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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Alzheimer’s Disease and Dementia

A Guide For Adult Protective Services Workers
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WHAT IS DEMENTIA?

Dementia is a broad term for a group of symptoms that may include:

- Memory loss
- Confusion
- Disorientation
- Judgment loss
- Personality changes
- Mood changes

A person with dementia will need assistance with activities of daily living, such as dressing, eating, bathing and toileting.

Alzheimer’s Disease (AD) affects more than 5 million Americans and, worldwide, an estimated 24 million people suffer from some form of dementia.

The terms Alzheimer’s Disease and dementia are often used interchangeably in language, but there’s a distinct difference in the meaning.

Alzheimer’s is a degenerative disease characterized by the progressive death of brain cells. Alzheimer’s, which occurs equally in both genders, is the most common form of dementia – but only one of the more than 70 types of dementia.

The less publicized and next most common type of dementia, Lewy

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

Body Dementia (LBD), is the result of protein deposits known as Lewy bodies collecting in brain cells involved in thinking and movement. Research tells us that Lewy bodies are also present in the brains of some Alzheimer’s patients.

Unlike Alzheimer’s, Lewy Body Dementia occurs more among men and is more often characterized by symptoms of visual hallucinations.

Many other medical conditions can cause dementia. Parkinson’s disease, which is closely associated with LBD, Huntington’s disease or a cerebral vascular accident can result in dementia. So could alcohol abuse or vitamin deficiencies. So could a head injury.

Infectious diseases like Acquired Immune Deficiency Syndrome (AIDS), syphilis and Creutzfeldt-Jakob Disease - also known as Mad Cow Disease - might lead to dementia.

Atrophy of the brain from repeated blows to the head can cause Dementia Pugilistica. Boxers whom have died as a result of complications from this type of dementia include Sugar Ray Robinson, Floyd Patterson, Billy Conn and Jerry Quarry.

Like most dementias, there’s no cure for Alzheimer’s or LBD. Some may live as long as 20 years, but the average survival time from the appearance of first symptoms for both dementias is about eight years.

Examples of conditions that could cause a reversible dementia would be depression, vitamin B-12 deficiency and adverse effects from a medication.

For family members and caregivers, the challenges posed are enormous. People with dementia tend to wander. They tend to ask the same questions over and over. A person with dementia might sleep in the daytime and be awake all night.
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.

Due to the cognitive decline, there can be verbal outbursts, episodes of agitation, sexually inappropriate behaviors and, on rare occasions, aggressiveness.

NON-PHARMACOLOGICAL INTERVENTIONS
Most feel the best approach in caring for people with dementia is a combination of treatments and therapies tailored to the individual, with non-pharmacological interventions often being the best first-line strategies:

• Activity Therapy – aerobic exercise such as dancing can have significant health benefits. Studies show exercise during the day can reduce agitation at night. Research also reveals a reduced number of falls and improved sleep patterns with exercise.
• Reminiscence Therapy - the person with dementia is encouraged to revive the past, especially experiences
INDIVIDUALIZED TREATMENT MODALITIES

that were personally significant and optimistic. For example, a person with dementia might find relaxation in listening to an old, favorite record.

- **Art Therapy** – the effectiveness of drawing or painting on improving levels of self-esteem has been documented. Art therapy can provide meaningful stimulation and improve social interaction.
- **Music Therapy**—singing or playing an instrument can reduce agitation. So can listening to an individualized music program instead of traditional relaxation music.
- **Validation Therapy**—the idea with this therapy is to accept the beliefs of people with dementia. Since they find the present so painful, they retreat into an inner-reality based on their feelings. Using this approach, one would go along with whatever the person with dementia thinks is right, then steer the conversation toward a topic that might be less upsetting. Caregivers should not attempt this type of therapy without proper training.
- **Aromatherapy** – while not widely used, some studies show that having essential plant oils applied can reduce agitation. For instance, one study revealed less social withdrawal when a caregiver applied lotion to a resident’s arms and face twice daily. The two main oils used in aromatherapy for dementia are extracted from lavender and melissa balm.
- **Speech Therapy**—can help with poor enunciation or low voice volume. Speech therapy can also help those having swallowing difficulties.
- **Occupational Therapy**—promotes independence and socialization. OT can help people with dementia to improve their performances in activities of daily living and reduce the burden on caregivers.

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 access to 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.
“SILVER ALERT” SYSTEM FOR WANDERERS

Florida’s Department of Elder Affairs estimates that more than 500,000 people in the state have Alzheimer’s Disease. Thousands of Floridians suffer from other forms of dementia, or are cognitively impaired due to brain injuries or developmental disabilities.

Many of these people wander from the nursing home, assisted living facility or home where they reside. Some are able to gain access to a motor vehicle. If these cognitively impaired people are not found within 24 hours, statistics show more than half will suffer a serious injury or die.

In response, many states have established a “Silver Alert” program to coordinate and expedite law enforcement agencies in finding and returning the missing.

Governor Charlie Crist’s executive order for the enactment of Silver Alert in Florida in 2008 helped the push for a nationwide Silver Alert system.

Such a system would work much like the current Amber Alert system that has been so successful in finding missing children.

Costs for a nationwide Silver Alert system could be piggy-backed with the established Amber Alert system.

CONTACT INFORMATION

For more information about Alzheimer’s Disease or Lewy Body Dementia, please call:

- Lewy Body Dementia Association: 1-800-539-9767

Scientists have struggled to find pharmacological answers for dementia. Cholinesterase inhibitors donepezil (Aricept), galantamine (Razadyne) and rivastigmine (Exelon) are approved by the U.S. Food and Drug Administration (FDA) for the treatment of AD.

Cholinesterase inhibitors prevent the breakdown of acetylcholine, a chemical messenger important for memory and learning. These drugs can improve or help maintain mental function, but the effectiveness may only last for a short period of time.

Some studies suggest rivastigmine as the cholinesterase inhibitor of choice for Lewy Body Dementia and LBD-associated Parkinson’s Disease.

Memantine (Namenda) is FDA-approved for treating moderate to severe Alzheimer’s Disease. The drug blocks the action of a natural substance in the brain called glutamate, which has been linked to the dysfunctional memory process in AD.

Depression associated with dementia is usually treated with selective serotonin reuptake inhibitors (SSRIs) like fluoxetine (Prozac) and citalopram (Celexa).

Buspirone (Buspar) is often the initial medication used to treat anxiety. Benzodiazepines such as diazepam (Valium) and lorazepam (Ativan) are generally avoided because they can increase agitation, cause sedation, and possibly worsen cognitive problems.

When trying to manage the common psychiatric symptoms associated with dementia, physicians have to weigh the benefits against the risks.

- Hallucinations— are false perceptions. A person with dementia may see, hear or feel things that are not there. For instance, a person with dementia might hear a
former neighbor (auditory hallucination) talking about him, or see the face of the neighbor (visual hallucination) in his room.

- Delusions—are beliefs held that clearly are not real or true. An example of delusional thinking would be a dementia resident thinking the caregiver was a relative.

Theft delusions are fairly common due to confusion over misplaced personal items. Delusions involving life circumstance are also common. A resident of a nursing home might think she is at home or living in some other surrounding.

Infidelity is yet another common delusion that can be stressful, especially when the caregiver is the accused.

These psychiatric manifestations are evident in early stages of LBD, but they’re more likely to occur in the middle to late stages with Alzheimer’s.

The FDA currently has no specifically-approved drug interventions for treating these psychiatric symptoms of dementia, but “off-label” medications are sometimes prescribed by doctors.

Twenty percent of all drugs and 30 percent of all psychiatric drugs are prescribed off-label by physicians. When a drug is ordered for a purpose outside the scope of the drug’s approved label, the drug is being prescribed off-label.

Extreme caution has been advised when this practice is used with the dementia population.

by the middle of the century.

A positive development was the 1995 opening of The Ronald and Nancy Reagan Research Institute in conjunction with the National Alzheimer's Association in Chicago.

Former President Reagan was diagnosed with AD in 1994.

The Alzheimer’s Study Group (ASG), which was convened by Congress, announced a National Alzheimer’s Strategic Plan in March of 2009.

Among ASG’s recommendations were specific incentives for scientists who perform long-term research. But the ASG was less specific about the source of the money for the research.

Research holds the key to finding a cure for Alzheimer’s and other dementias. Is there another Alzheimer, Lewy or Nissl out there?
Alzheimer’s colleagues also included Emil Kraepelin, who is considered the founder of scientific psychiatry, and Franz Nissl, who revolutionized histological tissue staining. The Nissl Stain technique continues to be a standard in today’s labs.

Lewy, the son of a Jewish physician, fled Nazi Germany in 1933, eventually taking refuge in the United States.

Alzheimer was usually the first person back to work after lunch. He reportedly loved a good cigar and often smoked as he made rounds. Students recalled Dr. Alzheimer patiently answering each of their questions as he looked through their microscopes.

At the end of the day, Alzheimer’s partially-smoked stumps could be found next to the microscopes at the students’ histology work stations.

**DIAGNOSTIC DETECTIVES**

Doctors often have to play detective in determining what form of dementia they’re dealing with because the only definitive way to determine the diagnosis for most dementias is by autopsy.

Helpful tools for treatment are the Mini-Mental State Examination (MMSE), which quantifies a resident’s cognitive status, and the Global Deterioration Scale (GDS), which rates a resident’s cognitive function on a seven-stage scale.

**RESEARCH FOR A GROWING EPIDEMIC**

The greatest risk factor for dementia is age and, given that people are living longer now than they were 100 years ago, some experts are predicting an epidemic.

Estimates indicate as many as 15 million Americans and 100 million people worldwide will have Alzheimer’s Disease.
In 2006, the Centers for Medicare & Medicaid Services (CMS) instituted more rigorous regulations for nursing facilities to follow when anti-psychotic medications were being used. The new surveyor guidelines included gradual dose reductions for anti-psychotic medications and closer monitoring of residents for adverse effects.

**TIPS FOR FAMILY MEMBERS AND CAREGIVERS**

- Make good eye contact with the person with dementia. Good eye contact lets the person know that you’re listening and that you do care.
- Simplify the environment. At meals, keep the table settings very basic and serve one or two foods at a time.
- Maintain a calm environment. A loud television, for instance, can trigger anxiety in a person with dementia.
- Call the person by name and, when interacting, approach the person from the front.
- Provide choices whenever possible.
- Use verbal cues in conjunction with tangible objects. For example, when helping to dress a person, the staff member could hold up two pairs of pants and say: “Do you want to wear these pants or these pants?”
- Don’t interrupt when the person with dementia is talking.
- If the person is getting anxious due to having trouble finding the right word, try guessing the word for the person.
- Talk slowly and clearly and, if necessary, repeat slowly and clearly what already has been said once.
- Ask the person with dementia to point or gesture if that helps in communicating needs or concerns.
- Medical concerns should immediately be brought to the attention of the medical staff and the person’s doctor.

Behavior plans can be vastly different depending on the diagnosis. For instance, a resident with LBD would probably have more interventions planned for dealing with expected visual hallucinations.

Gwen Kaldenberg, Director of The Bresler Alzheimer’s Disease and Related Disorders Program at Menorah Manor, customizes care plans and interventions depending on the cognitive ability of the resident.

The St. Petersburg facility has one living area for residents with mild-stage dementia, separate units for persons with early- and late-stage dementia, and a palliative care unit on the grounds.

**DR. ALOIS ALZHEIMER’S DISCOVERY**

Dr. Alois Alzheimer first identified the "peculiar disease of the cerebral cortex" that later was named after him. Before an audience of psychiatrists in Tubingen, Germany, in 1906, Alzheimer described a thinned cortex speckled with unusual brown clumps, and irregular knots that appeared to be growing inside the brain cells.

Alzheimer’s findings were what he had seen in the autopsied brain of 55-year-old Auguste Deter. Deter’s case was the first documented case of AD. The wife of an office clerk, Deter’s classic symptoms of dementia had been treated by Alzheimer five years earlier at a mental asylum in Frankfurt.

The microscopic clumps and spidery knots Dr. Alzheimer referred to over 100 years ago are now called amyloid plaques and neurofibrillary tangles. They’re the hallmark signs of AD.

**ALZHEIMER’S LAIDBACK LAB**

Alois Alzheimer’s neuropathology laboratory in Munich was known for being laidback yet intensely academic. Among the remarkable array of scientific talent Alzheimer had on hand in his lab were Hans Gerhardt-Creutzfeldt and Alfons Maria Jacob, who were credited with identifying Creutzfeldt-Jacob Disease, and Lewy bodies discoverer Fritz Lewy.