

UNDERSTANDING LEVELS OF HOME AND COMMUNITY-BASED SERVICES AND RESIDENTIAL CARE

(A companion piece to the tri-fold pamphlet of the same title)

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CurePSP is committed to providing its constituents – patients, families, caregivers, and healthcare providers – with up-to-date educational information about topics relevant to living with prime-of-life neurodegenerative diseases.

Among the ever-increasing population of older and/or disabled adults and their caregivers and family members, confusion and misunderstanding abound with regards to the broad spectrum of available choices for home and community-based services, residential facilities, long-term care, and rehabilitation. Part of the reason for this is that, throughout the 50 states, a lack of consistency exists in terminology, regulations, licensing, on-site services, costs (up-front and add-ons), amenities, and more.

This article will help you to understand the spectrum of services and care options for adults with physical impairments or chronic disease. You will become aware of questions to ask when searching for a type of care or care facility.

Each of the services and care levels discussed are potentially appropriate for people with PSP and related diseases. That said, it is most important and acceptable for family caregivers to inquire as to a staff's experience with prime-of-life neurodegenerative disorders like PSP. Family members can and should make providers aware of the symptoms and needs of these patients, and offer to ascertain educational materials, speakers, and in-service training for staffs.

I. ADULT DAY SERVICES (ALSO CALLED OLDER ADULT DAY PROGRAMS, OR ADULT DAY CARE CENTERS)

Adult Day Services are community-based, daytime group programs for cognitively or functionally limited adults who require supervision, socialization, structure and some personal assistance. The programs are provided in a safe and secure setting, sometimes in stand-alone buildings and sometimes within hospital campuses or Continuing Care Retirement Communities (CCRC's).

Adult day centers feature exercise, socialization, and recreational activities.

Other possible components are:

- Transportation

- Health-related services, such as medication reminders, incontinence care, nurse oversight
- Meal and snack
- Social Work services, such as counseling, information and referral, care coordination

Features and fees vary from program to program, and state to state. It is important to ask specific questions about what is and is not included in any one center.

Note: In addition to the benefits to participants, Adult Day Programs afford family caregivers much-needed respite from the demands of caregiving full-time for someone who needs constant supervision.

II. MEDICAL/REHABILITATION SERVICES: PHYSICAL, OCCUPATIONAL, AND SPEECH THERAPIES

Even with a neurodegenerative disorder such as PSP, rehabilitation therapies can offer helpful safety instructions and can help to re-stabilize an individual's functioning. The skilled rehabilitation therapies of Physical Therapy, Occupational Therapy, and Speech Therapy are provided in multiple different settings:

In-patient Rehabilitation takes place in either a dedicated rehabilitation center or institute, or in a rehabilitation unit of long-term care facilities or hospitals. To qualify for admission to an in-patient rehab center, one must meet specific criteria related to one's ability to participate in and benefit from daily, intensive, multiple therapy sessions.

Day Rehabilitation Treatment Centers offer community-based treatment in an out-patient setting or clinic. Some day rehab programs are housed within a larger rehabilitation institute. The patient must meet specific criteria related to ability to undertake several hours of skilled therapy throughout the day.

Out-patient centers provide therapy in a community clinic, hospital, or agency. Therefore, as with Day Rehabilitation, the person must be able to leave his home for therapy. Unlike day rehabilitation, out-patient therapy consists of a one-hour session at a time, of physical, speech, or occupational therapy.

Home Health Care: If a patient is deemed to be "home-bound," then skilled care, or rehabilitation therapies along with visits from a Registered Nurse, can take place in one's home. During the time that a case is open for home rehab, the patient is also eligible to receive a bath aide. However, once the course of rehabilitation ends, so too does the bath service.

Medicare or insurance covers skilled rehabilitation therapies, subject to initial evaluation and periodic re-evaluations.

III. NON-MEDICAL OR PERSONAL IN-HOME CARE

Non-medical or Personal Home Care refers to **personal care with activities of daily living**, such as bathing, grooming, and dressing. In-home care providers are also called companions, personal aides, home health aides, homemakers, or personal caregivers. These kinds of home-care providers work for themselves (privately), or are employees of an agency that takes responsibility for setting fees, making caregiving assignments, insuring and bonding the caregivers, and training them. Home health agencies offer caregiving services in any of 3 ways: 1) by task, e.g. bathing assistance, 2) by blocks of time or shifts, e.g. 4 hours or 8 hours, or 3) live-in. For the most part, personal care is a *private* expense. Medicare or health insurance does not cover personal care. However, it *may* be covered by one's long-term care insurance policy. In addition, some states, through their local Area Agencies on Aging, offer subsidized, and usually "capped," personal care services for individuals with limited financial means.

IV. INDEPENDENT LIVING: SENIOR APARTMENTS, ACTIVE SENIOR COMMUNITIES, RETIREMENT HOMES

Independent Living is a broad term that encompasses **Senior Apartments, Active Senior Communities, and Retirement Homes**. These types of buildings are age-restricted (e.g. 55 and over, 65 and over) and are not licensed to provide personal care or nursing services. Basic services include: a certain number of meals (per day, week, or month, depending on the particular facility), housekeeping and/or laundry (This could mean laundry of only linens, or also of personal clothing), social activities, well-being checks, transportation to doctors and outings. For an additional cost, personal care assistance can be purchased, either on-site or from an outside home care company (see Number III above). Some Independent Living buildings are federally or state subsidized; however, most are private-pay. Families need to ask detailed, specific questions about what features and services are and are not included in the cost of any one Independent Living facility. Costs and inclusions can vary greatly.

V. ASSISTED LIVING

Assisted Living refers to an entire building, a specified unit of a building, or a part of a Continuing Care Retirement Community (CCRC) that is *licensed to provide 24-hour-a-day personal care* for activities of daily living, in addition to offering the basic services of independent living (see IV above): i.e. meals, housekeeping, and social programs. However, the assisted living license – and its definition of which care services or how many – can differ from state-to-state. *Assisted Living is the fastest-growing type of residential care with the most discrepancy in definition*. Again, it is crucial for prospective residents to ask very specific questions as to the type of care – and caregivers – offered in a particular building. In general, assisted living caregivers are trained, certified aides who assist with daily tasks, for example bathing, dressing, escort to meals, medication set-up and dispensing, and routine checks on

residents. The role of registered nurse may vary from facility to facility. At the least, the RN should be the one who sets up and stores a person's medications. The aide may be the person who delivers the medicines to the resident. Even the definition of the term "delivers" the medication may vary. "Deliver" could mean: to drop off the medication in the person's room; to pour it into the hand of the resident, who then takes the medicine herself; or to administer the medicine to the person. Assisted Living facilities may also supply transportation to and from medical appointments, errands, and group outings. Some facilities may offer rehabilitation therapies, hospice care, and specialized care for different disorders (such as dementia). If the facility offers rehab or hospice, the same regulations for physician referral, evaluation, and insurance or Medicare coverage apply as when someone is living in his own home. In addition, residents are free to choose their own rehabilitation provider, even if the facility houses its own or another company on-site.

VI. SUPPORTIVE LIVING

Supportive Living refers to State-funded facilities – in some but not all states – for seniors who need assistance with daily living, as in Assisted Living (above). Individuals need to check with their own state's Area Agency on Aging, or a social worker familiar with community resources.

VII. SKILLED NURSING FACILITIES (SNF'S) OR NURSING HOMES

Skilled nursing facilities are institutions that are licensed and regulated by state and federal governments to provide room and board, daily personal care, supervision, medical care and oversight, and 24-hour-a-day care from registered nurses (RN's) and certified nurses' aides (CAN's). Physicians (MD's) serve as medical directors of skilled nursing facilities. Many, if not most, nursing homes are certified for Medicare and/or Medicaid coverage, for a certain number of "beds" (i.e. residents) per facility. *Medicare certification allows for short-term rehabilitation stays only.* Medicare and supplemental insurance policies usually cover 100 days of nursing home care that results from a hospitalization and meets the criteria for rehabilitation therapies. For those people who are not on Medicaid or the short-term allowance of Medicare, skilled care is a private expense and/or may be covered by a long-term care insurance policy.

Skilled nursing facilities are composed of various types of care:

- *Custodial or Basic Care:* Assistance with personal care (activities of daily living such as bathing, dressing, or toileting); ambulation, safety, supervision, medication dispensing.
- *Skilled Care:* Treatments or procedures, such as wound care; intravenous medications or feedings; or managing of machinery such as respirator or ventilator.
- *Sub-Acute Care:* Rehabilitation from an acute illness, injury, or exacerbation of a disease process. This is the "short-term rehabilitation stay" discussed above.

- *Respite Care*: Short-term or trial stays in the facility; or “vacation stays” while the family caregiver takes a break. Respite is a private-pay service. Additionally, some states and private or non-profit foundations may offer respite funds.

VIII. CONTINUING CARE RETIREMENT COMMUNITIES (CCRC’S)

Continuing Care Retirement Communities (CCRCs) are residential campuses comprised of a number of buildings, offering a range of care options, all on the same grounds. Within such a community there might be independent living, assisted living, and skilled nursing. However, not all CCRC’s provide all levels of care. Most CCRC’s require an upfront investment of some amount, as well as monthly payments. Specifics differ from community to community, so it is important to ask questions and do comparison “shopping.”

IX. SPECIAL CARE UNITS (SCU’S) AND MEMORY CARE UNITS (MCU’S)

Some states license, and thereby recognize the designation of, special units that exist *within* facilities that are already licensed to give care. Examples of specialty licenses are “memory care assisted living” and “memory care skilled nursing.” If facilities advertise as “memory care,” and are located in states that assign such licenses, then the facility must have that license.

X. VIAL OF LIFE

No matter where your loved ones live or participate in programs such as those described here, they should always keep with them, or in a specified location in their living space, a “Vial of Life.” This paper, which some people roll up and keep in a bottle in their refrigerator – hence “Vial of Life” – should contain the following information:

- Date updated
- Name, Address, Phone Number
- Medications/Dosages/Frequency or Times
- Drug Allergies
- Medical Conditions
- Surgeries (including Year)
- Blood Type
- Power of Attorney for Healthcare

■ 2 Emergency Contacts

Because information can change, you should regularly review and update the Vial of Life.

XI. HELPFUL RESOURCES

AARP	www.aarp.org
Area Agencies on Aging	www.aoa.gov
Aging Life Care Association	www.aginglifecare.org
Eldercare Locator	800/677-1116, https://eldercare.acl.gov
Medicare	800/MEDICARE www.medicare.gov Nursing Home Compare Obtain the official government handbook <i>Medicare & You</i> , Centers for Medicare and Medicaid Services (CMS) Publication from U. S. Department of Health and Human Services Centers for Medicare and Medicaid Services - 7500 Security Boulevard - Baltimore, Maryland 21244-1850

National Center for Assisted Living (NCAL) of the American Health Care Association

202/842-4444, www.ahcancal.org

National Institute on Aging www.nia.nih.gov - Long-Term Care

Social Security Administration 800-772-1213 www.ssa.gov

Veteran's Administration Helpline 800-827-1000 www.va.gov

Caregiver Associations:

Family Caregiver Alliance www.caregiver.org

National Alliance for Caregiving 301/718-8444 www.caregiving.org

National Family Caregivers Assoc. 800/896-3650 www.nfcacares.org

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