

# Searching for the Lost Subject Suffering from Alzheimer's Disease

by Donald C. Cooper

When searching for subjects who might be suffering from Alzheimer's Disease, two questions that frequently arise shall serve as the focus of this paper: (1) what exactly is Alzheimer's Disease, and (2) how does one best find a lost subject suffering from Alzheimer's Disease?

## What is Alzheimer's Disease

Alzheimer's disease (pronounced Alz-hi-merz) is named after Alois Alzheimer (1864-1915), a German neuropathologist who first described the disease in 1907, and is one of a number of diseases collectively known as the "dementias" (Alzheimer's Association, 1990). Dementia is not a disease itself but a group of symptoms that characterize diseases and conditions. Dementia is commonly defined as a decline in intellectual functioning that is severe enough to interfere with the ability to perform routine activities (American Psychiatric Association, 1980).

Although there are similarities in the dementias, there are also both marked and subtle differences between the various specific diseases. Huntington's disease, Parkinson's disease, Creutzfeldt-Jakob disease, Pick's disease, and Multi-infarct Dementia (i.e., stroke or vascular) are among the many other specific dementias which can affect both the mental and physical capabilities of a patient. A number of other conditions can cause dementia or dementia-like symptoms including depression, drug reactions, thyroid disease, nutritional deficiencies, brain tumors, head injuries, alcoholism, infections (i.e., meningitis, syphilis, AIDS) and hydrocephalus.

In Alzheimer's Disease, the most common of the dementias, brain cells are damaged and/or destroyed resulting in functional impairment of the brain. The consequences of this impairment are changes in the intellect, emotions, and behavior of the affected person. However, positive diagnosis can only be confirmed after the subject's death, at autopsy by direct examination of the brain tissue. So, the phrase "Dementia of the Alzheimer's Type," or DAT, is used to describe patients who exhibit the well documented behavioral characteristics of Alzheimer's Disease (McKhann, et al., 1984).

The American Psychiatric Association (1980) describes DAT as a chronic progressive disorder in which the affected individual suffers a loss of intellectual abilities of sufficient severity to impair their social or occupational functioning. Severe memory loss, impaired judgment, and personality changes are also characteristic of the disease process. These changes are often difficult to detect and usually progress to such problems such as wandering, pacing, aggression, irritability, withdrawal, fear, and anxiety (Teri, et al., 1988).

From onset of symptoms, the life span of a person with Alzheimer's Disease can range anywhere from three to 20 or more years, but the average is eight years (Alzheimer's Association, 1995). Unfortunately, it is always fatal because the disease eventually leaves the patient less resistant to infections and other illnesses which ultimately lead to death. Toward the end, persons with the disease become totally incapable of caring for themselves.

Alzheimer's disease is the fourth leading cause of death in adults, after heart disease, cancer, and stroke, and affects woman as much as men. However, research indicates that males are more likely to be the subjects of organized searches than females (Koester and Stooksbury, 1996). Current estimates of the number of sufferers of Alzheimer's Disease is over four million in the United States at a cost—including the costs of diagnosis, treatment, nursing home care and formal or paid care—of more than \$100 billion each year alone (Alzheimer's Association, 1995).

## **Cause and Treatment**

The cause of Alzheimer's Disease is not currently known, however research would seem to indicate that there is no single responsible factor. Rather, it is likely that the disease results from a combination of factors which include genetic predisposition, abnormal protein deposits in the brain, and environmental influences (i.e., toxins and infectious agents).

While it is possible to develop strategies which deal with specific symptoms, there is currently no cure for Alzheimer's Disease and no proven treatment that reverses the disease process. However, new research findings give reason for hope. Several drugs (including tacrine or THA) are being studied in clinical trials to find out whether they can slow the progression of the disease or improve memory for a period of time. Until a cure is discovered, only thoughtful planning, in conjunction with good medical and social management, can ease the burdens on the patient and the family.

## **The Patient with D.A.T.**

Typically, but not exclusively, DAT presents in patients in their fifth and sixth decades (50 to 70 years old); however, most individuals diagnosed with DAT are older than 65. Commonly, initial symptoms are subtle and onset is gradual. The disease progresses steadily, presenting a picture of gradual deterioration over time.

The progression of DAT is divided into three stages: mild, moderate, and severe (Kahn, et al., 1960). In the mild (first) stage, the disease manifests itself by the development of absentmindedness and poor concentration accompanied by fluctuating moods. At this point the disease may not be noticed because the patient is often able to compensate for their impairment. However, the progression of the disease leads to increased memory loss, apparent carelessness and increased difficulty in performing daily tasks. While the patient may have some awareness of their failing, they typically blame others for their mistakes.

The earliest signs of DAT often appear in a scenario where the patient, visiting family or friends in unfamiliar surroundings, becomes confused only a short distance from the residence. Among mild cases of DAT, 18 to 50 percent of the patients wander (Teri, et al., 1988). The ability to judge the passage of time, which is critical to land navigation and local travel, is often a sensitive indicator of mild dementia (Koester, 1996).

In the moderate (second) stage of the disease, memory of recent events becomes increasingly poor and distant memories become affected. The patient may not be able to remember friends and relatives, their ability to make sense of surroundings is impaired, and they are unable to recognize or name familiar objects. In this stage, the ability to carry out any meaningful task becomes severely impaired as the patient's dexterity and muscular coordination is affected. Psychosis, agitation, and hallucinations are also common.

In the severe (third) and most advanced stage, the patient eventually becomes totally unable to attend to their personal needs. They exhibit complete confusion, often engage in apparently meaningless repetitive actions and/or speech, and lose control of their bladder and/or bowels. Violence is not uncommon in this stage as the patient fails to recognize his or her surroundings, friends, and relatives.

Although there is no clinical definition for wandering among the elderly (U.S. Veterans Administration, 1985), anyone with decreased cognitive ability (especially in spatial spheres) who leaves unescorted from their residence or nursing home, and away from their caregivers, is generally characterized as a wanderer, or more specifically, a "critical wanderer" (Koester and Stooksbury, 1996). Individuals prone to wandering include those subjects who are constantly disoriented, unable to comprehend when they are lost, possess better social skills, and are more active (Dawson and Reid, 1987). Such wandering is often a major problem for the families and caregivers of DAT patients in that it is difficult to either restrain or watch a potential wanderer around the clock.

## Some Search Considerations

The predictability of an individual suffering from DAT will depend to some extent on the severity of their disease. Individuals in early stages of the disease will possess greater intellectual abilities than those in whom the disease has progressed. They will usually be physically fitter, have better social skills and, thus, be able to travel further.

DAT patients, even in the initial stages, experience memory loss that progressively worsens. Thus, although the patient may wander off with the intention of visiting a familiar place, they may not remember the route or their original intention.

Reasoning and the ability to make sense of one's surroundings is also impaired in DAT patients. Thus, obvious dangers such as ditches, roads, rivers, and other obstacles may not be recognized. Likewise, patches of undergrowth or thick brush that would normally be considered impassable may be entered by a DAT patient. In addition, DAT patients may not recognize an obstacle that has been encountered, so they may make unsuccessful attempts to overcome a barrier until they become fatigued or entangled. One common characteristic of DAT patients is that they seem to go until they get stuck. So, physically fit DAT patients traveling over open areas can cover great distances. Indeed, where obstacles such as briars and streams are few, such as the western United States, DAT patients do travel farther (Koester, 1996).

A DAT patient may experience hallucinations or perceptual distortions and, therefore, not respond to reality. Due consideration should be given the individual's habits, abilities, medical history, and past practices, however this information should not be relied upon completely. DAT patients may function at a fairly high level within the confines of a familiar environment (i.e., home), but may rapidly deteriorate and become confused once they find themselves in unfamiliar surroundings.

Research conducted by Koester and Stooksbury (1992 & 1995) on DAT patients with the highest risk of harm in the state of Virginia, indicate that behaviors of patients suffering from DAT include:

- previous history of wandering
- generally unresponsive even when uninjured
- leave few physical clues concerning their location
- will attempt to travel to a former residence
- will wander across roads
- will usually be found 0.5 (0.8km) miles from point last seen (PLS), and rarely, if ever, travel further than 1.5 miles (2.4km) from the PLS

The following information was also discussed in the work of Koester and Stookesbury (1992, '95, '96) who studied 42 cases of dementia of DAT over a five year period:

- Seventy percent (70%) of the incidents took place between April and October (the frost-free period for Virginia), and most of those in the months of June, July, and August (the warmest months).
- Nearly three quarters of the incidents were in rural settings.
- There were no deaths when the patient was found within 24 hours.

- When the search resulted in a fatality, the average time to contact search and rescue resources was nearly 3.5 days.
- When the search resulted in finding an uninjured patient, the average time to contact search and rescue resources was 10.3 hours.
- Most critical wanderers succumb to the environment (i.e., hypothermia, dehydration, etc.).
- The mean distance from the PLS was 0.6 miles (0.88km), and the 90% probability zone was 0-1.5 miles from the PLS, but terrain and vegetation (barriers and obstacles) seem to affect travel distance.

With regard to searching for a critical wanderer, Koester and Stookesbury (1992, '95, '96) suggest the following:

1. A critical survival window of 24 hours exists in which the immediate and aggressive response to a missing critical wanderer is indicated, and early activation of skilled search and rescue resources is required.
2. Any delay in initiating the search for a critical wanderer will result in a greater chance of death.
3. The subject's residence/nursing home and surrounding grounds and buildings should be searched thoroughly and repeated every few hours.
4. Heavy briars, brush, and features that might normally be considered barriers must be searched well.
5. Previous local home sites and the region between home sites and the PLS must be searched well and repeatedly.
6. The use of skilled trackers and search dog teams are valuable hasty resources when applied at the PLS.
7. A strong and thorough investigation will go far in determining if the subject used transportation to leave the area and what might be attractive to the subject based on their earlier life experiences (i.e., previous residence, family, etc.).

Generally, when DAT is recognized and confirmed in a lost subject, it may be dangerous to make any presumptions regarding their behavior. But, as more is learned on how these patients act and react in specific situations, searchers will be able to take more appropriate measures.

For more information on this important topic, contact the Alzheimer's Association at 800-272-3900 or visit their web page at <http://www.alz.org/>. Additional information on Alzheimer's research and SAR can be obtained through the SAR web page of Robert Koester at <http://avery.med.virginia.edu/~rjk5a/sar.htm>.

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## Glossary of Terms

In learning about what constitutes Alzheimer's Disease, many confusing and often complex terms may be discovered by those searching for answers. It is in the interest of flattening this learning curve that the following definitions are offered.

*Acetylcholine* - A neurotransmitter that appears to be involved in learning and memory. Acetylcholine is severely diminished in Alzheimer's disease.

*Alzheimer's disease (AD)* - A progressive, neurodegenerative disease characterized by loss of function and death of nerve cells in several areas of the brain leading to loss of cognitive function such as memory and language. The cause of nerve cell death is unknown. Alzheimer's disease is the most common cause of dementia.

*Amyotrophy* - muscle wasting due to loss of muscle innervation.

*Apathy* - Indifference, lethargy, or general lack of emotion or feeling.

*Aspartate* - A neurotransmitter; aspartate can be an excitotoxin.

*Ataxia* - unsteady and inexact movement typically associated with cerebellar or brainstem dysfunction.

*Athetosis* - writhing movement.

*Autosomal dominant* - inherited by 50% of offspring of both sexes.

*Axons* - the "arm" of a nerve cell that normally transmits outgoing signals. Each nerve cell has one axon, which can be over a foot long. A nerve cell communicates with another nerve cell by transmitting signals from the branches at the end of its axon.

*Behavioral symptoms* - in Alzheimer's disease, the symptoms that relate to action or emotion, such as wandering, depression, anxiety, hostility, and sleep disturbances.

*Bradykinesia* - excessively slow, overly deliberate motions.

*Calcium* - an element taken in through the diet that is essential for a variety of bodily functions, such as neurotransmission, muscle contraction, and proper heart function. Imbalances of calcium can lead to many health problems, and excess calcium in nerve cells can cause their death.

*Calcium channel blocker* - a drug that blocks the entry of calcium into cells, thereby preventing cell death and loss of function caused by excess calcium. Calcium channel blockers are used primarily in the treatment of certain heart conditions and stroke, but are being studied as potential treatments for Alzheimer's disease.

*Caregiver* - the primary person in charge of care of an Alzheimer patient, usually a family member or a designated health care professional.

*Cell* - the fundamental unit of all organisms; the smallest structural unit that is capable of independent functioning.

*Cell body* - in nerve cells, this is the central portion containing the cell nucleus, from which axons and dendrites sprout. The cell body is primarily concerned with carrying out the life-sustaining functions of a cell.

*Cell membrane* - the outer boundary of the cell; the cell membrane helps control what substances enter or exit the cell.

*Central nervous system (CNS)* - one of the two major divisions of the nervous system. Composed of the brain and spinal cord, the CNS is the control center for the entire body.

*Cerebellar ataxia* - unsteady and inexact movement typically associated with cerebellar dysfunction.

*Cerebral cortex* - the outer portion of the brain, consisting of layers of nerve cells and the pathways that connect them. The cerebral cortex is the part of the brain in which thought processes take place. In Alzheimer's disease, nerve cells in the cerebral cortex die.

*Chelation* - the process of binding and removing metal ions from the body. Chelation is used to treat metal poisoning, such as lead poisoning.

*Choline* - a natural substance required by the body that is obtained from various foods, such as eggs; one essential component of acetylcholine.

*Choline acetyltransferase (CAT)* - an enzyme that controls the production of acetylcholine; appears to be depleted in the brains of Alzheimer patients.

*Cholinergic system* - the system of nerve cells that uses acetylcholine as its neurotransmitter; nerve cells in the cholinergic system are damaged in the brains of Alzheimer's patients.

*Cholinesterase* - an enzyme that breaks down acetylcholine to stop its action.

*Chorea* - dance-like adventitious fragments of normal movement in an abnormal context, usually movements of limbs. A hyperkinetic movement disorder (see choreoathetosis)

*Choreoathetosis* - a constant writhing and jerking motion, a hyperkinetic movement disorder due to dysfunction of the basal ganglia.

*Clinical trial* - carefully controlled studies to test the value of various treatments, such as drugs or surgery for disease, in human beings.

*Cognitive symptoms* - symptoms that relate to disorders in thought processes, such as learning, comprehension, memory, reasoning, and judging. These symptoms are prominent features of AD. See cognitive symptoms section for further explanation.

*Critical Wanderer* - anyone with decreased cognitive ability (especially in spatial spheres) who leaves unescorted from their residence or nursing home, and away from their caregivers.

*D.A.T.* - abbreviation for "Dementia of the Alzheimer's Type." The American Psychiatric Association (1980) describes DAT as a chronic progressive disorder in which the affected individual suffers a loss of intellectual abilities of sufficient severity to impair their social or occupational functioning

*Dementia* - Alzheimer's Disease, Pick's Disease, Lewy Body Disease and other related disorders that are characterized by progressive deterioration of cognitive functions of sufficient severity to interfere within an individual's daily functioning that will eventually lead to death.

*Dendrites* - branched extensions of the nerve cell body which receives signals from other nerve cells. Each nerve cell usually has many dendrites.

*Dominant Inheritance* - inherited by 50% of offspring of both sexes.

*Dopamine* - a neurotransmitter that is essential for normal movement, such as walking. The brains of Parkinson's disease patients are deficient in dopamine.

*Dorsal interosseous spaces* - the spaces between the finger which normally contain small hand muscles. These muscles shrink when denervated and make the hand look "skeletal."

*Dysphagia* - trouble swallowing.

*Dystonic* - abnormal posture, usually of the neck or limb, often twisted.

*Electromyogram* - a diagnostic recording of the electrical activity of muscles made with fine needles inserted into muscles and then recorded on an oscilloscope.

*Enzymes* - proteins produced by living organisms that promote or otherwise influence chemical reactions.

*Excitotoxin* - a chemical substance that can damage and kill nerve cells by overstimulating them.

*Fasciculations* - small visible muscle twitches.

*Festinating gait* - a shuffling rapid short stepped gait with the feet sliding on the ground, typical of Parkinsonism.

*Glutamate* - a neurotransmitter that is normally involved in learning and memory. Under certain circumstances it can be an excitotoxin, and appears to cause the death of nerve cells in a variety of neurodegenerative disorders. Early research has shown that glutamate may cause nerve cell death in AD, and further research is being performed to learn more about its possible role in AD.

*Hippocampus* - a part of the brain that is important for learning and memory.

*Hyperreflexia* - increased reflexes.

*Hypertonia* - increased muscle tone or involuntary resistance to motion.

*Monoamine oxidase (MAO)* - an enzyme that breaks down certain neurotransmitters, including dopamine, serotonin, and noradrenaline.

*Monoamine oxidase inhibitor (MAOI)* - a drug that interferes with the action of monoamine oxidase, slowing the breakdown of certain neurotransmitters. Used in the treatment of depression.

*Multi-infarct dementia (MID)* - also known as vascular dementia, this form of dementia is caused by a number of strokes in the brain. These strokes can cause specific symptoms, depending on their severity and location, and can cause general symptoms of dementia. MID cannot be treated; once the nerve cells die, they cannot be replaced. However, the underlying condition leading to strokes (e.g., high blood pressure, diabetes) can be treated, which may help prevent further damage.

*Multiple sclerosis (MS)* - a neurodegenerative disease that damages myelin, the insulation that controls the movement of electrical signals along axons. MS patients show a variety of symptoms (such as loss of coordination, slurred speech, and dizziness), depending on where in the central nervous system the degeneration occurs.

*Nerve cell (neuron)* - the basic working unit of the nervous system. The nerve cell is typically composed of a cell body containing the nucleus, several short branches (dendrites), and one long arm (the axon) with short branches along its length and at its end. Nerve cells send signals that control the actions of other cells in the body, such as muscle cells.

*Nerve growth factor* - a protein that promotes nerve cell growth and may protect some types of nerve cells from damage, including nerve cells in the cholinergic system.

*Neuritic plaque* - abnormal cluster of dead and dying nerve cells, other brain cells, and protein. Neuritic plaques are one of the characteristic structural abnormalities found in the brains of Alzheimer patients. Upon autopsy, the presence of neuritic plaques and neurofibrillary tangles is used to positively diagnose AD.

*Neurodegenerative disorder* - a type of neurological disease marked by the loss of nerve cells (i.e., Alzheimer's, Parkinson's disease).

*Neurofibrillary tangle* - accumulation of twisted protein fragments inside nerve cells. Neurofibrillary tangles are one of the characteristic structural abnormalities found in the brains of Alzheimer patients. Upon autopsy, the presence of neuritic plaques and neurofibrillary tangles is used to positively diagnose Alzheimer's disease.

*Neurological disorder* - disturbance in structure or function of the central nervous system resulting from developmental abnormality, disease, injury, or toxin.

*Neuropeptide Y* - a substance that sometimes functions as a neurotransmitter. Some research shows that neuropeptide Y may be involved in Alzheimer's disease.

*Neurotransmitter* - specialized chemical messenger (e.g., acetylcholine, dopamine, norepinephrine, serotonin) produced and secreted by nerve cells that sends a message from one nerve cell to another. Neurotransmitters play different roles throughout the body, many of which are not yet fully understood.

*Neurotransmitter system* - a group of nerve cells that use the same neurotransmitter to communicate.

*Norepinephrine* - a neurotransmitter that plays a role in mood, pain, and possibly learning and memory. Norepinephrine may be involved in Alzheimer's disease.

*Nucleus* - a large body within cells that contains DNA, the genetic material.

*Osteoarthritis* - a degenerative wear-and-tear inflammation of the joints associated with time and age characterized by hypertrophy of the joint and pain; common in distal finger joints and hips.

*Palpebral fissures* - margins of the eyes. Narrowed palpebral fissures would produce a squint; the opposite would be wide eyed.

*Paresthesia* - skin sensations that feel like bugs crawling on the skin, etc.

*Parkinson's disease* - a progressive, neurodegenerative disease characterized by the death of nerve cells containing the neurotransmitter dopamine in a specific area of the brain; the cause of nerve cell death is unknown. Parkinson patients have such symptoms as tremors, speech impediments, movement difficulties, and often dementia.

*Peripheral nervous system (PNS)* - one of the two major divisions of the nervous system. Nerves in the PNS connect the central nervous system (CNS) with sensory organs, other organs, muscles, blood vessels, and glands.

*Progressive dementia* - Alzheimer's Disease, Pick's Disease, Lewy Body Disease and other related disorders that are characterized by progressive deterioration of cognitive functions from month to month that will eventually lead to death.

*Receptor* - In the nervous system, a site on a nerve cell that receives a specific neurotransmitter; the "message receiver."

*Receptor agonist* - a substance that mimics a specific neurotransmitter, is able to attach to that neurotransmitter's receptor, and thereby produces the same action that the neurotransmitter usually produces. Drugs are often designed as receptor agonists to treat a variety of diseases and disorders when the original chemical substance is missing or depleted.

*Serotonergic system* - the system of nerve cells that uses serotonin as their neurotransmitter.

*Serotonin* - a neurotransmitter that plays a role in mood, sleep, and pain. Serotonin may be involved in sleep.

*Somatostatin* - a substance that sometimes functions as a neurotransmitter. Some research indicates that somatostatin may be involved in Alzheimer's disease.

*Strokes* - damage to a group of nerve cells in the brain as a result of interrupted blood flow; usually caused by a blood clot or blood vessel bursting. Depending on the area of the brain that is damaged, a stroke can cause coma, paralysis, speech problems, and/or dementia.

*Subdural hematoma* - a collection of blood beneath the dura mater but external to the arachnoid mater; usually due to trauma.

*Synapse* - the junction where a signal is transmitted from the axon of one nerve cell to the dendrite of another nerve cell, usually by a neurotransmitter.

*Synaptic vesicles* - small sac located in the area of nerve cell axons that contain neurotransmitters. During activity the vesicles release their contents at the synapse, and the neurotransmitter stimulate receptors on other cells.

*Toxin* - a substance that can cause illness, injury or death. Toxins are produced by living organisms.

*Volitional saccade* - voluntary eye movements.

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(Sidebar) **Ten Warning Signs of Alzheimer's Disease**

To help you know what warning signs to look for, the Alzheimer's Association has developed a checklist of common symptoms (some of them may also apply to other dementing illnesses). An individual who exhibits several of these symptoms should see a physician for a complete evaluation.

1. **Memory Loss That Affects Job Skills** - It's normal to occasionally forget assignments, colleagues' names, or a business associate's telephone number and them later. Those with a dementia, such as Alzheimer's disease, may forget things more often, and not remember them later.
2. **Difficulty Performing Familiar Tasks** - Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of the meal. People with Alzheimer's disease could prepare a meal and not only forget to serve it, but also forget they made it.
3. **Problems with Language** - Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute inappropriate words, making his or her sentence incomprehensible.
4. **Disorientation of Time and Place** - It's normal to forget the day of the week or your destination for a moment. But people with Alzheimer's disease can become lost on their own street, not knowing where they are, how they got there or how to get back home.
5. **Poor or Decreased Judgment** - People can become so immersed in an activity that they temporarily forget the child they're watching. People with disease could forget entirely the child under their care. They may also dress inappropriately, wearing several shirts or blouses.
6. **Problems with Abstract Thinking** - Balancing a checkbook may be disconcerting when the task is more complicated than usual. Someone with Alzheimer's disease could forget completely what the numbers are and what needs to be done with them.
7. **Misplacing Things** - Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer, or a wristwatch in the sugar bowl.
8. **Changes in Mood or Behavior** - Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit rapid mood swings—from calm to tears to anger—for no apparent reason.
9. **Changes in Personality** - People's personalities ordinarily change somewhat with age. But a person with Alzheimer's disease can change, becoming extremely confused, suspicious, or fearful.
10. **Loss of Initiative** - It's normal to tire of housework, business activities, or social obligations, but most people regain their initiative. The person with Alzheimer's disease may become very passive and require cues and prompting to become involved.