

Terms and Definitions that may be Helpful for Family Caregivers

Activities of Daily Living (ADL): Eating, bathing, grooming, going to the toilet. What allows you to function independently and be self-sufficient.

Advance Directive: a legal document that says what kind of medical treatment a person wants or doesn't want if/when they're in a state where they can't communicate

Ambulatory: The ability to walk.

Analgesic: Medication that is often available without prescription; used to treat pain; also includes "stronger" prescription medications

Chronic: A condition that is long term or consistent that will need to be managed for 6 months or more

Custodial Care: Non-medical care that helps individuals with bathing, dressing and other basic care that most people normally do themselves, such as using eye drops.

Competence: In a legal sense, a person's ability to understand information, make a choice based on that information and communicate that decision in an understandable way.

Continence: The ability to control bladder and bowel function.

Delirium: Short-term confused thinking and disrupted attention usually accompanied by disordered speech and hallucinations. It is potentially reversible but is a sign of a vulnerable brain/ at higher risk for dementia down the road.

Disability: Any medical condition that results in functional limitations that interfere with an individual's ability to perform his or her normal work and results in limitations in major life activities. Typically, disabilities become long-term and are not fully reversible.

Do Not Resuscitate (DNR) Order: signed by a doctor based on a patient's wishes, instructs medical personnel to not perform life-saving CPR or other procedures to restart the heart or breathing once they have ceased. Once signed, the DNR directive should be placed in the patient's chart. An accessible copy should be kept available in your personal records such as a scan to the internet.

Febrile: A term used when a fever is involved.

Home health aide: Individual who provides mainly non-medical healthcare to people at home. Typical services include assistance with activities of daily living, managing medications, and some household tasks.

Hospice Care: Focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Typically, it is expected that the patient has less than 6 months to live.

Hypertension: High blood pressure.

Instrumental Activities of Daily Living (IADL) – Activities that are important for daily life but do not involve personal care such as meal preparation, housekeeping, money management, communication, medication management and transportation.

Intractable: Difficult to cure or alleviate. Typically long term and not fully reversible.

International Units (IU): Another way of measuring out medication (besides in milligrams.) Ex. 1000 I.U. of Vitamin D.

Living Will: A written statement detailing a person's desires regarding their medical treatment in circumstances in which they are no longer able to express informed consent, especially an advance directive. This should not just be a DNR but preferably a "philosophy" of how the person wants their medical care to be handled. Ex. No feeding tube in the event of a severe stroke.

Medicaid: A government health insurance program for low-income individuals and those living with disabilities.

Medicare: A federal system of health insurance for people over 65 and for certain younger people living with disabilities

Over-The-Counter (OTC): Any medication/supplement/herbal preparation etc. available without a prescription

Palliative Care: This type of care is focused on providing relief from the symptoms and stress of illness(es). The goal is to improve quality of life and remaining time for both the patient and the family. Hospice is one type of this care, but it also can be given at the same time as treatment to try to cure/control a disease. Palliative care has no time limit and can be given over years to decades. Ex. A patient with early stage dementia

Sentinel Event: An adverse health event that could have been avoided through appropriate and medically necessary care. Often a marker of severe underlying disease. Ex. A stroke related to high blood pressure.

Sundown Syndrome (sundowning): A state of confusion that occurs later in the afternoon and into the night. It is most often found in patients who have dementia or Alzheimer's disease and includes a range of behaviors such as increased confusion, anxiety, agitation and sleeplessness.

Surrogate: An individual appointed to act in place of another; to act in the best interest of the patient, as if the patient were able to whisper in your ear from the days they were fully capable.

Terminal: A condition that is incurable or fatal.

Vertigo: A term to describe a sensation of dizziness or light-headedness.

Dementia Specific Terms and Definitions

Dementia: An umbrella term for any type of memory or cognitive impairment that progresses over time and interferes with daily functioning and abilities.

Agnosia: Loss of the ability to identify objects or people.

Anomia: Loss of ability to recall names of objects or people.

Aphasia: Loss of the ability to speak, write, and/or understand language

Apraxia: The loss of the ability to perform tasks that require remembering patterns or sequences of movements - giving a salute.

Atrophy: A loss of cells in the brain and the connections between them. The brain "shrinks".

Lewy Body Dementia: When protein deposits, called lewy bodies, develop in brain cells in regions involved in thinking, memory, and movement. Individuals with LBD may experience visual hallucinations and changes in alertness and attention and changes in behavior.

Parkinsonism: A set of several clinically recognizable neurological features, characterized by tremor, decreased bodily movement, rigidity, and postural instability/imbalance.

Parkinson's Disease Dementia: A decline in thinking and reasoning that develops in many people living with long standing Parkinson's disease.

Contractures: Shortenings of tendons and muscles round the joints that may cause the knees, arms, hands, and feet to curl up.

Mild Cognitive Impairment (MCI): The stage between the expected cognitive decline of normal aging and the more serious decline of dementia. It is characterized by problems with memory, language, thinking, or judgement. They can no longer do the things that they could easily do in the past without difficulty.

Alzheimer's Specific Terms and Definitions

Alzheimer's: A type of dementia that affects memory, thinking, and behavior. Symptoms eventually grow severe enough to interfere with daily tasks. This is a terminal disease and is not curable.

Amyloid: A protein found in the brains of people with Alzheimer's that build into plaques/ "lumps".

Amyloid plaques: hard, accumulations of amyloid proteins that clump together between the nerve cells (neurons) in the brains of Alzheimer's patients.

ApoE gene: A gene that may have mutations that lead to an increased risk of Alzheimer's (the ApoE4 gene)

Dysphasia: Being unable to find the right word or the meaning of a word.

Mini-Mental State Examination: A short test used to measure a person's basic memory skills. These skills include short term memory, long term memory, speaking, and writing.

SPECT scan: A type of nuclear imaging test that allows a doctor to analyze the functions of an internal organ, commonly the brain.

Tau: A protein in the body that aids in stabilizing other proteins that support the structure and shape of neurons and cellular transportation.

Neurons: Fundamental units/cells of the brain and nervous system that are responsible for receiving sensations from the external world and for sending motor commands to muscles. These cells make the brain "tick".

Cholinesterase inhibitors (Medications such as Aricept, Exelon, Razadyne): Usually prescribed to treat early to moderate stages of Alzheimer's. Treats symptoms related to memory, thinking, language, judgement, and other thought processes. These drugs at best are only moderately effective.

Memantine (Namenda): Usually prescribed for moderate to severe stages of Alzheimer's. It may improve memory, attention, reasoning skills, language, behavior and the ability to perform simple tasks. It can be used alone or with other Alzheimer's disease treatments.

Care Facility Specific Terms and Definitions

Accredited Facility: a care facility that provides The Joint Commission (JTO/ a federal oversight/ regulatory agency) levels of care. It can be a nursing home, hospital, etc.

Activity Director: someone who plans activities such as singing, art projects, and so on for the patients

Acute/hospital Care: medical setting like the ICU, hospital, or emergency room

Administrator: person who runs a care center

Adult Day Center: areas that allow patients to be social and engage safely in activities with other people; intended only for daytime care.

Advance Directive: a legal document that says what kind of medical treatment a person wants when they're in a state where they can't communicate. Duplicate

Aerobic Exercise: Exercise that increases breathing rate and ultimately raises heart and lung efficiency. Activities such as walking/ running are an example.

Allowable Cost: highest fee the state will pay for people with Medicaid or other insurance plans; most insurance plans do not cover 100% of expenses.

Assessment: testing a person's ability to think, feel, and react to others. This is usually performed by a doctor/nurse or nurse practitioner.

Assisted Living: Assisted living is a residential care facility that generally provides 24-hour staff, recreational activities, meals, housekeeping, laundry and transportation. Definitions of assisted living and the specific regulations differ from state to state. Residents may choose which services they receive from the residence such as house cleaning, help with grooming or medication reminders. The "residents" are expected to be independent in activities of daily living.

Attorney (elder law): An elder law attorney handles general estate planning issues and counsels clients about planning for the future with alternative decision-making documents, such as Advanced Care Directives. The attorney can also assist the client in planning for possible long-term care needs, including nursing home care. Not all attorneys specialize in elder law.

Bed-bound: A person who is bed-bound cannot walk or get out of bed without help from another person or a mechanical lift.

Burnout: Physical and/or mental exhaustion caused by long-term stress.

Certified nursing assistant (CNA): A type of nurse aide who helps feed and care for disabled adults. A CNA works under a nurse's supervision and must be certified to give such care.

Caregiver or Care Partner: Any person who provides care for another person. Does not require specific training or certification.

Charge Nurse: supervises the staff and residents of a floor or unit of a nursing home; the "captain" of the nursing team.

Clinical Trials: Research studies conducted in people to determine whether treatments are safe and effective. Clinical trials are the best way for researchers to find new ways to detect, slow, treat and hopefully someday prevent disease such as Alzheimer's disease. Research trials require certification by a review committee of experts.

Electroencephalogram (EEG): Non-Invasive procedure to measure electrical activity in the brain; a "brain wave".

Daily Plan: provides structure for the person with Alzheimer's or other types of dementia. A plan should include activities that provide the person meaning and enjoyment.

Deficiencies: problems an inspector notes while visiting a nursing home or other facility. The facility must correct any deficiencies. Otherwise, it may be fined and dropped from Medicare or Medicaid participation. Lack of long term correction is likely a "death blow" to the facility.

Director of Nursing Services (DON): oversees all nursing activities. These include scheduling and making sure staff members get continuing education. This is the "boss".

Discharge: release of an individual from a hospital or other facility such as a nursing home. The attending doctor must give an order for the discharge.

Family/Designated Caregiver: “Family members” can include people who are important to the resident, whether or not they are related.

Functional Impairment: being unable to dress, use the toilet, eat, bathe, communicate or walk without help.

Geriatric Care Manager: He/she helps to create a plan of care that meets the needs of the older adult and will explain what resources and options are available to the patient and family.

Geriatric Psychiatrist: trained to diagnose and treat mental disorders in older adults. These disorders include dementia, depression, anxiety and late-life schizophrenia as examples.

Incontinence: a lack of voluntary control over urination or defecation (or both).

MRI scan: A non-invasive medical imaging technique that involves no radiation and that creates a 3-D image of the brain. Can help to confirm a diagnosis of dementia by showing atrophy/shrinking of the brain.

PET scan: An imaging technique that uses radioactive substances to visualize and measure metabolic processes in the body. The type of radioactive agents used are not a threat to the patient or the staff doing the exam.

Sources

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