

Anosognosia (Unawareness of Decline or Difficulties)

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Purpose of Session on Anosognosia (Unawareness of Decline or Difficulties):

*The purpose of this educational session on **Anosognosia (Unawareness of Decline or Difficulties)** is to provide some information on a condition in which changes in brain cells lead to some or complete unawareness of decline in ability, such as decline in short-term memory or judgment.*

Anosognosia (Unawareness of Decline or Difficulties)

Being aware of how we are feeling and how we are functioning helps us take care of our daily personal needs, work or home tasks, and relationships. When we are aware that we have a tendency to forget an appointment, we write it down on a calendar. After doing yard work when we feel sweaty and dirty, we bathe and put on clean clothes. If we break a leg or arm, we know that we have to take special care of the limb until it is fully healed.

If we are unaware of a problem, there is no expectation that we need to act, take care of matters, or change anything. If there is no mismatch between how we expect to function and how we actually function, then there is no attempt to change, adjust, or fix anything.¹ We assume that everything is fine. We do not try to compensate, such as writing a list of errands for the day, because we are unaware of any memory difficulties and we never used such a list anyways.

Anosognosia

A lack of awareness of impairment, not knowing that a deficit or illness exists, in memory or other function is called *anosognosia*. The term *anosognosia* refers to brain cell changes that lead to a lack of self-awareness. Credit for the term to describe being unaware of illness or deficit goes to Joseph Francois Babinski, a French neurologist, who coined the term in 1914.² The impairment may be in memory, other thinking skills, emotion, or movement.

Anosognosia – not being aware of impaired function in:

1. the memory
2. general thinking skills such as language or math skills
3. the emotions
4. body movement

Anosognosia comes from three Greek word stems, 1) “a” meaning without, 2) “nosos” meaning disease, and 3) “gnosis” meaning knowledge. Put together the word stems form “a” + “nosos” + “gnosos” (or gnosis) which forms anosognosia. Loosely translated, anosognosia means “without knowledge of disease”.^{3,4}

Anosognosia versus Denial

Anosognosia differs from *denial*. *Denial* is a strategy used to reject something that a person wants to ignore, partially avoid, or reject outright because it is too difficult or causes too much stress. The person may minimize a problem or accept part of the truth, for example, the person may accept the fact of being chronically ill but want to avoid dealing with it by not taking medicine. Sometimes a person is in denial in order to avoid taking any responsibility for an issue or situation. *Anosognosia is not denial*.

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Brain Cell Changes

Anosognosia is a condition that results from physical changes in brain cells most typically in the right front side of the brain (right pre-frontal lobes, located in the front and top part of the brain) as well as in part of the parietal lobes (just behind the frontal lobes).⁵

The condition does not seem to result from faults in hearing, seeing, touching, smelling or tasting; these sensory systems usually work well. This condition is different from a stroke that often quickly leads to impaired sensory or motor systems. The mixing of the sensory information coming into the body seems to disconnect in some way with an understanding and ability to use the information, almost as if information is not coming in or does not exist.

For example, the person may be looking at a book on the table, but not able to “see” it. The visual information has entered the eye and optic nerve (the main front nerve that carries information to the back of the brain) but the information is not being translated so that the person can understand and use the information.

The body seems unable to pay attention to or apply the information that it receives. Often the unawareness concerns the left side of the body. The person may be unaware of disabilities in motor movement, such as being unaware that the left arm is paralyzed and not showing concern about the disability.^{5,6}

Decreasing self-awareness results from brain cell changes. The changes may result from brain trauma such as a head injury from a car accident, vascular changes such as from a stroke or an ongoing brain cell decline such as seen in Alzheimer's disease or a related dementia (dementia refers to a progressive decline in memory or thinking skills and is sometimes referred to as a memory disorder). Some people in psychotic crisis experience anosognosia and are helped by psychiatric therapy including medicines.

Brain cell connections that provide us with information about a situation, the people around us, and emotions in ourselves as well as others may not work well. If we do not get complete feedback, our response to our emotions or the emotions of others may be disturbed or not appropriate. Having an emotion and then paying attention to it raises an expectation of responding or acting in some way upon the emotion.

A disconnection may result in not paying attention to the emotion, not understanding the meaning and application of the emotion, and not reacting in any way, either physical or emotional, to the emotion. It may seem as if the unaware person is without feeling when, in truth, they are not receiving any translation of what the emotion means or how they should respond with appropriate emotion.

A Rating Scale

Some researchers have developed an *Anosognosia Rating Scale* used by for health practitioners to use in order to rate the level of awareness in people.⁷ The scale considers four levels of self-awareness and is summarized below with the example of rating self-awareness of memory loss:⁷

1. easily admits memory loss
2. admits (sometimes inconsistently) to small amount of memory loss
3. not aware of any impairment in memory
4. angrily insists that no memory problem exists

Anosognosia in Alzheimer Disease

Anosognosia may occur in different progressive memory disorders. Often the progressive dementia (sometimes referred to as a progressive memory disorder) is of the Alzheimer's disease type, sometimes it fits into the category of Lewy body disease or a frontal-temporal lobar degeneration (see the web site www.AlzOnline.net for more information about Lewy body disease or frontal-temporal lobar degeneration).

When the person who has anosognosia has a health history which includes many years of heavy daily alcohol intake and no other physical findings to explain the decline, the anosognosia may be an early sign of alcoholic dementia. Sometimes in progressive dementia when anosognosia occurs early on, there also occur problems in short-term memory, decision-making and judgment. At

the same time, however, good functioning may remain in language skills, visual-spatial skills (finding ones way around and not getting lost), and math skills until much later in the course of the disease.

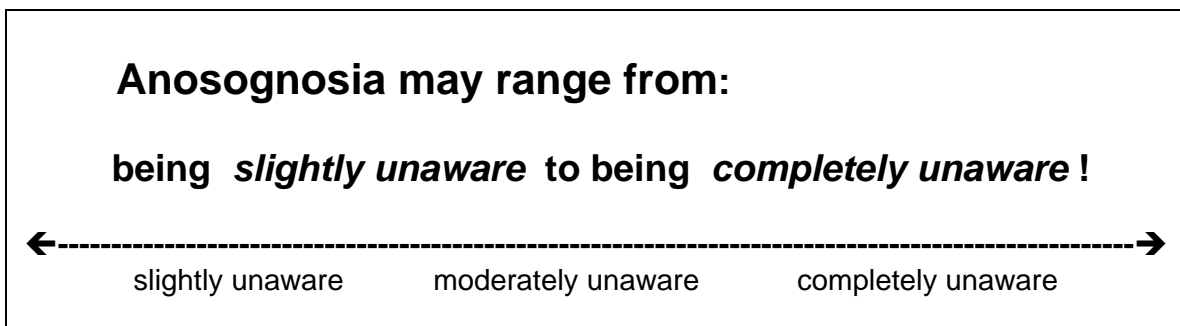
The population that is the focus of this session are people who suffer from anosognosia that results from physical changes in brain cells during the decline that is part of a progressive dementia such as Alzheimer's disease or a related dementia.

In progressive decline such as Alzheimer's disease, memory and thinking functions, such as short-term memory, difficulty recalling specific words when talking, planning an event, and making appropriate decisions, may suffer. Early on in the course of the disease the person may be aware of subtle deficits before other people become aware of them. As the disease continues, it is common among those who have a diagnosis of Alzheimer's disease to have anosognosia.⁸ Some researchers have estimated that as many as 60 % of people with Mild Cognitive Impairment⁹ and 81% of people with Alzheimer's disease have some form of anosognosia.⁷

As the dementia progresses, the anosognosia may progress. The person may be unaware that their memory is declining or that they have difficulty with routine tasks such as keeping fuel in the car and preparing fresh food and water for a pet.

Range of Self-Awareness

In anosognosia the self-awareness may range from being completely unaware to being somewhat aware of the deficits. For example, the person may not realize that there is a short-term memory problem. The person may insist that memory ability is fine. Or, the person may be somewhat aware of occasional episodes of forgetting and create an excuse such as saying, "We all forget things once in a while". The person may respond to family members who bring up the forgetfulness with the response, "Don't you forget once in a while!" The person may make the excuse that "all people over the age of 60 have problems with their memory".



Confabulation

People with anosognosia will often confabulate. Confabulation is making up an answer or responding with remarks that link pieces of information, time, places, and people that do not belong together. Sometimes people will combine memories from different events and insist that the event unfolded that way. They may describe an event as recent but it actually happened decades ago with different people. Sometimes they mix information from the newspaper or television with a personal event.¹⁰

A confabulation is not a lie. People who confabulate believe that their words are true. The response is essentially false, sometimes a mixing of past events, sometimes a mixture of past real events with imaginary details. The confabulation may be simple or hold great detail and elaboration. Sometimes the confabulation has such rich details such as describing a festive family gathering. Sometimes it is a simple, unimportant remark such as what was eaten at lunch a couple of hours before. To a stranger the remarks make sense; to the family member, who knows the person well, however, the remarks are distorted or untrue.

A confabulation is not a lie.

The purpose of the confabulation is not to mislead or lie. Typically, the person is trying to answer a question or contribute to a conversation. To those who do not know the person, the responses are reasonable, believable, socially acceptable (usually they are not outrageous or extremely bizarre), and appropriate. However, the significant other will testify that the statements are inaccurate or never occurred. People who know the individual will wonder about the confabulation because they know that the response is not accurate nor accurately reflects the normal behavior or functioning of that person. They know that the person's value system honors truth, not "tall tales", and that normally the memory is much better than the current responses indicate. Family members realize there is a problem.

The person may be self-aware of some memory problems but not completely aware of the extent of the problem...in other words they may realize that some unpaid bills have piled up, but not realize that the notices are serious about the cut-off of utility services. They may not realize that they have stopped bathing and doing laundry on a regular basis though their body odor and stained clothing reflect such neglect.

Caregiver Challenges

Anosognosia may be difficult for family caregivers because they are trying to help a person who insists there is no need for help. Not only may self-estimates of functioning be inaccurate, but people with anosognosia may overestimate their abilities to perform tasks especially when their estimates are compared with what their primary caregivers know.¹¹⁻¹³ The person with anosognosia may refuse to go for a medical evaluation. They may refuse any medical treatment.

They may become angry when others accuse them of forgetfulness, making poor decisions, making up stories, mishandling money, or not taking care of themselves. They are at risk because they may insist on driving¹⁴ and operating hazardous machines such as power tools or kitchen appliances such as a food chopper. They may not keep up with personal hygiene.

The refusals are based upon being anosognosic, unaware and convinced that there is no problem in daily functioning. They may become more spontaneous and make embarrassing or intimate comments; they may be less inhibited and start conversations with strangers without acting uncomfortable or concerned about their own behavior¹⁵.

It may be quite a challenge to provide help to a person who is unaware that abilities are changing and that help is needed. The caregivers may be expressing more concern about the deficits and about future implications than the person with anosognosia¹⁶. The person with anosognosia may not react appropriately or quickly enough to an unsafe situation; they may minimize the sense of threat to their safety¹⁶.

Interaction Tips

Providing regular assistance with daily chores, transportation, and personal care and restricting unsafe activities are important. For example, someone may need to make sure that meals are readily available, that spoiled food is discarded, and that alcoholic beverages are not accessible. The controls for operating the stove and water heater should be inaccessible. Someone should be responsible for setting the home thermostat at an appropriate temperature and then locking the thermostat so that the person who is not accurately interpreting body temperature cannot reset the room temperature at too high or too low. Soiled clothing should be laundered immediately or kept unavailable (out of sight – out of mind) until the clothing is clean.

The Checklist for Family Matters, located at www.AlzOnline.net is a useful tool to help families with planning for long-term care management. Regular respite for the family caregiver(s) is essential!

Examples of how to approach, interact and speak to someone who has anosognosia:

1. Down-size and decrease unnecessary chores and responsibilities.

Use a positive approach, such as, “It is time to plan ahead about moving to a retirement community where there are kind people and some of your friends so you have more time to do what you like, such as read and go for a walk every morning.”

Don’t use a negative approach, such as, “This house and yard are too much work for all of us. It is hard for you to take care of the house, the yard, and yourself. You need to move to a place where people are always around to help you.”

2. Partner with the person.

Use a positive approach, such as, “Let’s work together on the front porch, then go out for a nice dinner.”

Don’t use a negative approach, such as, “You really need to clean up that mess of old magazines, newspapers and piles of trash on the front porch.”

3. Focus on the person’s concern and subtly include your concern.

Use a positive approach, such as, “When you take this multi-vitamin, how about taking these “brain-vitamins” that the doctor prescribed to keep your memory strong?”

Don’t use a negative approach, such as, “The doctor prescribed these pills and you have to take them every morning.”

4. A gentle, positive voice should be part of a positive empathic approach.

Use a positive approach, such as, “To keep up with these bills, we should work as a team. I will come over on Saturday mornings with your favorite breakfast and we will write out the checks together. After you sign the checks, we will put them in their envelopes and take them to the mailbox.”

Don’t use a negative approach, such as, “You have to pay these bills on time. The utility companies have sent notices threatening to shut off the gas and electricity. I’ll handle the bills from now on.”

5. **Provide available assistance and a structured schedule of tasks including personal care, activities including chores and leisure activities, and “down-time” including a favorite activity or no activity.**

Use a positive approach, such as, “After we walk the dog, we will finish the laundry and then sit down for some of that applesauce I cooked this morning.”

Don’t use a negative approach, such as, “There is so much to do? What do you want to do this morning? We have to walk the dog, finish the laundry, and clean the kitchen. The work really piles up fast around here.”

Summary

The person who has anosognosia is unaware of deficits or the progressive decline in abilities to manage tasks and self-care. The person with anosognosia is not in denial; they have limited awareness or are unaware of the decline. When people with anosognosia confabulate, they believe what they are saying; they are not lying. Their remarks should be treated with respect, followed by a smooth transition to whatever tasks or activities need to occur next. Regular help for the home and family, planning ahead and working with a positive, partnership approach will help with the long-term, daily care management.

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