

A Comprehensive Resource for Family Caregivers

acetylcholine: Key chemical in neurons (brain cells) that acts as a neurotransmitter and carries information between two brain cells. It is involved in several functions including cognition, emotion, sensation and arousal. Some of the memory and cognitive symptoms of Alzheimer's disease and Lewy body dementias are commonly attributed to a loss of acetylcholine producing neurons.

acetylcholinesterase inhibitor (AChEI): Medication that increases the level of acetylcholine in the brain by inhibiting the function of substances which break down acetylcholine. These drugs can decrease some cognitive symptoms of dementia. They may also be used for treatment of agitation and hallucinations. Also called *cholinesterase inhibitor or anticholinesterase*.

action tremor: Rhythmic involuntary movement of a limb when movement is initiated to achieve a goal, such as when writing or picking up an object.

activities of daily living (ADL): Activities necessary for everyday living such as eating, bathing, grooming, dressing, mobility and toileting. People with dementia or movement disorders may not be able to perform these functions without assistance. Disability is sometimes measured by these limitations.

adult daycare: Supervised location where adults can go during the day for activities, socializing, education, physical therapy and health care. These services can provide valuable respite time for a caregiver. They offer participants opportunities to interact with others, usually in a community center or facility. Staffing at these facilities can include Registered Nurses (also

TIP: Definitions for words displayed in blue can be found in this glossary

called an RN), Certified Nursing Assistants (CNA), physical (PT) and occupational therapists (OT).

advance directives: Legal documents pertaining to the treatment preferences and the designation of a surrogate decision-maker in the event that a person becomes unable to make medical decisions on his or her own behalf. Advance directives generally fall into three categories: living will, power of attorney and health care proxy.

adverse drug reaction: Unexpected, negative reaction to a drug. The onset of the adverse reaction may be immediate or develop over time. Also termed *adverse effect or adverse event*.

agitation: Excessive motor or behavioral activity associated with a feeling of anxiety and restlessness. This may include wringing of the hands, pacing, and removing clothes and putting them back on or repetitious utterances and ruminations. In more extreme cases, the individual may be physically aggressive against others or injure themselves. Also can be called *psychomotor agitation*.

agitated depression: Clinical diagnosis of major depressive disorder with the addition of restlessness and agitation.

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agnosia: Loss of ability to recognize persons, objects, sounds, or smells without any significant dysfunction in the senses.

akathisia: Movement disorder characterized by unpleasant feelings of inner restlessness and a compelling need to be in constant motion. It is most often caused as a side effect of some antipsychotic drugs or from symptoms of Parkinson's disease and related disorders.

akinesia: Reduced or absence of normal, spontaneous, voluntary, bodily movements.

alpha-synuclein: Primary chemical/protein component of Lewy bodies and also a normal protein found in various regions of the brain.

Alzheimer's disease: Progressive neurodegenerative disease of the brain that includes impairment in memory, judgment, decision making, orientation to physical surroundings, and language. It is the most common form of dementia in the western world.

ambulatory: Capable of walking and moving about without assistance.

ambulatory care: Medical care including diagnosis, observation, treatment and rehabilitation that is provided on an outpatient basis. Ambulatory care is given to persons who are able to visit the doctor's office, whether walking in or using a wheelchair.

amnesia: Any of several types of memory impairment, involving loss of memory, difficulties in recalling old memories, and/or storing new memories.

amyloid: An aggregation of proteins that can be deposited in tissues including the brain, as in Alzheimer's disease.

anhidrosis: Complete or partial lack of the ability to sweat. This may be a symptom of numerous disorders, including as a result of nerve damage in conditions such as diabetes, small cell lung cancer, Parkinson's disease, and Lewy body dementias.

anosmia: Temporary or permanent lack of ability to smell. There are numerous causes including the common cold, head trauma, exposure to toxins, Down's syndrome, Alzheimer's disease, Parkinson's disease, and Lewy body dementias.

anticholinergic: A medication that reduces the effect of acetylcholine in the brain. They are often used to reduce cramps and spasms in smooth muscles such as the stomach, intestines, or bladder, and also tremors in the limbs and body.

anticholinesterase: See acetylcholinesterase inhibitor.

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antidepressants: Medication or substance used to treat depression. The most common pharmaceutical antidepressants include MAOIs, tricyclyics and SSRIs.

antipsychotic drug: Medication which can treat hallucinations, delusions and agitations. Also known as neuroleptic drugs. LBD patients can have severe neuroleptic sensitivity to antipsychotic drugs, with possible worsening of symptoms and increased mortality rate.

anxiety: Abnormal, sometimes overwhelming sense of apprehension and fear often marked by physical symptoms such as sweating, muscle tension, and increased heart rate.

anxiolytic: Medication used to treat the symptoms of anxiety.

apathy: Lack of emotion, social withdrawal, and general lack of interest.

aphasia: Deterioration of language function, which can affect the ability to produce and/or understand language. It is a severe form of dysphasia.

apraxia: Inability to perform a voluntary motor movement despite being able to physically perform the movement. Apraxia is caused by dysfunction in the brain that affects the ability to perform the required movements in the correct sequence.

apraxia of speech: Speech disorder characterized by an inability to speak clearly and consistently. It is not due to dysfunction of the muscles involved in speaking, but with the neurological coordination of these muscles.

assisted living facility: Type of long-term care facility for elderly or disabled individuals who require assistance with some activities of daily living, but do not need full-time nursing care. These facilities may be part of a retirement community or a nursing home and offer private or semi-private rooms or apartments.

ataxia: Unsteady and uncoordinated voluntary motor activity due to the brain's failure to coordinate the movements. Ataxia is usually a consequence of disease in the brain, specifically in the cerebellum. It is distinct from muscle weakness.

atrophy: Wasting away of a body part or tissue. Muscle atrophy is wasting of muscle and can be visibly seen through a decrease in muscle mass. Brain atrophy results from the loss of brain cells. Limited atrophy of both muscle and brain can be a normal part of aging. It is more severe in diseases of the muscle and brain.

attention deficit: Difficulty in sustaining attention.

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atypical antipsychotic drug: Newer generation of antipsychotic drugs differing from typical antipsychotic drugs in their pharmacalogical action. LBD patients can have severe neuroleptic sensitivity to antipsychotic drugs, with possible worsening of symptoms and increased mortality rate.

auditory hallucination: Hallucination involving the sense of hearing.

aura: Symptoms that occur before a migraine or seizure that most often involve visual disturbances, such as the perception of lights, lines, shimmering, distortions in the appearance of objects, or blind spots in the field of vision. Disturbances in other senses can also occur, such as auditory or olfactory hallucinations, as well as somatic symptoms, including numbness or tingling, weakness, and nausea.

autonomic nervous system: Part of the peripheral nervous system which regulates mainly involuntary processes of the body including heart rate, digestion, breathing, salivation, and perspiration. The autonomic nervous system has two divisions: the sympathetic nervous system and the parasympathetic nervous system.

basal ganglia: Region of the brain responsible for a variety of functions including motor control, learning, and cognition. The basal ganglia are abnormal in a number of conditions including Parkinson's disease and Huntington's disease.

benzodiazepine: Drugs that have various depressive properties, such as anti-anxiety, hypnotic, muscle relaxant, anti-convulsant, or amnesiac.

Binswanger disease: Rare form of dementia caused by widespread vascular lesions to areas of white matter in the brain. The lesions are caused by damage to the blood vessels that reach the deeper areas of the brain. Also called *subcortical vascular dementia* and *subcortical leukoencephalopathy*.

biomarker - A biological feature (often in blood, spinal fluid or brain imaging) that can be used to diagnose a disease, measure its progress, or the effects of treatment.

black box warning – The strongest warning issued by the U.S. Food and Drug Administration, required to be included on prescription package inserts when medical studies indicate a prescription drug carries a significant risk of serious or even life-threatening adverse effects. It is so named for the black border that surrounds the text of the warning.

bradykinesia: Slowness of movement.

brain stem: Area at the base of the brain which connects the brain to the spinal cord, thus relaying all neural information to and from the rest of the body and the brain. It provides motor and sensory control of the face as well as basic bodily functions such as the regulation of breathing, heart rate, and the sleep cycle.

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Capgras syndrome: Delusionary belief that a person, usually a close relative or friend, has been replaced by a similar-looking imposter. It most commonly occurs as a symptom in brain disorders such as schizophrenia or dementia. Also called *Capgras delusion*.

case management: Term used to describe formal services planned by care professionals. The coordination of a written plan of action for a patient, often performed by a social worker or other health care professional. Dementia patients often require case management in order to receive the best care from the multiple health care professionals involved.

central nervous system (CNS): Part of the nervous system consisting of the brain and spinal cord.

cerebellum: Portion of the brain in the back of the head below the cerebrum and behind the brain stem. The cerebellum primarily controls motor movements and coordination, and is involved in the processing of some cognitive functions.

cerebral: Pertaining to the brain, the **cerebrum** or the intellect.

cerebral cortex: The outer portion of the cerebrum responsible for complex processes such as problem solving, attention, perception, advanced motor function, language, and memory.

cerebrospinal fluid (CSF): Watery fluid, continuously produced and absorbed, which flows around the surface of the brain, the spinal cord, and within their cavities.

cerebrovascular: Referring to the system of blood vessels and arteries that supply blood to the brain (cerebral=brain and vascular=blood vessels).

cerebrovascular disease: Changes in the **cerebrum** as a result of diseases of the blood vessels supplying it.

cerebrum: Largest part of the brain. It is divided into the left and right hemispheres. It is located above the cerebellum and brainstem.

cholinesterase: Enzyme responsible for breaking down the neurotransmitter acetylcholine.

cholinesterase inhibitor: See acetylcholinesterase.

clinical psychologist: Non-MD professional specializing in diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems. Unlike a psychiatrist, a psychologist cannot prescribe medication but instead relies on other methods such as talk therapy or cognitive behavioral therapy.

clinical psychology: Professional specialty concerned with diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems.

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clinical trials: Federally regulated and closely monitored studies designed to evaluate the effectiveness and safety of medications or medical devices by monitoring their effects on large groups of people.

cognition: Process of being aware, knowing, thinking, learning and judging.

cognitive: Pertaining to cognition.

Computerized Axial Tomography (CAT or CT): Type of scanning that utilizes X-ray images with the aid of a computer to generate cross-sectional views of an internal organ or bodily tissues. In dementia cases, CT scans of the brain are sometimes used to support the diagnosis.

competency: Legal term describing the mental or cognitive capacity of an individual to participate in legal proceedings.

COMT inhibitors: Medication which inhibits the action of the enzyme Catechol-O-methyl transferase (COMT). COMT is responsible for degrading the neurotransmitters dopamine, epinephrine, and norepinephrine.

confabulation: Type of memory impairment occurring in dementia and other disorders in which a person spontaneously makes up answers to questions they cannot answer. This may involve false memories or even seeing things that are not actually present.

conservator: Person responsible for making decisions about personal matters for the conservatee, including decisions about medical care, food, clothing, and residence. Under a probate conservatorship, the conservator may not place the conservatee into a locked mental institution against his or her will.

convalescent home: See nursing home.

cortex: Outer layer of the cerebrum and cerebellum which are parts of the brain.

Creutzfeldt-Jakob disease: Very rare and fatal degenerative disease of the brain, generally characterized by a rapidly progressive dementia and gradual loss of muscle control. Also called *Jakob-Creutzfeldt disease*.

deep brain stimulation (DBS): Surgical procedure used to treat symptoms of neurologically based disorders such as Parkinson's disease, obsessive compulsive disorder, depression or chronic pain. A brain pacemaker is implanted and sends electrical impulses to specific regions of the brain known to cause the symptoms.

delusion: A false and irrational belief or gross distortion of reality. Different themes of delusions can involve grandeur, jealousy, or paranoia.

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delusional misidentification syndrome: Category of disorders in which an individual falsely believes that a person, object or place has been modified or replaced. Examples include the belief that a person's own mirror reflection is really that of another person, or that a familiar place has been replaced by an identical duplicate. Capgras syndrome is also another example of a delusional misidentification syndrome.

dementia: Progressive loss of cognitive abilities such as memory, attention, language, and motor skills, due to disease or damage to the brain, and of sufficient severity to impair daily functioning. It most often occurs in elderly populations, and Alzheimer's disease is the most common cause of dementia. The other most common causes of dementia are Lewy body dementias (includes dementia with Lewy bodies and Parkinson's disease dementia), vascular dementia, and frontotemporal dementia. Before this diagnosis, less common and often reversible causes of cognitive changes include brain injury, brain tumors, drug toxicity, encephalitis, and meningitis need to be evaluated and excluded.

Dementia–capable: Medical professionals who are skilled in working with people with dementia and their caregivers. They are knowledgeable about the kinds of services that may help them as well as know which agencies and individuals provide such services.

dementia with Lewy bodies (DLB): See Lewy body dementias.

depressant: Medication or substance depressing the activity of the central nervous system, resulting in calmness, slowed breathing, reduction in anxiety, muscle relaxation, and sleepiness. Examples of depressants include benzodiazepines, alcohol, anesthetics, and anticonvulsants. Also known as a sedative or sedative-hypnotic.

depression: General term describing a prolonged feeling of sadness and decreased mood, often serious enough to affect a person's daily functioning. Individuals may also have a loss of interest in previously enjoyable activities, a feeling of helplessness, difficulty sleeping, poor appetite, and weight loss. See also *agitated depression, dysthymia*, and *major depression*.

disinhibition: Difficulty or lack of ability in preventing an impulsive behavior.

dizziness: General term describing feelings include a loss of balance, lightheadedness, unsteadiness and vertigo. There are many possible causes including disturbances of vision, brain trauma, inner ear infection, sleep deprivation, and sudden changes in blood pressure.

dopamine: One of the primary neurotransmitters in the brain, it is involved in several functions including movement, cognition, motivation, and pleasure. The motor symptoms of Parkinson's disease and Lewy body dementias are commonly attributed, at least in part, to a loss of dopamine producing neurons.

dopamine agonist: Medications which mimics the action of the neurotransmitter dopamine, activating dopamine receptors. They are often used to treat Parkinson's disease.

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drug induced parkinsonism: Symptoms of Parkinson's disease caused as a side effect of medications used to treat other conditions, which is usually reversible.

durable power of attorney: Type of advance medical directive in which legal documents provide the power of attorney to another person in the case of an incapacitating medical condition. The durable power of attorney allows another person to make bank transactions, sign Social Security checks, apply for disability, or simply write checks to pay the utility bill while an individual is medically incapacitated.

dysarthria: Speech disorder where speech is slow, slurred, and distorted. Other voice qualities may also be affected, such as pitch, loudness, and rhythm. It is usually caused by some form of neurological injury, such as stroke or Parkinson's disease.

dysautonomia: Abnormal functioning of the autonomic nervous system.

dyskinesia: Abnormal involuntary muscle movements. Dyskinesias can occur as a side effect of certain medications such as levodopa and antipsychotic medications.

dysphagia: Difficulty in swallowing, caused by problems in the muscles used in swallowing and/or the parts of the brain responsible for controlling these muscles.

dysphasia: A speech disorder in which there is impairment in the expression and comprehension of spoken or written language. The term aphasia, although traditionally reserved for more severe forms of dysphasia, is sometimes used in order to avoid confusion with the similarly pronounced with dysphagia.

dysphonia: A general term for different types of dysphonias, where an individual has an impairment in speaking such as hoarseness or weakness of the voice. A common form of dysphonia is spasmodic dysphonia. In dysphonias, the problem lies in the vocal cords, producing changes in the "musical" aspect of speech, rather than in the articulation, which is produced by the pharynx, tongue and lips.

dysphoria: A term for a reduced and uncomfortable mood state, characterized by depression, anxiety, and/or restlessness.

dyspnea: Difficult or painful breathing; shortness of breath.

dysthymia: A chronic, long-lasting form of depression, though less severe than major depression.

dystonia: Neurological condition involving involuntary muscle contractions that can cause sometimes painful, repetitive, twisting motions, and abnormal intermittent or sustained postures.

early-onset familial Alzheimer's disease: Alzheimer's disease that occurs at an unusually early age, onset under 65, and affects some individuals in every generation.

end stage: Final phase in the course of a terminal illness.

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elder law attorney: Attorney who practices in the area of elder law, which is a specialized area of law focusing on issues typically affecting older adults.

essential tremor: Most common form of tremor when shaking occurs in a part of the body, usually the hands, during an intentional movement or maintaining of a posture (e.g. holding a coffee cup). An individual with this condition is otherwise normal.

euphoria: Persistent and intense sense of well-being.

excessive daytime somnolence (EDS): Tendency to fall asleep intermittently during the day. In LBD, EDS is generally categorized by two or more hours of sleep during the day, despite sufficient sleep at night.

executive dysfunction: Problems in the executive functions of the brain, which include attention, organization, problem solving, and decision making.

explicit memory: Memory in which there is need for conscious recollection in order to recall something, such as an event in the past or an appointment. This type of memory can decline with age and in dementia.

facial affect: Emotion as conveyed by facial expression. See mask-like face.

familial: Tending to occur at a higher rate among family members than expected by chance alone. A familial disease may be due to genetic or environmental factors, whereas "hereditary" refers to genetic factors only.

festinating gait: A gait abnormality in which a person holds their head and neck bowed forward, and walks with short, rapid steps which often accelerate as the person has trouble stopping. Also known as *propulsive gait*.

fluctuating cognition: Unexplained waxing or waning in thinking skills, abilities and alertness, such as episodes where the individual cannot focus his or her attention, has excessive sleepiness during the day, speaks incoherently for a time, or is temporarily unable to do a familiar task. These unexplained episodes are followed by a return to better or nearly normal abilities, speech and alertness.

flushing: Reddening of the skin, typically over the face or neck. A flush is usually temporary and can be brought on by an emotion such as excitement, anger or embarrassment, or a physiological cause such as fever or exercise. It may also be caused by various diseases, medications or other substances. Flushing is an involuntary (uncontrollable) response of the autonomic nervous system leading to the widening of capillaries in the involved skin.

Foley catheter: Flexible plastic tube inserted into the bladder to provide drainage of urine on a continuous basis.

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frontal lobe: Area in the front of the brain involved in complex functions such as attention, decision making, motivation and drive, classifying and categorizing, emotion, personality, and social behavior.

frontotemporal dementia: A form of dementia affecting the frontal lobe and temporal lobes of the brain. Pick's disease is a type of this dementia.

gait: Manner of walking.

geriatric care worker: Professional working in the health field, such as a social worker, nurse, gerontologist or counselor with specialized knowledge and experience related to the elderly.

geriatric psychiatrist: Psychiatrist (M.D.) with special training in the diagnosis and treatment of mental disorders and behavioral complications occurring in older adults.

geriatric medicine: Branch of medicine concerned with the prevention, diagnosis, and treatment of disease in the elderly.

geriatrician: A medical doctor who specializes in geriatric medicine and works directly with elderly patients.

gerontologist: A professional, often a researcher, who specializes in gerontology, the study of aging and its consequences, and typically does not work directly with patients, like a geriatrician.

gerontology: Study of the aging process including physical, mental and social changes.

glutamate: Main excitatory neurotransmitter in the brain.

guardian: Legally appointed individual who is authorized to make financial and legal decisions for another individual.

gustatory hallucination: Hallucination involving the sense of taste.

hallucination: A hallucination is the perception of something in any of the five senses that is not actually there. See also auditory hallucination, gustatory hallucination, hypnagogic hallucination, somatic hallucination, tactile hallucination and visual hallucination.

healthcare proxy: Form of advance directive. It is a legal document in which a person, called an agent or proxy, is granted power of attorney over a patient, thus having authority to make medical decisions in case of incapacitation. A healthcare proxy goes into effect when the attending physician determines that the patient lacks the capacity to make their own decisions.

hereditary: Genetically transmitted from parent to child.



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home health agency: Organization that provides home health care.

home health care: In-home health care services, such as disease management, nursing care, physical therapy, occupational therapy, and speech therapy. Assistance with every day activities may also be provided, such as with activities of daily living, shopping, transportation, and housekeeping. In the United States, home health care is covered under Medicare Part A and Medicare Part B, provided it is prescribed by a physician. Durable medical equipment is also covered when provided by a home health agency.

hospice: Program or facility that provides hospice care to patients near the end of their life.

hospice care: Supportive care provided to patients in the final phase of a terminal illness where focus is on the relief of disease symptoms, general comfort, and quality of life, rather than curing the disease itself. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. The philosophy of hospice care is to provide a combination of medical, social, psychological, and spiritual support to the patient. Hospice care may take place in the patient's home, a hospital, hospice center, or nursing facility. It differs from palliative care in that it is specialized for those in the terminal stages of their illness.

Huntington's disease: Degenerative brain disease involving jerky, uncontrolled movements and cognitive impairments in areas such as memory, spatial skills, and executive dysfunction. It is a hereditary disease and the child of an affected individual generally has a 1 in 2 chance of also being affected.

hypnagogic hallucination: Vivid dreamlike hallucination occurring at the onset of sleep.

hypnopompic hallucination: Vivid dreamlike hallucination on awakening.

hypokinesia: Abnormal decrease or slowness in muscular movement.

hypophonia: Abnormally weak voice due to uncoordination of the muscles involved in voice production.

idiopathic: Of unknown cause.

illusions: Perception that objects appear differently than is actually the case.

implicit memory: Type of memory without conscious awareness of the recollection. It is an automatic form of memory, such as knowing how to tie one's shoelaces or ride a bicycle. It may survive largely unimpaired even though the individual's explicit memory declines with age or through dementia.

incontinence: Inability to control bodily excretions. Urinary incontinence is the inability to control the excretion of urine. Fecal incontinence is the inability to control bowel movements. Both forms may be caused by a dysfunction in the neural control of the muscles involved in urination (e.g., in dementia), in



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the muscles themselves or may be due to inadequate care. Urinary incontinence can also be caused by a physiological action, such as coughing or laughing.

insomnia: Sleeping disorder characterized by difficulty falling asleep, waking up frequently during sleep, difficulty returning to sleep, and/or waking up too early. Daytime sleepiness, fatigue, and restless can occur as a result of poor quality sleep.

intention tremor: Tremor occurring or made worse when a person attempts voluntary movement.

instrumental activities of daily living (IADLs): Activities not necessary for basic functioning, but required for independent living, such as writing, driving, managing money, or using a telephone.

irritability: A state of excessive emotional sensitivity and response. A person may become easily stressed, frustrated, or angry.

kinesthetic hallucination: Hallucination involving the sense of bodily movement.

late onset Alzheimer's disease: Most common form of Alzheimer's disease usually occurring after age 65.

Lewy bodies: a spherical body seen under a microscope, caused by clumping of proteins, primarily alpha-synuclein. They are seen as an inclusion or protein aggregations in the brains of patients with Parkinson's or LBD.

Lewy body dementias (LBD): The second most frequent type of degenerative dementia in elderly adults in the developed world, LBD is an umbrella term for two related diagnoses, 'Parkinson's disease dementia' and 'dementia with Lewy bodies.' It is a neurodegenerative disorder associated with abnormal structures (Lewy bodies) found in certain areas of the brain. These structures and many of the symptoms of LBD are associated with Parkinson's disease and may also co-exist with Alzheimer's disease. Researchers do not yet understand whether dementia with Lewy bodies is a distinct clinical entity or perhaps a variant of Alzheimer's or Parkinson's disease. Recent research has revealed that Lewy bodies contain deposits of a protein called alpha-synuclein that is also linked to Parkinson's disease and multiple system atrophy. Symptoms can range from typical parkinsonian symptoms, such as loss of spontaneous movement, rigidity, tremor, and shuffling gait, to those experienced in Alzheimer's disease, such as confusion, loss of memory, and loss of, or fluctuating cognition. Visual hallucinations may be one of the first symptoms noted and patients may suffer from other psychiatric disturbances such as delusions and depression. Disturbed sleep patterns with nightmares and abnormal behavior may also occur. May also be referred to as Lewy body disease, dementia with Lewy bodies, Parkinson's disease dementia, diffuse Lewy body disease, and Lewy body variant of Alzheimer's.





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licensed clinical professional counselor (LCPC): Mental health professional trained in the application of psychotherapy.

lilliputian hallucination: Hallucinations in which people, animals, or objects are perceived as smaller than they would be in reality. Often associated with confusion ("delirium") that occurs during a severe systemic illness (e.g., pneumonia) or as a reaction to a medication.

living will: Legal document in which a person requests specific instructions as to their medical treatment in case they are incapacitated.

long term care (LTC): Various rehabilitative, restorative, and/or ongoing skilled nursing care given at home or medical facility for people with chronic disability or illness.

long term care facility (LTCF): Facility that provides long term care to patients in need of assistance with activities of daily living. Long-term care facilities may be in hospitals, nursing homes, rehabilitation facilities, or inpatient behavioral health facilities.

long term memory (LTM): Brain system meant to permanently store, manage, and retrieve information for long term use. Information stored as long term memory may be available anywhere from a few days to a lifetime. Examples of long term memory include facts and events from a person's past (e.g., place of birth), as well as the knowledge to perform a certain skill or function, such as playing a musical instrument or riding a bicycle.

major depression: Severe and persistent state of decreased mood and sadness, sometimes including suicidal thoughts. It seriously affects an individual's ability to function in daily activities. Individuals can also have a loss of interest in previously enjoyable activities, a feeling of helplessness, difficulty sleeping, poor appetite, and weight loss.

magnetic resonance imaging (MRI): Medical imaging technique designed to produce images of internal structures of the body using a magnetic field. The image and resolution is often more detailed than other older imaging methods such as CT scans, and also does not subject the patient to radiation.

managed care: Any system that manages healthcare delivery with the aim of controlling costs and improving quality of care. Organizations that provide managed care typically negotiate agreements between healthcare providers and patients to offer health care benefits to individuals.

MAO inhibitor: Class of antidepressant drugs usually used to treat depression. They can also be used to treat Parkinson's disease by inhibiting the breakdown of dopamine.

mask-like face: Expressionless face with little or no sense of animation, often seen in Parkinson's disease. Also known as *Parkinson's facies*.



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Medicaid: A healthcare program in the United States managed by individual states to provide healthcare to individuals with insufficient income and resources. Both the federal government and states provide funding to Medicaid programs.

Medicare (Canada): Unofficial name for Canada's publicly-funded universal health care program.

Medicare (United States): Government health insurance program for individuals 65 years of age or older, or for those who both have specific conditions such as kidney failure or amyotrophic lateral sclerosis and other qualifications, usually eligible for other government programs.

Medicare Part A (United States): Medicare program that covers inpatient hospital stays.

Medicare Part B (United States): Medicare program that covers outpatient services, such as physician and nursing services, and some medical tests.

Medicare Part C (United States): Option for those enrolled in Medicare Part A or B to receive their health benefits through a private insurance plan.

Medicare Part D (United States): Medicare program that covers prescription medications, for anyone enrolled in Part A or B.

medication management: Program for prescribing, storing, administering and/or reminding a patient of medication.

Medigap (United States): Private health insurance plans that are intended to supplement Medicare benefits and fill the gaps in healthcare coverage.

memory: Process of storing and recalling information about past events or knowledge. Some disorders, such as dementia, damage the systems that control memory. Usually long-term memory is retained early on while short-term memory is lost. Normal memory function is necessary to recognize familiar people or places. See also explicit memory, implicit memory, short-term memory, long-term memory, and working memory.

memory span: The number of items, usually words or numbers, that a person can recall. A typical test may include a series of numbers, given at approximately one per second, in increasing lengths. The individual's working memory is gauged on how many numbers they can accurately recall immediately following the presentation of numbers.

Mini Mental State Examination (MMSE): Brief exam performed by a health care professional to determine the level of a person's basic cognitive skills, such as attention, memory, language use, and comprehension. The test is often used to screen for dementia, where lower scores, on a scale of 30, correlate to a stronger degree of cognitive impairment.



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mood stabilizer: Medication typically used to treat symptoms such as mania and agitation in bipolar disorder.

multiple system atrophy (MSA): Degenerative neurological disorder characterized by a combination of damage to the autonomic nervous system, causing symptoms such as incontinence, dry mouth, and low blood pressure when standing, and Parkinsonian symptoms, including slow, slurred speech, and loss of muscle coordination.

musical hallucination: Rare form of auditory hallucination in which music is heard. It is often music that is familiar to the person. It typically occurs in older individuals with existing conditions such as hearing impairment and epilepsy.

National Institutes of Health (NIH): United States government health agency devoted to medical research. It consists of approximately 20 separate organizations each devoted to a particular medical area, including the National Institute of Mental Health, National Institute of Neurological Disorders and Stroke, and National Institute on Aging, and is responsible for a large portion of all medical research funding.

National Institute of Mental Health (NIMH): One of the component organizations of the National Institutes of Health, whose focus is on understanding, preventing and treating mental health conditions and disorders. The NIMH conducts and funds studies related to the genetics, neuroscience, and psychiatry of mental health, as well as clinical trials.

National Institute of Neurological Disorders and Stroke (NINDS): A component organization of the National Institutes of Health, the NINDS's mission is to reduce the burden of neurological disease by conducting and supporting research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke.

National Institute on Aging (NIA): A component organization of the National Institutes of Health, whose aim is to better understand the process of aging to extend and support healthy and active years of life. The NIA supports and conducts research on better understanding aging, age-related diseases, and other needs specific to the elderly.

nerve: A bundle of fibers that uses chemical and electrical signals to transmit sensory and motor information from one part of the body to another.

nerve cell: See neuron.

nervous system: Complex network of the brain and neurons spread throughout the body, responsible for both cognition, involuntary functions such as heart rate, and voluntary functions such as movement. Composed of the central nervous system and peripheral nervous system.



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neurofibrillary tangles: Abnormal bundles of proteins, predominantly the tau protein, found in the neurons of those with Alzheimer's disease and other similar conditions.

neurodegenerative: Relating to or characterized by degeneration of nervous system tissue.

neuroleptic: Term referring to antipsychotic medications.

neuroleptic drugs/neuroleptics: See antipsychotic drug.

neuroleptic malignant syndrome (NMS): Rare neurological disorder caused by an adverse reaction to neuroleptic drugs, characterized by high fever, unstable blood pressure, muscular rigidity, and autonomic dysfunction. In severe cases, NMS can be fatal. People with LBD who are treated with neuroleptics are at risk for developing NMS.

neuroleptic sensitivity: An adverse reaction or event to a neuroleptic drug such as Parkinson-like side effects including rigidity, immobility and difficulties with posture. Individuals with Lewy body dementias have particularly high, sometimes fatal, neuroleptic sensitivity.

neurological: Having to do with the nervous system.

neurologist: Physician who specializes in diagnosing and treating disorders pertaining to the nervous system.

neurology: Medical specialty dealing with the diagnosis and treatment of disorders of the nervous system (the brain, the spinal cord, and nerves).

neuron: Nerve cell that sends and receives chemical and electrical signals within the body and brain. Neurons are the core components of the brain.

neuropathologist: Pathologist who specializes in the diagnosis of diseases of the brain and nervous system by direct examination of tissue, obtained either by biopsy in a live patient or from tissue obtained after death at autopsy.

neuropathy: Any kind of disease or malfunction of the peripheral nerves.

neuropsychiatrist: Psychiatrist who specializes in both neurology and psychiatry, and specifically with psychiatric disorders attributable to diseases of the nervous system.

neuropsychologist: Psychologist who has completed special training, and specializes in diagnosing brain disorders using a complex set of neuropsychological tests.

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neuropsychological test: Any type of test used to assess of cognitive function known to be associated with specific parts of the brain. The degree of impairment of a certain skill is used to determine the location and extent of injury in the brain.

neurotransmitter: Chemical that transfers from one neuron to another cell, causing it to either augment or decrease the activity of the receiving neuron. It is thought to be the primary way that neurons communicate with each other in the brain.

NMDA antagonist: Class of drugs which inhibit the action of N-methyl d-aspartate (NMDA). They are mainly used as anesthesia for animals and sometimes for humans. Certain NMDA receptor antagonists such as memantine can be used to treat dementia.

nurse, licensed practical (LPN): Nurse who has completed a one or two year training program in health care and earned a state or national license. Usually under the supervision of a physician or registered nurse, LPNs can provide general patient care in a clinical setting such as a hospital or also for people with chronic illness, in a home health care setting. LPNs are known as *state enrolled nurses* in England and Australia.

nurse, licensed vocational (LVN): Term for a licensed practical nurse in California and Texas.

nurse practitioner (NP): Registered nurse (RN) who has completed an advanced training program, usually a master's degree. NPs can work in a variety of settings and may provide many of the functions of a physician such as being the primary care provider of health care and prescribing medication. Also may be called *advanced registered nurse practitioner* (ARNP).

nurse, registered (RN): Nurse who has completed a two to four year degree program in nursing, and provides direct patient care in a clinical setting such as a hospital or also for people with chronic illness, in a home health care setting. RNs may further specialize in a particular area. For example, psychiatric nurses are RNs with special training in working with mental illness, and trauma nurses work with physicians to help patients in a hospital emergency room.

nursing home: Residential care facility for people with chronic illness or disability, particularly older people who may require assistance with mobility and activities of daily living. Also called a *convalescent home*, long term care facility or a skilled nursing facility.

nursing assistant (CNA): Individual who has completed a brief health care training program, and provides routine care to patients and assistance to RNs and LPNs.

occupational therapist (OT): Professional who works with anyone who has a permanent or temporary impairment in their physical or mental functioning, in order to assist them in performing daily activities and help develop the skills required to sustain independent living and maximize quality of life.

olfactory hallucination: Hallucination involving the sense of smell.

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ombudsman: A person, usually appointed by the government, who investigates complaints and mediates settlements, often between members of the public and an institution or corporation.

orthostatic hypotension: A form of low blood pressure occurring after a person stands up, often after prolonged rest. The change in position causes a temporary reduction in blood flow to the brain and symptoms which include dizziness, lightheadedness, blurred vision and fainting. May also be called postural hypotension.

palilalia: Speech in which a word or syllable is repeated, often sounding like stuttering.

palliative care: Care designed to relieve the symptoms of a disease and provide general improvement in quality of life for the patient, but not to cure or change the path of the disease. Palliative care services can be provided to a patient at any stage of an illness, in an inpatient or outpatient setting.

parasympathetic nervous system (PNS): Part of the autonomic nervous system that is responsible for slowing the body's response to stimuli, or calming the body. Among other functions, the PNS slows the heart rate, stimulates digestive activity, constricts the pupils, and relaxes the sphincter muscles.

Parkinson's disease (PD): A complex progressive neurological disease characterized initially by motor symptoms, such as rigidity, resting tremor, slowed movements, and postural instability. Other symptoms include speech difficulties, as well as some non-motor symptoms, including slowed reaction time, executive dysfunction, and sleep disturbances. Dementia can also occur in PD, which is called Parkinson's disease dementia (PDD). PD is caused in part by a loss of neurons that produce the neurotransmitter dopamine, thought to play an important role in the motor symptoms.

Parkinson's disease dementia (PDD): See Lewy body dementias.

parkinsonism: Symptoms that resemble Parkinson's disease, whether from Parkinson's itself, a similar degenerative disorder such as LBD or multisystem atrophy, or as side effects of a medication (e.g., antipsychotics). Also known as *Parkinsonian syndrome*.

parkinsonian: Describes the symptoms of parkinsonism or Parkinson's disease, although the individual may or may not be diagnosed with Parkinson's disease

peripheral nervous system: Division of the nervous system, a network of nerves outside the brain and spinal cord responsible for bodily movements and sensations, as well as regulating heart beat, blood pressure, and organ function.

Pharm.D (Doctor of Pharmacy): Professional degree required to become a registered pharmacist.

physical therapy (PT): Branch of rehabilitative medicine in which a patient employs special exercises and equipment in order to maintain and improve functional movement, whether from injury, disease, aging, and/or other factors.





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physician assistant (PA): Health professional who has completed a 2 year physician assistant program and works as a practitioner under the supervision of a licensed physician.

Pick's disease: Rapidly progressive form of frontotemporal dementia. Individuals with Pick's disease have abnormal deposits called Pick bodies inside the neurons of affected regions of the brain.

plaques: Complex brain pathology typically observed in Alzheimer's disease. Composed of abnormal protein deposits (particularly the amyloid beta protein) surrounded by abnormally distended processes of neurons ("neurites").

positron emission tomography (PET): Imaging method use to view the metabolic activity of various bodily functions. The patient is injected with a short-lived radioisotope, whose emissions are picked up by the PET scanner, which in turn creates images of functional processes within the body. PET is used most frequently in oncology, neurology, and cardiology. PET can assist in diagnosing types of dementia by localizing regions of decreased metabolism in the brain.

postural instability: Inability to maintain a correct posture in either a standing or sitting position.

power of attorney: An authorization to act on someone else's behalf in a legal or business matter.

progressive: Gradual increase in scope or severity and typically not reversible.

progressive supranuclear palsy (PSP): Rare neurologic disorder characterized by problems with motor and eye movement. Symptoms include frequent falls and difficulty looking down with the eyes. Often misdiagnosed as Parkinson's disease. Non-motor symptoms include depression, apathy, and dementia. Symptoms are caused by the development of neurofibrillary tangles in various regions of the brain. Also known as Steele-Richardson-Olszewski syndrome.

propulsive gait: See festinating gait.

protein: Large molecule composed of one or more chains of amino acids in a specific order determined by the genetic coding for the protein. Proteins are fundamental components of cells and can serve many functions, required for the proper functioning of a living organism.

psychiatrist: Physician (M.D.) who specializes in the prevention, diagnosis, and treatment of mental illnesses. Psychiatrists have a graduate degree earned from four years of medical school and have received additional training in a supervised residency. They may also have additional training in a subspecialty, such as neuropsychiatry or geriatric psychiatry. Psychiatrists typically work in a clinical setting and differ from psychologists in that they can prescribe medication.

psychologist: The most common type of psychologist, a clinical psychologist (PhD), is a professional specializing in the prevention, diagnosis, and treatment of psychological conditions. Psychologists have earned a graduate degree from a four to eight year program which typically includes a supervised





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internship. In a clinical setting, they may rely on methods such as psychotherapy and counseling more than a psychiatrist. Psychologists may also work strictly in a research setting, investigating the functioning of the mind, cognition and behavior. They receive more intensive training than other mental health professionals, such as social workers (MSW) or master's level counselors.

psychomotor: Of or relating to movement or muscular activity associated with mental processes.

psychopharmacology: The study of medications that have an effect on mood, behavior, or cognition. Medications include antidepressants, stimulants, anxiolytics, antipsychotics, mood stabilizers, and depressants.

psychosis: Symptoms such as hallucinations, delusions, changes in personality, unusual displays of emotion, disorganized thinking, and other behaviors that significantly impact the person's ability to carry out the activities of daily living.

psychosocial: Referring to both a person's psychological and social behavior.

rapid eye movement sleep (REM): One of the stages of sleep, characterized by rapid eye movements. Dreams occur during REM sleep. Electrical activity from the brain at this stage is characterized by rapid, low-voltage brain waves, and resembles that of the waking state more than in other stages of sleep. Heartbeat and breathing can also be irregular. During normal REM sleep the person is paralyzed except for the eye movements and the muscles involved in breathing.

receptor: Structure on a cell that receives various molecules, such as neurotransmitters, hormones, or pharmaceuticals, which subsequently modify the cell's activity.

REM sleep behavior disorder (RBD): Disruption of normal sleep paralysis, which relaxes the muscles during REM sleep. As a result, an individual may move excessively and even act out their dreams, sometimes resulting in injury to themselves or a bed partner.

resting tremor: Tremor occurring at rest that diminishes or ceases during voluntary movement.

retropulsion: Spontaneous loss of balance causing the patient to start uncontrollably walking backwards while trying to stand in one place. Similar to festinating gait, but moving backwards instead of forward and more often leading to falls.

rigidity: Increased muscle tone which results in resistance to passive movement.

Safe Return: Alzheimer's Association nationwide identification, support and registration program that assists in the safe return of individuals with Alzheimer's or other related disorders who may wander and become lost.

sedative: See depressant.





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short term memory: Brain system for temporarily processing and storing recently acquired information.

skilled nursing facility (SNF): Institution providing elderly and younger disabled people with daily medical care, rehabilitation, and general assistance with activities of daily living.

sleep apnea: Temporary pauses of breathing during sleep, which can result in low oxygen levels, poor sleep quality, and fatigue or excessive sleepiness during the day.

SNRI (Serotonin-norepinephrine reuptake inhibitor): Class of antidepressant which increases levels of both serotonin and norepinephrine. It used to treat depression and other mood disorders such as anxiety and obsessive-compulsive disorder.

somatic hallucination: See tactile hallucination.

somnolent: Sleepy or drowsy. See also excessive daytime somnolence.

spasmodic dysphonia: Voice disorder characterized by involuntary movements of the muscles of the voice box, resulting in interruptions of speech and/or a voice with a tight, strained quality.

spatial disorientation: Difficulty interpreting the geometric relationship between items in the environment, which may result in problems navigating in both familiar and unfamiliar surroundings.

SPECT scan: Single Photon Emission Computed Tomography, an imaging procedure in which a gamma camera rotates around the patient and takes two-dimensional images from multiple angles, which a computer then uses to form a three-dimensional image. A short-lived radioisotope can be used for functional imaging, to assess metabolic function in a specific part of the body, such as the heart or brain.

speech therapy: Treatment of speech defects and disorders, especially through use of exercises and audio-visual aids that develop new speech habits. Also known as speech language therapy.

SSRI (Selective serontonin reuptake inhibitor): Common class of antidepressant used to treat depression and anxiety. SSRIs function by reducing the reabsorption of serontonin by certain nerve cells in the brain.

stimulant: Class of medication used to increase alertness and awareness. Stimulant effects commonly include increased heart rate, blood pressure, and respiration rate.

substantia nigra: Small region in the brainstem which is darkly pigmented (hence the term "nigra") containing neurons that produce dopamine and whose destruction is associated with the motor aspects of Parkinson's disease.



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sundowning: Symptom of dementia, where an individual becomes increasingly confused, disoriented or agitated, occurring from late in the day into the night

sympathetic nervous system: Part of the autonomic nervous system which accelerates the heart rate, constricts blood vessels, and raises blood pressure.

synapse: Specialized junction between two neurons at which a neuron communicates with another using neurotransmitters.

syncope: Sudden, momentary loss of consciousness often due to a lack of blood and oxygen to the brain, but can also be associated with other disorders such as epilepsy. Also called *fainting*.

tactile hallucination: Hallucination involving the sense of touch, where there is the false perception of a physical sensation occurring in or to the body. Also called *somatic hallucination*.

tau protein: Normal protein found commonly within the brain. When this protein stops folding properly, they may form neurofibrillary tangles, which are involved in the development of Alzheimer's disease and several other neurodegenerative diseases.

transient global amnesia: Sudden, short-term episodes of amnesia usually lasting less than 24 hours, when there is an inability to recall recent events and form new memories.

tremor: An abnormal, unintentional, repetitive shaking of a part of the body. It can be due to multiple causes such as neurological disease, stress, and/or medication. See also *action tremor*, *essential tremor*, *intention tremor*, *resting tremor*.

vascular dementia: Common form of dementia in older persons that is caused by vascular lesions in the brain. Symptoms may be visible after a single stroke, multiple smaller strokes, or a narrowing of the blood vessels in the brain. Symptoms are generally similar to those of other dementia disorders and can include confusion and agitation, problems with language and memory, personality and mood changes, incontinence, and motor difficulties such as unsteady gait and walking in rapid, shuffling steps. Vascular dementia also frequently coexists with Alzheimer's disease. It affects more men than women and risk increases with age.

visual hallucination: Hallucination involving the sense of sight.

visuospatial dysfunction: Difficulty in interpreting geometric relationships between objects in space and/or drawing complex images such as intersecting pentagrams.

wanderer: Person with dementia, who walks, seemingly aimlessly due to confusion, agitation, and/or memory problems.

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working memory: System meant to temporarily store and manipulate information for short term use. This system may be impaired early on in Parkinson's disease, even in the presence of intact short term memory.

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SOURCES:

<u>www.medicinenet.com</u> MedicineNet.com is an online, healthcare media publishing company with an online medical dictionary and medications directory.

<u>www.thefreedictionary.com</u> An online dictionary of medical and legal terms <u>www.alzinfo.org/glossary/glossarywords.aspx</u> Fisher Center for Alzheimer's Research Foundation <u>www.alz.org</u> Alzheimer's Association

