

# Alzheimer's Disease and Dementia

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## A Guide For Professionals and Caregivers



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## Purposes of this Guide:

- To define and distinguish Alzheimer’s Disease and “Dementia”
- To define abuse, neglect and exploitation, and describe the laws addressing these issues
- To provide basic information on the variety of neurocognitive disorders prevalent in our population

## What is “Dementia”?

Dementia by itself, is NOT a diagnosis. It is a term that refers to a group of symptoms. These symptoms may include:

- Memory loss
- Disorientation and confusion
- Failure of “executive functions”, such as paying bills, driving a car, planning and creating meals, etc.
- Mood and/or personality changes

Symptoms of dementia **may be treatable!** Treatable causes



for these symptoms may include:

- Dehydration
- Underactive thyroid (“hypothyroidism”)
- Vitamin B12 deficiency
- Brain tumor
- Depression
- Medication interactions and/or side effects
- Infections
- Normal Pressure Hydrocephalus (“NPH”) – treatable if addressed early by surgery to relieve the pressure of excess fluid on the brain
- Decreased oxygen or sugar levels

## ALZHEIMER'S AND LEWY BODY DEMENTIA: THE MOST COMMON TYPES OF DEMENTIA

Treatable causes should always be explored before it is assumed that the patient has an *irreversible neurocognitive disorder*! Physicians perform a thorough “head-to-toe” examination with appropriate laboratory tests and imaging studies, in order to address any of the treatable causes. Physicians also review **all** medications (prescription and over-the-counter), as well as any vitamins/supplements the patient takes to evaluate for interactions and side effects.

### What is a “Neurocognitive Disorder”?

The American Psychiatric Association advocates for the term “neurocognitive disorder” as the **alternative** to the term “dementia”. A neurocognitive disorder involves disease of the brain which produces cognitive decline.

### Irreversible Causes for Symptoms of Dementia, Irreversible Causes of Neurocognitive Decline

**Alzheimer’s disease (AD)** is recognized as the *most frequent* type of irreversible neurocognitive disorder, responsible for 60 – 80% of patients with neurocognitive impairment.

Discovered in 1906 by Dr. Alois Alzheimer, the disease results from the malfunction of two specific proteins, *beta-amyloid* and *tau*, the buildup of which causes the brain’s nerve cells (“neurons”) to die. The disease begins by affecting short-term memory. As neurons continue to die throughout the brain, a variety of symptoms appear, such

as problems with language, movement, balance, etc. Alzheimer's disease can cause death when it ultimately destroys neurons in the *brain stem*, which is responsible for heart rate and breathing.

**Lewy Body disease (LBD)** is the **second most common** irreversible neurocognitive disorder. **Lewy bodies** are protein deposits that, similar to Alzheimer's disease, cause the brain's neurons to die. Unlike Alzheimer's, Lewy Body disease is more often characterized by hallucinations (typically visual), sleep disorder (sometimes resulting in the acting out of dreams), cognition that fluctuates, and changes in gait. Also **unlike** AD, Lewy Body disease does **NOT** necessarily begin with short-term memory loss.



Though patients with AD and/or LBD may live for 20 years after diagnosis, the average is 8 – 10 years.

**Vascular dementia** results when blood circulation to the brain is poor. This may occur when the patient has generalized vascular disease and/or when the patient has had a stroke.

**Frontal Temporal disease (FTD)** occurs when Tau protein and another specific protein become malformed, and impact the frontal and temporal lobes of the brain. It is important to note that FTD may develop at a younger age than AD and LBD, and involve significant behavioral or personality changes.



**Chronic trauma** such as that resulting from contact sports (football, soccer, boxing) may also lead to neurocognitive impairment similar to that of AD, and at a younger age. This is now known as **Chronic Traumatic Encephalopathy (CTE)**. Head injuries such as those experienced by veterans of combat, automobile accidents, repeated physical abuse, gunshot wounds, etc., may also lead to neurocognitive decline.

**Down Syndrome** is noted as the most common genetic condition, affecting one of every 691 newborns in the United States. Down Syndrome results when there is a full or partial extra copy of the 21<sup>st</sup> chromosome. According to the National Institute on Aging, *“Many people with Down Syndrome have Alzheimer’s-like brain changes in their 30s that can lead to dementia in their 50s and 60s.”*

Other, less common, causes of neurocognitive decline and symptoms of dementia include:

- Huntington's disease (an inherited disorder)
- Creutzfeldt-Jakob disease ("mad cow" disease)
- Chronic alcohol abuse
- Acquired Immune Deficiency Syndrome (AIDS)
- End-stage syphilis

Challenges for caregivers include:

- The risk of **wandering** – according to the International Association of Chiefs of Police (IACP), 60 - 70% of these patients will wander from a supervised *at some point* in the course of their disease. Patients may become lost while driving, or lost on foot. Both situations represent significant risk. Those lost while driving may travel extensive distances, possibly through several states. Those lost on foot have been known to be found deceased due to drowning, being struck by vehicles, exposure to heat, or for medical reasons related to other conditions they may have.
- **Sleep** disturbances – patients may remain awake at night, needing to sleep during the day.
- **Personality** changes – caregivers may isolate themselves and the patient if concerns as to how the patient will behave in public arise. Social isolation for both results.
- **Behavioral** changes – as above, behavior may become unpredictable and in some patients be perceived as aggressive, combative, and/or sexually inappropriate.

- **Financial** costs – caregivers bear a significant cost of the care of a loved one with a neurocognitive disorder, and many must continue working as a result. Costs can reach an average of \$150,000 with families bearing more than one-third of this cost.
- **Threats** to caregivers' health – caregivers often devote **all** of their resources to the patient (physical, emotional, financial, etc.), resulting in their neglect of their own health.

The American Medical Association has maintained that caregivers who do not get support are at a 63% higher risk of dying within 4 years!

## **Communicating with a Patient with Alzheimer's Disease or Related Neurocognitive Disorder**

There are a number of *positive techniques* that will facilitate communication with patients.

One of the most important is **validation**. The patient may believe that he/she needs to go to work or to church, or "home" (even though the patient is in his/her home).





Patients with a neurocognitive disorder often perceive that they are far younger than their actual age. Their long-term memory is generally still intact, and they may “retreat” to that time of life they recall. They may want to go to the homes they remember.

When we **validate**, we accept what the patient says – we **do not** argue or correct the patient. We redirect the conversation from the patient’s starting point.

Example: The patient is pacing, appears agitated and says *“I need to get to work”*

Your response: *“Tell me about your work”, OR “What do you enjoy doing at work?”*

Example: The patient says *“I want to find my mother”*

Your response: *“Tell me about your mother”*

Sometimes, simply saying *“Tell me more”* **validates** the patient, and redirects the conversation.

Validation is recommended because it avoids agitating the patient. Instead of challenging or correcting, the patient’s thoughts and opinions are acknowledged and valued.

Additional effective communication techniques include:

- Speak to the patient at **eye level** – if the patient is sitting, sit or squat so as to be at eye level with the patient
- Speak slowly, and in a calm voice
- Avoid touching the patient or anything the patient is holding without first explaining what you are doing, and asking permission to touch

- Avoid approaching from behind
- Keep extraneous noise/lights to a minimum
- Give ample time for responses as it may take the patient longer to process what you have said or asked
- Give simple instructions, one small step at a time
- **Demonstrate** what you are asking the patient to do. If you are asking the patient to stand, pretend you are sitting – demonstrate standing up. The patient may not remember what your words mean

## Behaviors

It is vital to understand that for patients with Alzheimer’s disease or a related neurocognitive disorder (ADRD), ***all behaviors have a reason, and represent an unmet need.***

Patients may no longer be able to communicate their needs. This can lead to fear, frustration, restlessness, agitation, even combativeness, as well as the risk of wandering and becoming lost, discussed earlier.

Imagine:

- a patient who simply needs to use the bathroom, but can no longer express the need, cannot locate the bathroom, cannot unbutton/unzip clothing, etc.
- a patient who is hungry or thirsty, and can no longer find the words to ask for food or drink, or even remember what to do with these sensations.
- a patient who no longer remembers herself at her current age of 90, believes she is 50 years old, and is wanting to speak with her mother

Early in the disease process, patients may be quite adept at making it ***appear*** as though they are able to care for themselves and perform ***executive functions***, such as driving, paying their bills, preparing meals, operating the stove, etc. The patient may ***say*** that he/she can accomplish these tasks. Asking the patient to actually demonstrate such

tasks will reveal whether or not he/she can perform these executive functions and remain safe in the community.

## Medications

Medications have been of limited value in the treatment of Alzheimer's disease.

Aricept (*generic: donepezil*), Razadyne (*generic: galanatamine*), and Exelon (*generic: Rivastigmine*) are "cholinesterase inhibitors" believed to be of value when given to patients with Alzheimer's and/or Lewy Body disease *early* in the disease process. These medications may stabilize or actually improve cognitive function, however, the effectiveness may last for only a relatively short period of time. These diseases will progress.

Namenda (*generic: memantine*) is given in middle to late-stage Alzheimer's disease. Namenda is believed to slow progression of Alzheimer's disease in some patients.

Antidepressants such as Prozac (*generic: fluoxetine*), Celexa (*generic: citalopram*), and Paxil (*generic: paroxetine*) are generally prescribed for patients exhibiting signs and symptoms of clinical depression. Depression can actually intensify symptoms of dementia, making this treatment appropriate and important for patients. Some patients with ADRD exhibit hallucinations (hearing, seeing or feeling something that is not there), or delusions (an unshakeable belief that could clearly not be true).

Patients may also exhibit agitation, combativeness, extreme restlessness.

Sometimes, **psychoactive medications** are prescribed for patients with ADRD, although the Food and Drug Administration cautions that these medications carry a risk of severe side effects or death in patients with symptoms of dementia. These warnings are known as “**black box warnings**”.

Commonly-prescribed antipsychotics and antianxiety medications include:

<b>Antipsychotics</b>	<b>Risperdal</b> ( <i>generic: risperidone</i> ), <b>Seroquel</b> ( <i>generic: quetiapine</i> )
<b>Antianxiety medications</b>	<b>Ativan</b> ( <i>generic: lorazepam</i> ), <b>Xanax</b> ( <i>generic: alprazolam</i> )

Because of the risk of severe side effects or death from these medications, the **communication techniques** noted above are preferred, to help calm, or even prevent, agitation and combativeness.

Behavioral **interventions** are also preferred to the use of psychoactive medications.

For example, does the patient enjoy word search puzzles, painting, listening to music from the 1940’s, 50’s or 60’s, doing simple chores, such as folding laundry, setting the dinner table, etc.?

Activities that the patient enjoys, and which may relate to the work they did earlier in life can be very effective in **redirecting** challenging behaviors.

# **Abuse, Neglect and Exploitation of Persons with Dementia**

Chapter 415, Florida Statutes, requires that Florida's Department of Children and Families (DCF) investigate all reports received that allege *abuse, neglect or exploitation* of a vulnerable adult.

The purpose of such investigations is to determine if there is evidence that an alleged victim has been abused, neglected or exploited, and if assistance is necessary, to protect that individual's health and safety.

In such cases, a DCF adult protective investigator (API) makes face-to-face contact with the alleged victim within 24 hours of receiving an abuse, neglect or exploitation report.

If any person refuses to allow the API to access the victim, law enforcement may be called to assist.

Once access to the victim is obtained, the API will interview all persons who may have knowledge of the victim's situation, evaluate the information obtained, and make a decision as to whether the reported allegations did or did not occur.

## **DEFINITIONS** **(c. 415 Florida Statutes)**

### **Abuse**

Any willful act or threatened act by a relative, caregiver, or household member which causes or is likely to cause significant impairment to a vulnerable adult's physical, mental, or emotional health. Abuse includes acts and omissions.

**Capacity To Consent:** A vulnerable adult has sufficient understanding to make or communicate responsible decisions regarding his/her person or property, including whether or not to accept Protective Services.

**Exploitation:** A person who stands in a position of trust and confidence with a vulnerable adult knowingly, by deception, or intimidation, obtains or uses, or endeavors to obtain or use, a vulnerable adult's funds, assets, or property with the intent to temporarily or permanently deprive a vulnerable adult of the use, benefit, or possession of the funds, assets, or property for the benefit of someone other than the vulnerable adult.

**OR**

That a person who knows or should know that the vulnerable adult lacks the capacity to consent, obtains or uses, or endeavors to obtain or use, the vulnerable adult's funds, assets, or property with the intent to temporarily or permanently deprive the vulnerable adult of the use, benefit, or possession of the funds, assets or property for the benefit of someone other than the vulnerable adult.

**Neglect:** Failure or omission on the part of the caregiver or vulnerable adult to provide the care, supervision, and services necessary to maintain the physical and mental health of a vulnerable adult, including but not limited to food, clothing, medicine, shelter, supervision and medical services, which a prudent person would consider essential for the well-being of a vulnerable adult. The term "neglect" also means the failure of a caregiver of a vulnerable adult to make a reasonable effort to protect a vulnerable adult from abuse, neglect or exploitation by others. "Neglect" is repeated conduct or a single incident of carelessness, which produces or could reasonably be

expected to result in serious physical or psychological injury, or a substantial risk of death.

**Sexual abuse:** Acts of a sexual nature committed in the presence of a vulnerable adult without that person's informed consent. Sexual abuse includes, but is not limited to the acts defined in s. 794.011(1)(h), Florida Statutes, fondling, exposure of a vulnerable adult's sexual organs, or the use of a vulnerable adult to solicit for or engage in prostitution or sexual performance. Sexual abuse does not include any act intended for a valid medical purpose or any act that may reasonably be construed to be normal care giving action or appropriate display of affection.

**Vulnerable adult:** A person 18 years of age or older, whose ability to perform the normal activities of daily living, or to provide for his or her own care or protection is impaired due to a mental, emotional, sensory, long-term physical, or developmental disability or dysfunction, or brain damage, or the infirmities of aging.

**Vulnerable adult in need of services:** An adult who has been determined by a protective investigator to be suffering from the ill effects of neglect not caused by a second party perpetrator, and is in need of protective services or other services to prevent further harm.

## **Research for a Growing Epidemic**

The greatest risk factor for developing the symptoms of dementia is age, with 1 out of 3 of those over 65 years of age at increased risk, and 1 of 2 age 85 at risk.

It is estimated that in the absence of discoveries in the areas of prevention and/or effective treatment,

approximately 1.5 million Floridians will have ADRD by the year 2050. Nationally, the number is expected to reach more than 15 million.

Research efforts and clinical trials continue to search for effective treatments or a cure. Research is also directed at identifying these diseases at the earliest possible stage in the hope that treatments will be more effective.

Numerous ***risk-reducing lifestyle strategies*** are also being promoted in an effort to reduce or eliminate risk factors believed to contribute to the development of ADRD.

These include:

- not smoking (or being exposed to “second-hand” smoke)
- eating a Mediterranean diet (emphasizing fruits, vegetables, olive oil, salmon, tuna, etc.)
- continually challenging yourself to learn new things: languages, musical instruments, new types of puzzles, crafts, etc.
- staying physically active: walk, dance, swim, chair exercise
- maintaining social activities, and engaging with friends and family
- controlling high blood pressure, high cholesterol and diabetes
- getting adequate rapid eye movement (“REM”) sleep
- reducing exposure to things that stress you
- avoiding head trauma (wearing a helmet for bike-riding, always wearing vehicle seat belts, etc.)



## REFERENCES

American Psychiatric Association – position on identifying **Neurocognitive Disorders**:

[www.ncbi.nlm.nih.gov/pmc/articles/PMC3076370](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3076370)

**Down Syndrome**-general information and relationship to dementia and Alzheimer's disease:

[www.ndss.org](http://www.ndss.org)

[www.nia.nih.gov/newsroom/2015/11/nih-supports-new-studies-find-alzheimers-biomarkers-down-syndrome](http://www.nia.nih.gov/newsroom/2015/11/nih-supports-new-studies-find-alzheimers-biomarkers-down-syndrome)

**International Association of Chiefs of Police**:

[www.iacp.org](http://www.iacp.org)

**Abuse-Neglect-Exploitation** – Florida Statute:

[www.flsenate.gov/laws/statutes/2012/chapter415](http://www.flsenate.gov/laws/statutes/2012/chapter415)

Alzheimer's disease – **risk-reducing strategies**:

[www.helpguide.org](http://www.helpguide.org)

This pamphlet is produced by the Florida Department of Children and Families Adult Protective Services program in conjunction with Alzheimer's Community Care. It is provided to the APS regional offices to hand out as reference material.

To procure copies for your own use, please contact APS Headquarters by phone at (850) 488-2881 or by email to [jason.kenyon@myflfamilies.com](mailto:jason.kenyon@myflfamilies.com)

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To report abuse, neglect or exploitation of a vulnerable adult, call:

## Florida Abuse Hotline

**1-800-96-ABUSE  
(1-800-962-2873)**

TDD (Telephone Device for the Deaf):

**1-800-453-5145**

or fax:

**1-800-914-0004**



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