

## Definitions of Common Terms Used in Long-Term Care and Culture Change

Activities of Daily Living (ADLs): Daily functions such as getting dressed, eating, taking a shower or bath, going to the bathroom, getting into a bed or chair, or walking from place to place. The amount of help a person needs with ADLs is often used as a measure to determine whether he or she meets the requirements for long-term care services in a nursing home as well as government subsidized homeand community-based services. (Also see Instrumental Activities of Daily Living.)

Acute Care: Medical care for health problems that are new, quickly get worse, or result from a recent accident. Acute care has recovery as its primary goal, typically requires the services of a physician, physician assistant, nurse practitioner, nurse, or other skilled professional, and is usually short-term. It is usually provided in a doctor's office, a clinic, or a hospital.

**Adult Day Services**: Community-based programs that provide meals and structured activities for people with cognitive or functional impairments, as well as adults needing social interaction and a place to go when their family caregivers are at work. (See also Respite.)

Advance Directive: Legal documents that allow you to plan and make your own end-of-life wishes about health care and treatment known in the event that you are unable to communicate. Advance directives consist of (1) a living will and (2) a medical (health care) power of attorney, sometimes called "health care surrogate," depending on the state. (See Living Will and Medical Power of

Attorney). You can create a living will and medical power of attorney form without a lawyer. However, it is very important that you use advance directive forms specifically created for your state so that they are legal. Caring Connections (www.caringinfo.org) provides free advance directives and instructions for each state.

Advance Practice Nurse (APN): These are registered nurses with specialized education and training beyond the basic registered nurse level. Some are called clinical nurse specialists, and some are called nurse practitioners. (See Nurse Practitioner.)

Alzheimer's Disease: A progressive, degenerative form of dementia that causes severe intellectual deterioration. The first symptoms are impaired memory, followed by impaired thought and speech, an inability to care for oneself and, eventually, death. Onset can be associated with or preceded by depression.

Area Agencies on Aging (AAAs): AAAs coordinate and offer services that help older adults remain in their home, if that is their preference. Services might include Meals-on-Wheels, homemaker assistance, and whatever else it may take to enable the individual to stay in his or her own home. By making a range of options available, AAAs make it possible for older individuals to choose homeand community-based services and a living arrangement that suits them best. (See Eldercare Locator.)

Assisted Living/Personal Care Homes/Residential Care Facilities: A state-regulated residential long-term care option that may have different names depending on the state. Assisted living provides or coordinates oversight and services to meet residents' individualized, scheduled needs, based on the residents' assessment and service plans, and their unscheduled needs as they arise. There are more than 26 designations that states use to refer to what is commonly known as "assisted living." There is no single uniform definition of assisted living, and there are no federal regulations for assisted living. In many states, most assisted living is private pay. Be sure to check with your state about any waiver programs that might be available through Medicaid to pay for the care provided in assisted living.

Care or Case Manager: A nurse, social worker, or other healthcare professional who plans and coordinates services for an individual's care. This person usually works for an agency or care setting. (Also see Geriatric Care Manager.)

Care Plan: A detailed written plan that describes what is needed for an individual's care and provided by a range of health professionals, including nurses, therapists, social workers, nursing or personal assistants. For those living at home, a good care plan should also list the caregiving activities that family members are able to do, need help learning how to do, and will be doing. "I" Care Plans are written in the first person, as if the person receiving care wrote it her- or himself, and express the desires of the individual for her or his care. Care plans can describe the risks that an individual is prepared to take in exercising his or her autonomous self-determination and choice. Creating the care plan should involve an interdisciplinary team of the care recipient, caregivers, including the nursing assistant, as well as the family as appropriate.

Caregiver: A caregiver is a spouse, family member, partner, friend, or neighbor who helps care for an elder or person with a disability who needs assistance. Caregivers can also be people employed by the care recipient, a family member, agencies, or care settings to provide assistance with activities of daily living (see ADLs) and instrumental activities of daily living (see IADLs).

**Case Management**: Assistance for families in assessing the needs of older adults and making arrangements for services to help the older adult remain as independent as possible.

Centers for Medicare & Medicaid Services (CMS): With a budget of approximately \$650 billion and serving approximately 90 million beneficiaries, the Centers for Medicare & Medicaid Services (CMS) plays a key role in the overall direction of the healthcare system. With regard to long-term care, CMS is responsible for regulating and paying nursing homes, home health agencies, and hospices for the care of Medicare and Medicaid (in conjunction with the states) beneficiaries.

Certified Nursing Assistant (CNA): A person trained and certified to assist individuals with non-clinical tasks such as eating, walking, and personal care. (See definitions for Personal Care and ADLs.) This person may be called a "direct care worker" (DCW). In a hospital or nursing home the person may be called a *nursing assistant*, a *personal care assistant*, or an *aide*.

**Citizen Advocacy Group (CAG)**: A CAG is a state or regional nonprofit organization dedicated to improving the quality of long-term care. Members of a CAG may include long-term care recipients, their families and friends, citizen advocates, long-term care ombudsmen, and organizations subscribing to the CAG's purpose.

**Cognition**: The process of knowing; of being aware of thoughts. The ability to reason and understand.

**Cognitive Impairment**: A diminished mental capacity, such as difficulty with short-term memory. Problems that affect how clearly a person thinks, learns new tasks, and remembers events that just happened or happened a long time ago. Problems that affect cognition. (See definition of cognition.)

Consistent Assignment: Residents receive care from the same caregivers (registered nurse, licensed practical nurse, direct care worker/certified nursing assistant) during a typical work week. Consistent assignments give the caregiver and resident the opportunity to build a close relationship, allowing the caregiver to gain a deep understanding of the resident and allowing the resident to develop a true level of comfort and trust with the caregiver.

Continuing Care Retirement Community (CCRC): A housing option that offers a range of services and levels of care. Residents may move first into an independent living unit, a private apartment or a house on the CCRC campus. The CCRC provides social and housing-related services and might have an assisted living residence and a nursing home, often called the health care center, on the campus. If and when residents can no longer live independently in their apartment or house, they move into assisted living (unless it is provided in their apartment or house) or the nursing home.

Culture Change: The common name given to the national movement for the transformation of older adult services, based on person-directed values and practices, where the voices of elders and those working with them always come first. Core person-directed values are choice, dignity, respect, self-determination and purposeful living. Culture change transformation supports the creation of both long- and short-term living environments as well as community-based settings where both older adults and their caregivers are able to express choice

and practice self-determination in meaningful ways at every level of daily life. Culture change transformation may require changes in organizational and leadership practices, physical environments, relationships at all levels, and workforce models—leading to better outcomes for all involved. While culture change may focus on elders, it improves the quality of life for all care recipients.

**Dementia:** A general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by structural and physiological changes in the brain. Alzheimer's disease is the most common type of dementia. It is estimated that 47 to 67 percent of nursing home or assisted living residents have Alzheimer's disease or a related form of dementia.

Direct Care Staff or Direct Care Worker (DCW): An individual working in a nursing home or assisted living community that provides "hands on" help with activities of daily living (ADLs) to residents. (See Certified Nursing Assistant.)

**Discharge Planner**: A nurse, social worker, or other professional who coordinates a patient's transition (move) from one care setting to the next, such as from hospital to nursing home or to one's own home with home health care and other services. (See "What Level of Care Should I Be Looking For?" on page 23)

Elder Abuse: Any knowing, intentional or negligent act by a caregiver or any other person that causes harm or a serious risk of harm to a vulnerable older adult. The specificity of laws varies from state to state. Types of elder abuse may include Physical Abuse—Inflicting, or threatening to inflict, physical pain or injury on a vulnerable elder, or depriving them of a basic need; Emotional Abuse—Inflicting mental pain, anguish or distress on an elder person through verbal or nonverbal acts; Sexual Abuse—Non-consensual sexual contact of any kind; Exploitation—Illegal taking, misuse, or concealment of funds, property or assets of a vulnerable elder; Neglect—Refusal or failure by those responsible to provide food, shelter, health care or protection for a vulnerable elder; Abandonment—The desertion of a vulnerable elder by anyone who has assumed the responsibility for care or custody of that person. The specificity of laws varies from state to state. (See National Center on Elder Abuse.)

**Elder Law Attorney**: A lawyer who specializes in the legal rights and issues of older adults and their health, finances, and well-being.

Family Caregiver: Any family member, partner, friend, or neighbor who provides or manages the care of someone who is ill, disabled, or frail. There may be more than one family caregiver involved in a person's care. Sometimes family caregivers are referred to as informal caregivers. This is meant to show that they are different from formal caregivers (professional healthcare workers). But many caregivers do not like the term informal because it incorrectly implies less skill and commitment.

Family Council: Family members of nursing home or assisted living residents who join together to provide a consumer voice and perspective to communicate issues to administrators and work for resolution and improvement. Family Councils can play a crucial role in voicing concerns, requesting improvements, discussing the mission and direction of a nursing home or assisted living community, supporting new family members and residents, and supporting the residence's efforts to make care and life in the home the best it can be. When Family Councils meet independently (without representatives of the nursing home or assisted living community) they are able to speak more freely and openly. Such independent family councils in nursing homes are supported by federal (and some state) legislation.

Geriatric Care Manager: A person with a background in nursing, social work, psychology, gerontology or other human services field, who has knowledge about the needs of and services available for older adults. A geriatric care manager coordinates (plans) and monitors (watches over) a person's care. He or she also keeps in contact with family members about the person's needs and how their loved one is doing. Most geriatric care managers are privately paid and usually not covered by private insurance. Some long-term care insurance companies use care managers to assess the individual's need for services and arrange for the needed services.

**Geriatrician**: A medical doctor with special training in the diagnosis, treatment, and prevention of illness and disabilities in older adults.

**Geriatrics**: The branch of medicine that focuses on providing comprehensive health care for older adults and the treatment of diseases associated with the aging process.

**Gerontologist**: A professional trained in Gerontology. Gerontologists have a Masters or doctoral degree, either in Gerontology, or in another discipline (psychology, biology, social work, etc.) with a focus in gerontology.

**Gerontology**: The study of the aging process and individuals as they grow from midlife through later life including the study of physical, mental and social changes; the investigation of the changes in society resulting from our aging population; the application of this knowledge to policies, programs, and practice.

**Health Care Practitioner**: A professional providing medical, nursing, and other healthcare related services.

Home Health Aide (HHA): A person trained to provide basic health care tasks for older adults and persons who are disabled, in their home. Tasks include personal care, light housecleaning, cooking, grocery shopping, laundry and transportation. Tasks may also include taking vital signs (such as heart rate and blood pressure) or applying a "dry dressing" for certain kinds of wounds. They are supervised by a registered nurse when they are employed by a home health agency.

Home Health Care: Services given to patients at home by registered nurses, licensed practical nurses, therapists, home health aides, or other trained workers. Certified home health agencies often provide and coordinate these services. These services, provided on a short-term basis and ordered by a physician, are usually covered by Medicare and Medicaid. With Medicaid, there are differences in coverage between states.

Home- and Community-Based Services (HCBS): Services provided in an individual's home or a setting in the community, such as adult day services, senior centers, home-delivered meals, transportation services, respite care, housekeeping, companion services, etc. These services are primarily designed to help older people and people with disabilities remain in their homes for as long as possible. Many states have requested and received "Medicaid waivers" in order to enable low income Medicaid recipients to receive long-term care services in their own homes, adult day care, or an assisted living community instead of moving into a nursing home.

Home-delivered Meals (Meals on Wheels): Meals brought to people who cannot prepare their own meals or are homebound (cannot leave their homes).

Hospice: A program of medical and social services for people diagnosed with terminal (end-stage) illnesses that focuses on comfort, not curing an illness. Hospice services can be given at home, in a hospital, hospice residence, assisted living community, or nursing home. They are designed to help both the patient and his or her family. Hospice care stresses pain control and symptom management. It also offers emotional and spiritual support. Medicare will pay for hospice if a doctor states that a person probably has six months or less to live. Hospice care can last longer than six months in some cases.

Household Model: A small group of residents living within a physically-defined environment that "feels like home" and that has a kitchen, a dining room, and a living room. Staff is consistently assigned so they can develop meaningful relationships with the residents, work in self-led teams, and perform a variety of tasks. The sense of being at home is expressed in recognizing and honoring the rhythm of each individual's life. For example, there is a wide variety of food accessible to residents around the clock, including breakfast-to-order and on demand. All residents in the household have opportunities to participate in the daily life of the household in a manner and to the extent they choose.

HUD Housing/Affordable Senior Housing: The U.S. Department of Housing and Urban Development (HUD) 202 Program offers subsidized housing and rental assistance for low-income individuals over 62 years of age who meet the eligibility requirements of the federal program. These housing communities often help residents access a variety of healthcare and supportive services as well as transportation.

**Incontinence**: Loss of bladder (urine) or bowel movement control. This condition can be transient, intermittent, or permanent. Incontinence nurse specialists and physicians can diagnose the kind of incontinence that is present and suggest ways to effectively manage the situation through exercises and timed toileting programs.

**Independent Living**: A residential location that may or may not provide hospitality or supportive services. Includes rental-assisted or market-rate apartments or cottages. Residents can choose which services they want. There may be an additional fee for some services.

**Informal Caregiver**: A family member, friend, or any other person who provides long-term care, generally without pay.

In-Home Care: This is often done by family members who become caregivers. Agencies also provide in-home care that is not medical in nature, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) or older adults or their families may hire in-home caregivers on their own. (See Definitions). Unlike home health care provided on a short-term basis, these services are not covered by Medicare but may be covered by Medicaid in your state.

Instrumental Activities of Daily Living (IADLs): A series of life tasks necessary for maintaining a person's immediate environment, e.g., shopping for food and medications, cooking, laundering, house cleaning, managing one's medication and finances. An elder may need help with IADLs and not need help with ADLs (See definition of ADL).

Licensed Practical Nurses or Licensed Vocational Nurses (LPN or LVN): LPNs or LVNs have one to two years of technical training. They assist RNs (see definition of Registered Nurses) with data collection, care planning and monitoring residents' conditions. They are licensed to administer medications and treatments, transcribe physician orders, etc. Most of the licensed nurses working in nursing homes are LPNs or LVNs, especially on the evening and night shifts.

Living Will: An advance directive that guides your family and health care team through the medical treatment you wish to receive if you are unable to communicate your wishes. According to your state's living will law, this document is considered legal as soon as you sign it and a witness signs it, if that is required. A living will goes into effect only when you are no longer able to make your own decisions.

Long-Term Care (LTC): A term used to describe the care needed by someone who must depend on others for help with daily needs. LTC is designed to help people with chronic health problems or dementia live as independently as possible. While many people think that long-term care happens only in a nursing home, in fact most long-term care is given by family caregivers in the care recipient's home.

**Long-Term Care Insurance**: Private insurance designed to cover (pay for) long-term care services provided at home, adult day care, assisted living or a nursing home. There are many long-term care insurance policies with a wide range of benefits. Medicare and Medicare supplemental insurance policies (Medigap) do not pay for long-term care.

**Long-Term Care Services**: A variety of services and supports to meet health or personal care needs over an extended period of time. This includes medical and non-medical care to people with a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care assists people with Activities of Daily Living (ADLs), such as dressing, bathing, and using the bathroom. Long-term care can be provided at home, in an adult day care center, an assisted living community, or a nursing home. In order for state Medicaid programs to pay for home care or assisted living for an individual that meets the income eligibility requirements, the individual must require a level of care equivalent to that received in a nursing home.

**Medicaid**: The federally- and state-supported, state-operated public assistance program that pays for healthcare services to low-income people, including older adults or disabled persons who qualify. Medicaid pays for long-term nursing home care and some limited home health services, and it may pay for some assisted living services, depending on the state. It is the largest public payer of long-term care services, especially nursing home care. Each state can determine the breadth and extent of what services it will cover above a certain federally required minimum.

**Medical Director**: A physician who oversees the medical care and other designated care in a healthcare organization or care setting. The medical director is responsible for coordinating medical care and helping to develop, implement, and evaluate resident care policies and procedures that reflect current standards of practice.

**Medical** (**Healthcare**) **Power of Attorney**: The advance directive that allows you to select a person you trust to make decisions about your medical care if you are temporarily or permanently unable to communicate and make decisions for yourself. This includes not only decisions at the end of your life, but also in other medical situations. This document is also known as a "health care proxy," "appointment of health care agent or health care surrogate," or "durable power of attorney for health care." This document goes into effect when your physician declares that you are unable to make your own medical decisions. The person you select can also be known as a health care agent, surrogate, attorney-in-fact, or health care proxy. With a medical power of attorney you can appoint a person to make health care decisions for you in case you are unable to speak for yourself.

Medicare: The federal program that provides medical insurance for people aged 65 and older, some disabled persons and those with end-stage renal disease. It provides physician, hospital, and medical benefits for individuals over age 65, or those meeting specific disability standards. Benefits for nursing home and home health services are limited to short-term rehabilitative care. There are different parts of Medicare which cover specific services if you meet certain conditions. For detailed information, visit the website (www.medicare.gov) or call for assistance: 1-800-Medicare.

Mild Cognitive Impairment: A transition stage between the cognitive decline of normal aging and the more serious problems caused by Alzheimer's disease. The disorder can affect many areas of thought and action, such as language, attention, reasoning, judgment, reading and writing. However, the most common variety of mild cognitive impairment causes memory problems. According to the American College of Physicians, mild cognitive impairment affects about 20 percent of the population over 70. Many people with mild cognitive impairment eventually develop Alzheimer's disease, although some remain stable and others even return to normal.

**Nurse Practitioner (NP)**: A registered nurse with advanced education and training. NPs can diagnose and manage most common, and many chronic, illnesses. They do so alone or in collaboration with the health care team. NPs can prescribe medications and provide some services that were formerly permitted only to doctors. There are a number of types of nurse practitioners (e.g. geriatric, adult, or psychiatric) that work with older adults.

**Nursing Home or Skilled Nursing Facility (SNF)**: A residential care setting that provides 24-hour care to individuals who are chronically ill or disabled. Individuals must be unable to care for themselves in other settings or need extensive medical and/or skilled nursing care.

Ombudsman/Long-term Care Ombudsman: An Ombudsman is an advocate for residents of nursing homes, board and care homes, and assisted living. Ombudsmen provide information about how to find a nursing home or other type of LTC facility and what to do to get quality care. They are trained to resolve problems. An ombudsman can assist you with expressing complaints, but this requires your permission because these matters are held confidential. Under the federal Older Americans Act (OAA), every state is required to have an Ombudsman program that addresses complaints and advocates for improvements in the long-term care system. To find the ombudsman nearest you, visit the National Long-Term Care Ombudsman Resource Center at www.ltcombudsman.org.

Palliative Care: Care that focuses on the relief of the pain, symptoms, and stress of serious illness. The goal is to improve quality of life for patients and families. Palliative care is appropriate at any point in an illness, not just for end-of-life care, and it can include treatments that are intended to cure as well as comfort. It is both a philosophy of care (as is hospice) as well as an approach to caring activities. Palliative care is provided by trained staff in a hospital, home, nursing home, assisted living community or hospice. For more information, visit GetPalliativeCare.org or the National Hospice and Palliative Care Organization (NHPCO) (www.nhpco.org).

Person-Directed Care/Person-Centered Care: An approach to care in which the voices of individuals needing care and those working closest with them always comes first. Core person-directed values include dignity, respect, purposeful living and having the freedom to make informed choices about daily life and health care. It involves a continuing process of listening, trying new approaches, seeing how they work, and changing routines and organizational approaches in an effort to individualize and de-institutionalize the care (e.g., nursing home or assisted living environment).

**Personal Care**: Non-skilled nursing service or care, such as help with bathing, dressing, eating, getting in and out of bed or chair, moving around, using the bathroom, or any other activity of daily living (ADL) required or desired by the individual needing care.

**Primary Care Provider (PCP)**: This term almost always refers to doctors, nurse practitioners or physician assistants who provide routine care and preventive

care (before people are sick). PCPs diagnose and treat common medical problems, determine how urgent these problems are, and may refer patients to other specialists if needed. PCPs practice in the community, not a hospital or other healthcare facility. Some PCP's follow their patients into the hospital, while others do not. Sometimes a "hospitalist" is assigned to the patient who will likely communicate with your PCP while you're in the hospital.

**Provider**: A provider is typically a professional healthcare worker, agency, or organization that delivers health care or social services. Providers can be individuals (doctors, nurses, social workers, and others), organizations (hospitals, nursing homes, assisted living communities, or continuing care retirement communities), agencies (e.g., home care and hospice), or businesses that sell healthcare services or assistive equipment (e.g., colostomy care supplies, wheelchairs, walkers, etc).

Registered Nurse (RN): A graduate from a formal nursing education program (three to four years) who has passed a national examination and is licensed to practice by the state board. RNs assess, plan, implement, teach, and evaluate a person's nursing care needs, along with the rest of the healthcare team. In addition, they may do data analysis, quality assurance, research implementation, and research. They work in all types of health care settings and educational programs. In addition to providing care to individuals, RNs also works with groups of people or populations to determine how to promote health and prevent problems on a larger scale.

**Rehabilitation** ("**Rehab**"): Services to help restore mental and physical (bodily) functions lost due to injury or illness. Rehabilitation may be given at the hospital or in a nursing home, some assisted living residences, a special facility or the patient's home. The types of services offered generally include physical therapy, occupational therapy, speech therapy, social services, and nursing.

**Resident**: A person who lives in a residential long-term care setting, such as a nursing home or assisted living community.

**Resident Council**: Required by nursing home regulation, the Resident Council gives persons living in care settings the opportunity to communicate concerns to administrators, work for resolutions and improvements, and provide feedback

about new programs (e.g., food services). Independent and empowered Resident Councils can play a crucial role in voicing concerns, requesting improvements, supporting new residents and supporting efforts to make care and life in the care setting the best it can be.

Respite Care: Temporary (a few hours or up to a few days) care to offer relief for the family caregiver. Respite care may be given in the elder's home, a community-based setting such as adult day care, an assisted living facility, or a nursing home. It can be scheduled regularly (for example, two hours a week) or provided only when needed. This service can be particularly valuable for family members taking care of persons with dementia.

**Senior Centers**: Centers that provide services to senior citizens, aged 60 and over. They may offer social activities (like music or crafts), meals, health screenings (such as blood pressure checks, diabetes monitoring), learning programs, creative arts and exercise classes.

Skilled Care/Nursing Care: This level of care includes help with more complex nursing tasks, such as monitoring medications, giving injections, caring for wounds, and providing nourishment by tube feedings (enteral feeding). It also includes therapies, such as occupational, speech, respiratory and physical therapy. This care can be given in a patient's home or in a care setting. Most insurance plans require at least some level of skilled care need requiring the services of a licensed professional (such as a nurse, doctor, or therapist) before they will cover other home-care services.

**Subacute Care/Rehabilitation**: Care or monitoring after hospitalization in a less intensive and less costly setting, such as a rehabilitation service in a nursing home or in a special unit in a hospital. Subacute care is usually short-term. Check with Medicare to see specifics of how it is covered. (See definition of Medicare.)

Survey (or State Survey): As used in long-term care, the word survey refers to the process a state agency uses to ensure that all nursing homes that receive federal and state funding are in compliance with state and federal regulations, including standards of care. All federally funded nursing homes are surveyed at least annually to ensure compliance with CMS (Center for Medicare & Medicaid Services) regulations. The results of the latest survey must be posted

and readily accessible in all nursing homes and is also available online at Nursing Home Compare (www.medicare.gov/NHcompare/).

**Telephone Reassurance Program**: A service that provides reassurance calls to check on the safety and well-being of older adults at home. These calls can also offer reminders, such as when to take medication. This type of service may be purchased or volunteer service organizations may provide it.

**Transition**: A move from one care setting (hospital, home, assisted living, nursing home) to another. Care during transitions involves coordination and communication among patients, providers, and family caregivers. For example, it is critical that there is a way to assure that the proper medication list is communicated from setting to setting.

**Turnover**: This is the average percentage of staff who stop working at a care setting each year. Virtually all healthcare organizations (hospitals, nursing homes, assisted living, etc.) track and measure the number of staff who stop working (turnover) and the length of stay of staff (retention) in the same or similar jobs. A nursing home or assisted living community with high turnover rates means that new caregivers are constantly being hired and trained.

**Visiting Nurse**: A term often used for a nurse who visits patients in their homes. The job of a visiting nurse includes checking vital signs (such as heart rate and blood pressure), and assessing physical and mental health and how well the person is functioning at home. The visiting nurse consults with the physician regarding treatment plans, implements the treatment plan, and may education and train families and other caregivers to perform care tasks. Some, but not all, are affiliated with the Visiting Nurse Association of America agencies.

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