cognitive decline severely affects all motor planning and execution abilities. Individuals may be unable to perform even the simplest tasks or gestures on command and might not recognize common objects or their uses. Physical assistance is required for almost all movements and activities, including basic expressions of needs.
- **Anosognosia:** Complete. At this final stage, individuals have very limited cognitive function, making it impossible for them to have any insight into their condition. Anosognosia is not so much a feature as it is a default state due to the near-total cognitive decline.
- **Brain Changes:** In the final stage of Alzheimer's disease, there is extensive brain atrophy throughout. The brain's shrinkage reflects the widespread loss of neurons and the severe disruption of neural networks. This stage is characterized by the near-total loss of cognitive functions and the ability to respond to the environment.
- **Care Partner Challenges:** In the final stage, individuals may lose the ability to communicate and perform basic movements. Care partners must provide full physical care, which is highly demanding. Challenges include managing end-of-life care, making difficult medical decisions, and coping with anticipatory grief. Ensuring comfort and dignity for their loved one while dealing with personal emotional pain and loss is a significant challenge.
- **Living Setting:** Memory care community with the capability to provide high levels of medical and personal care or hospice care.
- **Support Needed:** 24-hour care focusing on comfort, managing symptoms, and providing emotional support to both the individual and family.
- **Alzheimer's Support Network Services:** Keeping Connected Wellbeing visits. Family Support & Guidance.

## Summary & Suggestions

The PAST is designed to guide family care partners through the progression of Alzheimer's disease in a loved one, offering insights into the level of care and support required at each stage. It emphasizes the shift in care needs from independence to full-time support, providing a framework for planning care and living arrangements. This tool also aims to prepare care partners for the progression of the disease, helping them make informed decisions about care, support services, and adjustments to living arrangements as needed.

## **Importance of Focusing on Retained Capabilities**

Focusing on retained skills and abilities at each stage of Alzheimer's can help care partners tailor activities, interactions, and care strategies to what their loved ones can still enjoy and participate in. This approach fosters a sense of achievement, dignity, and quality of life for individuals with Alzheimer's, supporting their well-being and strengthening the person-centered bond throughout the disease's progression.

## **Inclusion of the Six A's of Alzheimer's**

The Practical Alzheimer's Staging Tool for family care partners (PAST) incorporates the 6 A's of Alzheimer's—Apraxia, Aphasia, Amnesia, Anomia, Agnosia, and Anosognosia—offers a more comprehensive understanding of what individuals and their care partners might expect. This approach not only helps in recognizing the progression of cognitive impairment but also guides care partners on how to adapt care.

### **Aphasia (Speaking)**

As aphasia progresses, adapting communication techniques becomes essential for caregivers. Strategies include using simple, clear sentences, speaking slowly, employing visual aids or gestures, and ensuring a calm, patient approach to interactions. Understanding and patience are key, as is creating an environment that reduces frustration and supports the individual's ability to communicate to the best of their abilities.

### **Agnosia (Difficulty Recognizing)**

Agnosia significantly impacts the care needs of individuals with Alzheimer's disease, requiring caregivers to adopt strategies that help mitigate these recognition difficulties. This might include labeling items with large, clear words or pictures, maintaining a consistent environment to reduce confusion, and using verbal cues to guide interactions and activities. Understanding

and compassion are crucial, as agnosia can be distressing for the individual, who may not understand why they can no longer recognize familiar objects and faces.

### **Apraxia (Difficulty Using)**

Apraxia adds a layer of complexity to caregiving in Alzheimer's disease, as it affects the individual's ability to perform daily tasks and maintain independence. Understanding the progression of apraxia can help caregivers adapt their support to the changing needs of their loved ones, focusing on simplifying tasks, providing step-by-step guidance, and ensuring a safe environment to prevent frustration and accidents. Patience and creative problem-solving become key strategies in managing apraxia at various stages of Alzheimer's disease.

### **Anomia (Naming)**

As anomia progresses, caregivers need to adapt their communication strategies to maintain engagement and understanding with their loved ones. This can include speaking in simple sentences, using visual aids or gestures to convey meaning, and encouraging the use of alternative forms of communication when verbal abilities decline. Patience and a non-rushing attitude are crucial, allowing the individual time to express themselves as best as they can and affirming their efforts to communicate.

### **Anosognosia (Denial of Deficits)**

Anosognosia poses significant challenges for caregivers and healthcare professionals, as it can lead to resistance to care, denial of the disease, and reluctance to engage in treatment plans or safety measures. Understanding the progression of anosognosia can help caregivers develop strategies for communication and care that respect the individual's perceptions while ensuring their safety and well-being. It emphasizes the importance of a compassionate, patient approach that minimizes confrontation and focuses on maximizing the individual's quality of life.

## **Attention Deficient**

As Alzheimer's disease progresses, attention deficits become more pronounced, significantly affecting the individual's ability to engage with their environment, communicate effectively, and participate in daily activities. These changes require care partners to adapt communication strategies, simplify tasks and instructions, and create a safe, structured environment that minimizes distractions and helps maintain the individual's focus as much as possible.

Understanding the progression of attention deficits can help care partners provide appropriate support and interventions tailored to their loved one's current abilities.

## **Apathy**

Apathy in Alzheimer's disease can be challenging for caregivers, as it affects the individual's quality of life and can complicate efforts to provide care and stimulation. Understanding the progression of apathy can help caregivers tailor their approaches, ensuring that activities and interactions are appropriate for the individual's stage of disease and remaining abilities.

Strategies might include simplifying tasks, providing clear and direct prompts, and incorporating elements that align with the individual's long-standing preferences and interests to stimulate engagement as much as possible.

## **Altered Perceptions**

Altered perceptions in Alzheimer's disease can lead to confusion, distress, and challenging actions and responses. Understanding how these perceptions change throughout the disease can help care partners provide appropriate responses and environments to minimize distress.

Strategies include ensuring adequate lighting, reducing environmental clutter, and maintaining a calm, reassuring presence. In some cases, medical intervention may be necessary to address significant hallucinations or delusions. Tailoring care approaches to the individual's experiences

and maintaining a safe, supportive environment are key in managing altered perceptions throughout the progression of Alzheimer's disease.

## **Responding to Changes in Use and Understanding of Language**

As Alzheimer's disease progresses, care partners need to adapt their communication strategies. This includes speaking slowly and clearly, using simple words and sentences, and relying more on non-verbal communication methods. Patience and empathy become crucial, as does the recognition of non-verbal cues from individuals to understand their needs and emotions. Effective communication strategies can significantly impact the quality of care and the emotional well-being of both the individual with Alzheimer's and their care partners. As language comprehension declines, caregivers need to adapt their communication strategies to ensure they continue to connect with and support their loved ones effectively. This includes using simple, clear language, maintaining eye contact, and paying close attention to non-verbal signals for cues on how the individual is feeling or what they may need. Reinforcing verbal communication with visual aids and maintaining a calm, patient demeanor can also help in fostering understanding and reducing frustration.

## **Responding to Difficult “Behaviors”**

It's important to note that the timing and presence of actions such as wandering, shadowing, hoarding, rummaging, repetitive questions or actions can vary widely among individuals with Alzheimer's disease. Care partners might encounter these challenges at slightly different stages depending on the unique progression of the disease. Strategies to manage these actions include creating a safe and structured environment, maintaining a routine, using gentle redirection, and providing reassurance and comfort. Understanding and patience are key in responding to these actions, which are symptoms of the disease rather than intentional actions by the individual. It

can be helpful to think of these actions not as “behaviors,” but rather as clever coping strategies when a person’s brain is processing sensory information in new ways due to the disease.

### **Common Stressor Care Partners Face Across Stages**

- **Emotional Toll:** Watching a loved one decline mentally and physically can be emotionally devastating. Care partners may experience feelings of loss, sadness, and helplessness throughout the progression of the disease.
- **Physical and Financial Strain:** The physical demands of caregiving, coupled with the financial burden of care needs and potential loss of income, can be overwhelming.
- **Social Isolation:** care partners might find themselves increasingly isolated from friends and family due to the demands of caregiving, leading to a lack of social support.
- **Health Impact:** The stress and demands of caregiving can have a significant impact on the care partner's own health, leading to increased risks of physical and mental health issues.

### **Brain Change Continuum**

It's important to note that the progression of brain changes in Alzheimer's disease can vary significantly between individuals, influencing how symptoms manifest and progress. The PAS scale provides a general framework for understanding how these changes may relate to the observable progression of the disease, aiming to help care partners anticipate and meet the evolving care needs of their loved ones.