

# Glossary of Acronyms and Terms

## Acronyms

AABD	-Aid to the Aged, Blind, and Disabled	DRG	-diagnosis-related group
AAHA	-American Association of Homes for the Aged	DRR	-Division of Research Resources, NIH
AARP	-American Association of Retired Persons	DRS	-Dementia Rating Scale
ACGME	-Accreditation Council for Graduate Medical Education	DSM-III	-Diagnostic and Statistical Manual of the America Psychiatric Association, 3rd edition
AD	-Alzheimer's disease	ECA	-epidemiologic catchment area
ADL	-activities of daily living	FAI	-Functional Assessment Inventory
ADRDA	-Alzheimer's Disease and Related Disorders Association	FDA	-Food and Drug Administration, DHHS
AFAR	-American Federation for Aging Research	FHT	-face-hand test
AFDC	-Aid to Families With Dependent Children	GAC	-geriatric assessment center
AGS	-American Geriatrics Society	GAO	-General Accounting Office, U.S. Congress
AHEC	-Area Health Education Center	GDS	-Global Deterioration Scale
AHPC	-Aging and Health Policy Center	GEC	-Geriatric Education Center, HRSA
AIDS	-acquired immune deficiency syndrome	GEU	-geriatric evaluation unit
AMA	-American Medical Association	GNP	-geriatric nurse practitioner
ANA	-American Nurses Association	GRECC	-Geriatric Research, Education, and Clinical Center, VA
ANT	-Alzheimer neurofibrillary tangle	GS	-geriatric specialist
APA	-American Psychological Association	GSA	-Gerontological Society of America
AOA	-Administration on Aging, DHHS	HDL	-high density lipoprotein
BHPr	-Bureau of Health Professionals, HRSA	HHMI	-Howard Hughes Medical Institute
BPRS	-Brief Psychiatric Rating Scale	HMO	-health maintenance organization
CARE	-Comprehensive Assessment and Referral Evaluation	HRSA	-Health Resources and Services Administration, DHHS
CDR	-Clinical Dementia Rating Scale	HTLV	-human T-cell lymphotropic virus (now called HIV: human immunodeficiency virus)
CMHC	-community mental health center	IADL	-instrumental activities of daily living
COBRA	-Consolidated Omnibus Budget Reconciliation Act of 1985 (Public Law 99-272)	ICD-9	-International Classification of Diseases, 9th revision
COPS	-Comprehensive Service on Aging Institute for Alzheimer's Disease and Related Disorders, NJ	ICD-9-CM	-International Classification of Diseases, 9th revision, Clinical Modification
COTA	-certified occupational therapy assistant	ICF	-intermediate care facility
Cs	-Cushing's syndrome	IEC	-institutional ethics committee
CSF	-cerebrospinal fluid	IMA	-Individual Medical Account
CSWE	---council on Social Work Education	IMD	-institution for mental disease
CT	-computerized axial tomography (also known as CAT)	IQ	-intelligence quotient
DCF	-domiciliary care facility (also known as board and care facilities)	IRA	-Individual Retirement Account
DHEW	-Department of Health, Education, and Welfare (became DHHS in May 1980)	IRB	-institutional review board
DHHS	-Department of Health and Human Services (formerly DHEW)	JCAH	-Joint Commission on Accreditation of Hospitals
DNA	-deoxyribonucleic acid	LPN	-licensed practical nurse
DNS	-director of nursing services	LTC	-long-term care
DON	-director of nursing	LVN	-licensed vocational nurse
DPA	-durable power of attorney	MAD	-Multidimensional Assessment for Dementia scale
DPAHC	-durable power of attorney for health care	MID	-multi-infarct dementia
		MMSE	-Mini-Mental State Examination
		MPTP	-1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine
		MRI	-magnetic resonance imaging
		MS	-medical specialist
		MSQ	-Mental Status Questionnaire

NCHS	—National Center for Health Statistics, DHHS
NCOA	—National Council on the Aging
NFT	—neurofibrillary tangles
NGF	—nerve growth factor
NHLBI	—National Heart, Lung, and Blood Institute, NIH
NIA	—National Institute on Aging, NIH
NIAD	—National Institute on Adult Daycare
NIH	—National Institutes of Health, Public Health Service, DHHS
NIMH	—National Institute of Mental Health, DHHS
NINCDS	—National Institute of Neurological and Communicative Diseases and Stroke, NIH
NLN	—National League of Nursing
NMFI	—National Master Facility Inventory
NMR	—nuclear magnetic resonance
NOSIE	—Nurses' Observation Scale for Inpatient Evacuation
NP	—nurse practitioner
NPH	—normal pressure hydrocephalus
OAA	—Older Americans Act
OARS	—Older American's Research and Service Center instrument
OASDI	--Old Age and Survivors' Disability Insurance
OME	—Object Memory Evaluation
OT	—occupational therapist
OTA	—Office of Technology Assessment, U.S. Congress
PaCS	—Patient Care and Services (quality assurance instrument, DHHS)
PAMIE	—Physical and Mental Impairment of Function Evaluation
PET	—positron emission tomography
PGDRS	—Psychogeriatric Dependency Rating Scale
PPS	—Prospective Payment System, Medicaid
PSP	—progressive supranuclear palsy
RISA	—radioimmunosorbent assay
RN	—registered nurse
RNA	—ribonucleic acid
RRC	—residency review committee
RUG	—resource utilization group
RUG-II	—resource utilization group system used by New York State case mix evaluation
SCAG	—Sandoz Clinical Assessment Geriatric Scale
SDAT	—senile dementia of the Alzheimer type
S/HMO	—social/health maintenance organization
SNF	—skilled nursing facility
SPECT	—single photon emission computed tomography
SPMSQ	—Short Portable Mental Status Questionnaire
SSDI	—Social Security Disability Insurance
SSI	—Supplemental Security Income
WAIS	—Wechsler Adult Intelligence Scale
WMS	—Wechsler Memory Scale

## Terms

**Activities of daily living (ADL):** Self-care abilities related to personal care, such as bathing, dressing, eating, and continence.

**Acute care:** Short-term medical care provided by physicians, clinics, hospitals, mental health centers, and rehabilitation services in response to a medical crisis.

**Acute illness:** A sharp, severe sickness, having a sudden onset, a rapid rise, and a short course.

**Adult day care centers:** Centers that provide a range of mental health and social services for physically, cognitively, or emotionally impaired and socially isolated people. Services vary according to the clients they serve. Centers dealing with people with dementia emphasize personal care, supervision, socialization, and activities. Adult day care centers have developed largely without Federal regulation, and thus vary greatly in quality and services. Medicaid and participant fees are their main sources of revenue.

**Adverse selection:** Situation faced by insurance companies when potential clients know of special risks and therefore wish to buy insurance. This raises financial risk to the insurer and discourages risk-pooling.

**Ageism:** Discrimination on the basis of age. Often results in the denial of rights and services to the elderly; analogous to racism or sexism.

**Agnosia:** Failure to recognize things or people; the loss of the ability to comprehend the meaning or recognize the importance of various types of sensory stimulation.

**Aid to Families with Dependent Children (AFDC):** A State-administered program that provides financial support for children under the age of 18 who have been deprived of parental support or care because of death, continued absence from the home, unemployment of a parent, or physical or mental illness. The family of an individual with dementia may be eligible if he or she has children under the age of 18, although establishing eligibility may be difficult.

**Acquired Immune Deficiency Syndrome (AIDS):** A disease caused by the retrovirus HIV (human immunodeficiency virus; also known as HTLV-III: human T-cell lymphotropic virus, type 111) characterized by a deficiency of the immune system. The depression of the immune system often leads to infections unusual in individuals with normal immunity. A substantial portion of persons with AIDS also develop dementia.

**AIDS dementia:** A form of dementia that results from brain infections encouraged by the immune dysfunction of AIDS, or caused directly by the AIDS virus. AIDS dementia is now the most common dementia caused by infection, and a large number of AIDS patients develop dementia.

**Alzheimer's disease** A chronic progressive disorder that is the major cause of degenerative dementia in the U.S. (affecting 2 to 4 million people). The disease may be a group of diseases grouped under one name because scientific knowledge is incomplete. Possible causes include genetic, environmental, immunologic, or metabolic factors. The disease manifests itself with clinical symptoms of dementia and characteristic microscopic changes in the brain. Definitive diagnosis can be obtained only from examination of brain tissue. There is no fully effective method of prevention, treatment, or cure.

**Alzheimer's Disease and Related Disorders Association (ADRDA):** A non-governmental organization founded in June 1979 by several family support groups. ADRDA is based in Chicago, but has chapters nationwide. It is now the largest organization focusing on dementia and the needs of caregivers. ADRDA funds basic research in neuroscience, and is involved in public education, family support, and patient advocacy efforts.

**Alzheimer's Disease Research Centers:** Ten federally funded centers created to conduct basic, clinical, and behavioral research into Alzheimer's disease and related disorders. The centers are at various medical centers and universities around the country. The program is administered by the National Institute on Aging, part of the National Institutes of Health (NIH), U.S. Department of Health and Human Services.

**Aphasia:** Loss or impairment of the power to use words. Expressive aphasia is impairment in the ability to use language, to speak or write; receptive aphasia is the inability to understand language. In some persons aphasia is the first symptom of dementia.

**Apraxia:** Impairment of the ability to perform complex coordinated movements, such as buttoning buttons, walking, dressing, eating a meal, or maintaining a sitting position. Unlike the person who is paralyzed or injured, someone with apraxia is unable to perform these functions due to brain damage, although physically capable of doing them. Apraxia is another symptom of dementia.

**Assessment:** The process by which a physician or health care professional evaluates an individual, generally based on conversation with the person, the family, and other caregivers; and on informal

observations of the person's behavior. Assessment is related to, but distinct from diagnosis. Assessment of cognitive abilities is a prerequisite for diagnosis of dementia, and can also provide information about the severity of a dementing condition once it has been diagnosed.

**Assessment instruments:** Specific tests and scales used to measure and evaluate cognitive and self-care abilities, behavioral problems and other patient characteristics. Few tests were specifically designed to evaluate dementia, and they do not always focus on the full range of problems associated with it; thus there are questions of validity and reliability concerning many of them.

**Basic research** The pursuit of knowledge for its own sake, without regard for specific practical or commercial results.

**Behavioral problems:** Persons afflicted with dementia can exhibit various behaviors, which are often the most burdensome aspects of dementia for caregivers. These behaviors include wandering and getting lost, agitation, pacing, emotional outbursts, suspiciousness and angry accusations, physical aggression, combativeness, cursing, and socially unacceptable sexual behavior. They also include chronic screaming and noisiness; repetition of meaningless words, phrases, or actions; withdrawal and apathy; and sleep disruption. Some of these problems are treatable.

**Binswanger's disease** A form of vascular dementia caused by loss of blood supply to the white matter of the brain (rather than the cerebral cortex). Also known as Binswanger's dementia and subcortical arteriosclerotic encephalopathy.

**Biomedical research:** Research into biological, medical, and physical science. Such research could lead to enhanced knowledge of the brain and yield great benefits, especially in the field of neuroscience. NIH and non-governmental agencies such as ADRDA are providing support for biomedical research into dementia.

**Brain imaging:** The use of various techniques to directly assess the anatomy of the brain; an essential component in the diagnosis of dementia. The most powerful new technologies use computers to create images of the brain. The techniques include computerized axial tomography, nuclear magnetic resonance, positron emission tomography, and single photon emission computed tomography (cf.).

**Bureau of Health Professionals (BHP):** Part of the Health Resources and Services Administration, U.S. Department of Health and Human Services (DHHS). BHP coordinates, evaluates, and supports development of health personnel. It also disseminates and

assesses information on the training and education of health personnel, demonstrates new approaches to education, and provides financial support for educational programs. An example of this last function is BHP's support of geriatric education centers (GECS).

**Catastrophic reaction:** Inappropriate behavior episodes often displayed by persons with dementia in reaction to some outside stimulus. These can be minor (shouting or stubbornness) or major (violent and threatening behavior such as hitting or swinging a weapon).

**Cerebral infarction:** An area of dead tissue in the cerebrum caused by an interruption of blood circulation because of functional constriction or actual obstruction of a blood vessel resulting from a stroke, hemorrhage, or lack of oxygen. Dementia can be a symptom of cerebral infarction.

**Cerebrospinal fluid (CSF):** The liquid that bathes the brain and the spinal column. Measurement of chemicals and cells in the CSF (obtained by lumbar puncture) can be part of the diagnostic process. Because the test is relatively expensive, causes some discomfort, and picks up relatively few diseases, however, there is some debate over its use in diagnosing dementia.

**Cerebrum:** The main portion of the brain, occupying the upper part of the cranial cavity.

**Chronic illness:** Disease (usually incurable) characterized by long duration and frequent recurrence. People suffering from chronic degenerative diseases, such as those that cause dementia, have different medical and social needs from those suffering from short-term acute illness.

**Clinical research:** The application of basic knowledge to the search for preventive measures, treatments, and methods of diagnosing disease. Clinical research is often conducted in a medical setting and is based on direct observation of the patient.

**Clinical Research Centers on Psychopathology of the Elderly:** Three clinical research centers established by the National Institute of Mental Health (NIMH), two of which focus on research into Alzheimer's disease.

**Cognitive abilities:** The functions of memory, intelligence, learning ability, calculation, problem solving, judgment, comprehension, recognition, orientation, and attention. Impairment of these functions is a central feature of dementia, and the primary cause of the self-care and behavioral problems associated with it.

**Cognitive assessment:** The use of specific test instruments to identify and describe cognitive impairments and to measure the cognitive abilities of per-

sons with dementia. Some of these tests are derived from standard tests, while others have been specifically designed for evaluating individuals with dementia. Such assessments are particularly valuable for research and clinical applications, but they may be less successful in determining an individual's needs for long-term care or in establishing eligibility for services. Tests include the Dementia Rating Scale, the face-hand test, the Mini-Mental State Examination, the Mental Status Questionnaire, and the Sandoz Clinical Assessment Geriatric Scale. (cf.)

**Community Mental Health Centers (CMHCs):** Agencies that provide a range of mental health services, primarily on an outpatient basis. The number of persons served by CMHCs is not known, but some CMHCs do have special services for elderly people including some with dementia. CMHCs are jointly funded by Federal and State governments.

**Competence:** For the purpose of this assessment, competence is defined as the ability to make a decision using communication, understanding, reasoning, deliberation, and a relatively stable set of values. The process whereby the decision is reached is more important than the decision itself in determining competence. Competence may be determined by functional assessment. Legally, an individual is assumed to be competent until a court declares otherwise and appoints a guardian, although informal competency determinations between families, physicians, and psychiatrists are common.

**Computerized axial tomography (CAT or CT):** A diagnostic device that combines X-ray equipment with a computer and a cathode ray tube to produce images of cross-sections of the body. CT is a useful diagnostic tool in detecting some causes of dementia, such as tumors, and it has also been used to study Alzheimer's disease.

**Conservatorships and guardianships:** The designation of a surrogate decisionmaker on behalf of an incompetent individual, determined and supervised by a court after evidence of an individual's incompetence has been presented. There are two types of authority: conservatorship or guardianship of estate (covering finances) and possessions and conservatorship or guardianship of person (covering residency, certain kinds of health care and service decisions, and personal matters).

**Creutzfeldt-Jakob disease (CJD):** An infectious, usually fatal neurological illness believed to be transmitted by an atypical infectious agent, sometimes referred to as a "slow virus." Victims of CJD exhibit symptoms of dementia, involuntary jerks, and, frequently, abnormal gait.

**Decubitus:** Bedsores.

**Deeming** The process by which income and resources that is considered to be available to an applicant for Supplementary Security Income (SSI), and other government programs. An example is pension income received by one spouse being considered available to the other spouse applying for Medicaid. In determining eligibility the "deemed" income will be added to the applicant's own income even if the non-applicant spouse fails to make it available to the applicant.

**Degenerative disorders:** Diseases whose progression cannot be arrested. These disorders cause progressive deterioration of mental and neurological function often over years. Alzheimer's disease is the most prevalent degenerative dementia. The ultimate cause of such disorders is unknown.

**Delirium:** A decline in intellectual function with clouded consciousness. It differs from dementia in that it implies a temporary loss of ability. However, persons with dementia frequently develop delirium caused by other illnesses or drug reactions and delirium can be confused with dementia particularly in older individuals.

**Delusion:** A false, fixed idea. Persons with dementia often suffer from delusions and may maintain them for a long time.

**Dementia:** Impairment in mental function and global cognitive abilities of long duration (months to years) in an alert individual. Symptoms include memory loss, loss of language function, inability to think abstractly, inability to care for oneself, personality change, emotional instability, a loss of sense of time and place, and behavior problems. Dementia can be caused by over 70 disorders, but the leading cause in the United States is Alzheimer's disease. No cure is currently available for the vast majority of dementing conditions and may last for years to decades. Current criteria for dementia are generally based on the Diagnostic and Statistical Manual (DSM) (cf.). Contrast with delirium.

**Dementia pugilistica:** Brain damage resulting from repeated head trauma. Also known as boxer's or fighter's dementia.

**Dementia rating scales:** Multidimensional assessment instruments that define a person's level of mental functioning from least to most impaired, describe an individual's condition over time, and predict the course of the illness. The reliability and validity of these scales are controversial.

**Dementing disorders:** There are more than 70 dementing disorders, the major one in the United States being Alzheimer's disease. Disease of blood vessels is the second most common cause of dementia. Some of the diseases that cause dementia are

AIDS, Down's Syndrome, Creutzfeldt-Jakob disease, Huntington's disease, Binswanger's disease, and normal pressure hydrocephalus (NPH).

**Dependent care tax credit:** A credit subtracted from an individual's final tax liability. In its current form this provision is not generally useful to people with dementia, as credit for expenditures on personal care is only allowed if they enable the taxpayer to work.

**Diagnosis Related Groups (DRGs):** Medicare's classification of hospital patients by medical condition and other easily measured variables into 468 groups. Hospitals are paid a fixed price for care based on each patient DRG. This system will be fully implemented in October 1987.

**Diagnostic algorithm:** Step-by-step diagnosis procedures that medical personnel learn during their professional training and progressively refine during their practice.

**Diagnostic and Statistical Manual (DSM):** A set of guidelines for diagnosing mental disorders published by the American Psychiatric Association. The third edition, DSM III, is the most widely used system for classifying the symptoms of dementia. APA plans to revise DSM III (published in 1980) and issue DSM IV sometime in 1989.

**Disorders that simulate dementia:** These are disorders that may have some of the same symptoms as dementia, but which are more likely to respond rapidly to treatment (e.g., depression in older people). Disorders that simulate dementia may overlap dementing disorders,

**Disorientation** The lack of correct knowledge of person, place, or time; i.e., where a person is, who the people around him or her are, and what time of day, day of the week, or month it is.

**Domiciliary board and care facilities:** Non-medical residences, usually certified by a State, that provide room, board, and 24-hour supervision for residents. Some also provide personal care and other services. These facilities differ from nursing homes in that they do not provide nursing care. They vary in size from board or foster homes that provide care for one or two individuals, to group homes that may serve as many as 10. The term also embraces retirement homes, homes for the aged, and large domiciliary care facilities, including those operated by the Veterans Administration. The services provided and the number and type of these facilities vary greatly from State to State. State and Federal programs pay a significant portion of board and care charges and costs, primarily through Social Security and pensions. The number of persons with dementia who live in such facilities is unknown.

**Down's syndrome:** A genetic disorder characterized by mental retardation. The syndrome may also include congenital heart defects, immune system abnormalities, various morphological abnormalities, and a reduced life expectancy. People with Down's Syndrome who survive into middle age frequently develop dementia. There are several unexplained relationships between Down's Syndrome and Alzheimer's disease.

**Durable Power of Attorney (DPA):** A modification of the standard power of attorney that permits a competent individual to transfer specified powers to another person. When the individual becomes incompetent the power of attorney remains valid, thereby providing a surrogate decisionmaker designation that survives the incompetence of the individual. DPA is authorized by State statute throughout the United States except in the District of Columbia.

**Excess disability:** Impairments in function that are worse than necessary, considering the underlying biological deficits. Such disabilities are considered "excess" in persons with dementia because they can often be corrected (e.g., with a new hearing aid or treatment of a condition that exacerbates the dementia).

**Face-Hand Test (FHT):** A neurological test used to differentiate between cognitively normal individuals and those with organic dementia. In this test an individual is touched simultaneously on the face and hand, first with the eyes open and then with the eyes closed. Persons with organic dementia frequently report only one of the two stimuli.

**Family care:** The care provided by family members to a person with dementia. The majority of people suffering from dementia are looked after by families at home during part or all of the disease. The kind of care provided changes as the disease progresses. Initially, families make decisions for the affected individual and take over financial, legal, and domestic responsibilities. Later the family assumes responsibility for activities of daily living, and also often provide round-the-clock supervision, while at the same time dealing with the difficult behavior problems associated with dementia. Family care often continues even after the ill person enters a nursing home, as families continue to visit the ill person and often assume some of the expense involved. The task of providing such care may last for 10 years or more, and the costs of home care are generally not covered by health insurance, Medicare, or Medicaid.

**Family Survival Project:** An independent program in San Francisco that provides information, advice and referral, case coordination, legal counseling, and

support services to brain-damaged individuals and their caregivers. The program has been successful in serving caregivers and in generating government support for its programs.

**Functional assessment:** A means of determining competence by evaluating an individual's behavior and assessing his or her ability to function independently on a daily basis. Various assessment methods can be used, most of these involve the evaluation of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (cf. ) using specific assessment instruments.

**Geriatric Assessment Centers (GAGs):** Hospital-based centers designed to provide multidisciplinary assessment (based on functional status and medical, social, and financial needs), short-term treatment, and assistance with long-term planning for elderly patients. GAGs are common in England, but are relatively new in the United States, and until recently there were few of them.

**Geriatric Education Centers (GECs):** Centers sponsored by BHP that disseminate interdisciplinary and discipline-specific information and offer training models in geriatric care. Four centers were set up in 1983 and 16 more were established under the 1985 appropriations for BHP.

**Geriatrics:** A branch of medicine devoted to the diseases and problems of older people. Dementia is primarily, though not exclusively, a geriatric problem.

**Global cognitive impairment:** Impairment of many areas of mental function.

**Hallucinations:** Sensory experiences unique to the individual who sees, hears, smells, tastes, or feels something not experienced by other people. Some people with dementia are subject to hallucinations.

**Health services research:** For the purposes of this report, the multidisciplinary study of those with dementia and the people who serve them (including the community and family). Effective health services research will determine the future basis of public and private activities in financing, quality assurance, training, and service delivery to persons with dementia. Federal health services research is sponsored by agencies of the DHHS and the VA.

**Home care services:** The provision of medical, social, and supportive services in the home by outside organizations. Services can range from sophisticated (e.g., administering intravenous drugs) to relatively simple (providing home-delivered meals). Other services include skilled nursing care, physical or occupational therapy, personal care, home health aide, homemaker, paid companion, and housekeeping services. Although they can be important to families caring for individuals with dementia, not all

are covered by Federal or State programs and their delivery system and regulations governing their use are often fragmentary and complex.

**Home health aide:** A person, not a physician or nurse, who provides home care services, which may include assistance with medication and exercise; personal care, such as bathing, dressing, and feeding; and homemaker services.

**Huntington's disease:** A rare genetic disease characterized by chronic progressive disorders of movement and mental deterioration culminating in dementia. Symptoms do not usually appear until late middle age, and death usually results within 15 years. Children of affected parents have a 50 percent chance of developing the disease.

**Illusions:** The misunderstanding of abstract information, leading to an incorrect or distorted perception of reality.

**Intravenous:** Situated within a vein, or entering by way of a vein. Often refers to injections.

**Instrumental Activities of Daily Living (IADL):** Activities that facilitate independence, such as the ability to handle finances, use the telephone, use public transportation, take medication, prepare meals, go shopping, and do housework. (Also see Activities of Daily Living, above.)

**International Classification of Diseases (ICD-9):** A system used to code medical diagnoses. The usefulness of ICD-9 in refining epidemiological studies of dementia is limited, because many of the diagnostic categories (for example Parkinson's disease) do not separate those individuals who have dementia from those who do not. Revision of ICD-9, to be called ICD-10, is scheduled for 1989.

**Idiopathic dementia:** Disorders in which the clinical symptoms of dementia are present without abnormal findings in the brain. This kind of dementia is found in approximately 5 percent of cases. It is called idiopathic because its cause and mechanism are unknown.

**Licensed Practical Nurse (LPN):** A technical nurse licensed by a State board of nursing. LPNs (sometimes known as LVNs, or licensed vocational nurses) provide much of the hands-on care in nursing homes. Most LPNs train in vocational, community, or technical colleges.

**Life care community:** A facility that provides housing tailored to the needs of aging individuals and that provides medical services as needed, including nursing-home care, usually in the same complex. Such communities are expensive; only about 20 percent of the population aged 65 or older could afford to enter one, estimates say.

**Living will:** A declaration by a competent individual outlining his or her wishes, especially the intent to

refuse life-sustaining procedures, once he or she is incompetent and death is imminent. Because these documents are frequently ambiguous, their legality may be unclear. They are not recognized in all States, and requirements and conditions vary from State to State.

**Long-term care:** The provision of a continuum of care in a formal (institutional) or informal (home) setting to individuals with demonstrated need. Such services can be provided in nursing homes, board and care facilities, and mental health facilities and are often delivered indefinitely. Services may be continuous or intermittent. They include medical care and a variety of other services. Individuals with dementia are likely to need more long-term supervisory and personal care than medical attention. After informal home care, nursing homes are the most frequently used setting for persons with dementia. Although the United States has no national long-term care policy, the Federal government is extensively involved in providing funding for and regulation of a wide range of long-term care services. Long-term care is among the fastest-growing segments of the health services industry.

**Magnetic resonance imaging (MRI):** A technique that produces images of the body by measuring the reaction of nuclei in magnetic fields to radio frequency waves. This technique provides sensitive detection of strokes and tumors and good images of the white and gray areas of the brain. The machines are expensive and a CT scan can be used for many of the same purposes.

**Medicaid:** A joint Federal/State medical welfare program with strict means tests, intended to provide medical and health-related services to low-income individuals. Medicaid regulations are established by each State within Federal guidelines. Eligibility requirements and the long-term care services covered vary significantly from State to State, and are often complicated, especially those that concern individuals with dementia. Medicaid generally pays for nursing home and home health care for eligible individuals. Forty-eight percent of Medicaid spending was for long-term care in 1982. Medicaid pays 43 percent of national nursing home costs, and covers more than 70 percent of nursing home residents (fully or in part). In some States, Medicaid covers adult day care and in-home services. Because services such as respite and custodial care are not generally covered, however, Medicaid is of limited use for home care to individuals with dementia and their families.

**Medical expense tax deduction:** The deduction of medical expenses above a certain percentage of adjusted gross income. This deduction may be of lit-

tle help to people with dementia as many of their expenditures are not primarily medical ones.

**Medical model of care:** Provision of care and diagnostic and treatment services that emphasizes the role of the physician over that of other health and social service professionals.

**Medicare** The Federal insurance program, initiated in 1965, designed to provide medical care for elderly people. Generally, only those 65 or older are eligible, although disabled people under 65 and those with kidney diseases may also be eligible. Individuals with dementia who are under 65 may find it difficult to establish eligibility. Medicare provides reimbursement for hospital and physician services and limited benefits for skilled nursing home care, home health care, and hospice care. Medicare does not cover protracted long-term care, and by law it does not cover custodial care. The medical orientation of Medicare services and benefits means that its usefulness for individuals with dementia is limited to diagnosis and treatment.

**Memory:** The power or process of reproducing or recalling what has been learned or retained. There are several different forms of memory: immediate (remembering for a few seconds), short-term (remembering for a few months), and long-term (remembering material learned from year to year). Memory loss is a symptom of dementia, particularly short-term memory.

**Mental retardation:** Lower than normal intellectual competence, usually characterized by an IQ of less than 70. Although it is not always easy to distinguish from mental retardation, dementia indicates the loss of previous mental ability.

**Mental status tests:** Short screening tests used by mental health professionals to estimate changes in intellectual performance. Useful mainly for preliminary identification of symptoms.

**MPTP:** 1-methyl-4 phenyl-1,2,3,6, tetrahydropyridine, a contaminant of a heroin-like drug (originally produced illicitly), which causes symptoms similar to those of Parkinson's disease.

**Multidimensional assessment instruments:** Tests that focus on various categories of assessment, such as diagnosis, physical condition, cognitive status, self-care abilities, emotional and behavioral characteristics, family and social supports, financial status, and health and social service use patterns.

**Multidisciplinary team model of health care:** An approach that stresses the use of a wide range of health and social services personnel appropriate to certain care situations. Many consider this the most appropriate approach for dealing with the complexity of a dementing illness.

**Multi-infarct dementia (MID):** Dementia caused by brain damage resulting from multiple cerebral infarcts (cf).

**Nurse's aides:** Paraprofessionals who provide most of the direct care in long-term care facilities. Aides have the lowest education and training requirements and the highest rate of turnover among nursing home personnel. The Nurse Training Act of 1975 supports efforts to provide improved training for nurses' aides and other paraprofessionals.

**Nursing homes:** Facilities that provide 24-hour supervision, skilled nursing services, and personal care. An estimated 40 to 75 percent of nursing home residents are persons with dementia. Nursing homes fall into two categories, skilled nursing facilities (SNFs) and intermediate care facilities (ICFs). State Medicaid regulations that define these types of facility vary, as does the number of nursing homes in each category and the supply of beds. Medicaid pays a significant portion of nursing home costs, but nationally half the cost of nursing home care is borne by residents and their families.

**Nursing model of health care:** Nursing care of the chronically ill, emphasizing rehabilitative and personal services; the objective is to restore maximum function and independence in the patient.

**Nurse Practitioner (NP):** A nurse specialist (usually an RN), who has completed an academic program to obtain added medical skills and who can perform many tasks otherwise performed by a physician. Some NPs specialize in geriatrics.

**Nurse Specialist:** A nurse (usually an RN) who has completed graduate education or fulfilled certification requirements in a particular field (e.g., geriatrics).

**Nurse Training Act (PL 94-63):** Passed in 1975, this Act and its amendments emphasizes, among other things, the problems of providing health care for the elderly and the need for teaching and training programs specializing in geriatrics and long-term care.

**Older Americans Act:** This Act, passed in 1965, established the Administration on Aging (AOA) within the Department of Health, Education and Welfare (now DHHS). AOA coordinates grants and contracts to the States for development of new and improved programs for older persons. The Act also deals with the need for improved training and more personnel in the field of geriatrics. A 1984 amendment recognize the increasing need for personnel knowledgeable about the treatment and care of persons with Alzheimer's disease.

**Older Americans Act Title III:** Part of the Older Americans Act of 1965, Title III provides Federal

funding to the States for social services for people over 60. States determine specific services, but Title III funds are often used for home health, homemaker, and chore services; telephone reassurance; adult day care; respite care; case management; and congregate and homedelivered meals. Income tests are not generally used to determine eligibility, but these services are targeted to elderly people with social or economic need.

**Parkinson's disease:** A disease affecting movement and leading to dementia in approximately one-third of those affected. The disease is associated with destruction of cells in the substantial nigra in the brainstem. The cause is unknown. There are several varieties of Parkinson's disease.

**Perseveration:** The repetition of meaningless words or actions, a behavioral problem sometimes exhibited by persons with dementia.

**Pick's disease:** A rare dementing disorder, clinically similar to Alzheimer's disease.

**Positron-emission tomography (PET):** A scanning technique that measures the body's uptake of radioactively labeled substances. PET provides a dynamic image of the brain's metabolic activity and has been useful in detecting Huntington's disease and Alzheimer's disease. Its use is relatively limited, largely because it requires expensive facilities.

**Primary family caregiver:** The individual within a family who assumes most of the tasks involved in caring for an individual with dementia. Usually a member of the family related by blood or marriage to the ill person, often a middle-aged woman.

**Private charity:** Assistance provided by people outside a person's family, but not paid for by Federal or State funds. It may take the form of informal help from friends or unpaid volunteers, or more formal help provided by professionals paid out of charitable contributions.

**Progressive supranuclear palsy (PSP):** A disorder similar to Parkinson's disease. It differs from Parkinson's disease in that those affected lose the ability to gaze up or down and do not necessarily have a tremor. Half to two-thirds of people with PSP become demented.

**Psychological testing:** Tests used by physicians to screen for mental condition, including the presence of dementia. These tests are used primarily to confirm diagnoses. They are important in distinguishing between dementia and the normal effects of aging. They are also useful in the tracking the stages of illness.

**Psychotropic drugs:** Drugs that act on the mind. They are often used to control disruptive behavior in persons with dementia.

**Regulatory standards:** Nursing homes and home health agencies that participate in Medicaid and Medicare programs are obliged to conform with Federal and State regulations. There are no Federal regulations for board and care facilities but most States do have licensing standards for such facilities, though these vary widely from State to State. Thirty-three States and the District of Columbia also have licensing laws pertaining to home care services. Inspection and enforcement of these standards to ensure quality care is often unsatisfactory.

**Registered Nurse (RN):** A professional nurse licensed by a State board of nursing. By virtue of their training, RNs are certified to assume responsibilities and duties that other less-qualified personnel are not. Recent surveys show that there is little interest in work in long-term care facilities among RNs.

**Representative payee:** The guardian of an incapacitated individual's social security or other government benefits. Conservatorship and power of attorney are not recognized by many government agencies. A representative payee is usually appointed at the discretion of the head of the appropriate agency.

**Resource Utilization Groups (RUGS):** The classification by Medicaid of individuals in nursing homes into 16 groups, based on functional impairment. Each RUG category is assigned a fixed price per unit per day, and the nursing home is paid that amount for each resident based on his or her RUG classification. New York State has just implemented a RUG-based system, and similar systems are under consideration in other States.

**Respite care:** The intermittent provision of services to provide temporary relief for a family caring for an incapacitated individual. Respite programs include in-home companion care, in-home personal care, adult day care, or short-term stays in a nursing home, hospital, or boarding home. Such services are not always publicly or privately funded and are often difficult for caregivers to find.

**Single photon emission computed tomography (SPECT):** The use of radiation detection machines (available in hospitals with nuclear medicine facilities) to indirectly measure physiological activity. This technique may eventually be able to perform many of the diagnostic functions now only available through a PET scan though with less precision and resolution. It is currently useful in the detection of strokes, hemorrhage, and poor blood circulation in the brain.

**Social Health Maintenance Organization (s/HMO):** A new type of health maintenance organization (HMO) that is operating on an experimental basis in a few

- locations. An S/HMO is paid a flat amount per enrollee for a fixed period. During that period it provides all needed medical care and social support services for acute or chronic conditions suffered by the enrollee.
- Social Services Block Grant:** Provides Federal funding to the States for social services for the elderly and the disabled. Federal standards do not require provision of specific services, but many States use their grants for board and care, adult day care, home health, and similar community services that can improve the quality of life for individuals with dementia and their families.
- Staging:** The definition of a series of discrete and reliable steps describing the progress of a disease. The effort to develop accurate measures of the stages of Alzheimer's disease has just begun, and no ideal staging scale or tool is available at present.
- Supplemental Security Income (SSI):** A Federal income support program that provides monthly payments to aged, disabled, and blind people with incomes below a minimum level.
- Surrogate decisionmakers:** Persons responsible for making decisions concerning an individual's health care, life-style, and estate once the individual is incapable of making these decisions. A surrogate decisionmaker can be a court-appointed conservator or guardian, or someone legally designated by the individual before he or she became incompetent. De facto surrogates—often spouses or other family members—assume these powers for an incapacitated individual without being formally or legally charged to do so. The limits on and the types of decisions that can be made by surrogate decisionmakers vary from State to State.
- Toxic dementia:** Dementia caused by exposure to toxic substances, such as alcohol (associated with over a dozen forms of brain disease), or chronic exposure to heavy metals.
- Transmissible dementia:** Dementia associated with diseases caused by unusual infectious agents. Examples are Creutzfeldt-Jakob disease, Gerstmann-Strassler syndrome, and kuru.
- "2176 waiver":** A modification of the Medicaid program, introduced in 1981, that allows the waiver of standard Medicaid requirements to introduce new programs on a trial basis. Several States have used this waiver to establish programs for people with Alzheimer's disease.
- Vascular dementia:** Dementia resulting from brain damage caused by cerebral infarction, or other diseases of disorder due to the blood vessels. Vascular dementia is the second largest cause of dementia in the United States (after Alzheimer's disease).
- Veterans Administration (VA):** For purposes of this report, the largest single provider of long-term care services in the United States. In 1983, the I/A operated 99 nursing homes and 16 large board and care facilities. It also paid for nursing home care, board and care in private homes; 3 provided day care at 5 VA medical centers. These services are provided on a priority basis to veterans with service-connected disabilities. Thus, veterans with dementia are accorded a lower priority. The VA also supports research and education in geriatrics.