CurePSP is the leading nonprofit organization working to improve awareness, education, care, and cure for devastating prime of life neurodegenerative diseases. These include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and others. They often strike when people have careers, family responsibilities, and active lives. Their symptoms are incapacitating and there are no known causes, treatments, or cures.

Research has shown that there are important links between prime of life diseases and more common neurodegenerative conditions, such as Alzheimer’s disease and Parkinson’s disease. Your support will help advance this research, provide resources for families and caregivers of patients, and better educate the healthcare community. Together we are unlocking the secrets of brain disease.

CurePSP is a not-for-profit 501(c)(3) organization. Gifts and pledges of support are encouraged and donations are tax deductible to the extent allowed by law.

Levels of Care
Understanding levels of home and community-based services and residential care.

Resources for further information

The following pages will define and differentiate the wide spectrum of home and community care choices:

- Adult Day Services (Also called Older Adult Day Programs or Adult Day Care Centers)
- Medical/Rehabilitation Services
- Non-medical or Personal Home Care
- Independent Living (Also called Senior Apartments, Active Senior Communities, or Retirement Homes)
- Assisted Living
- Supportive Living
- Skilled Nursing Facilities (SNF’s) or Nursing Homes
- Continuing Care Retirement Communities (CCRC’s)
- Special Care Units (SCU’s) and Memory Care Units (MCU’s)
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 pamphlet will help you to understand the spectrum of options and to become aware of questions to ask when searching for a type of care or care facility.

THE BASICS

1. Adult Day Services (Also called Older Adult Day Programs, or Adult Day Care Centers)
   Community-based, daytime group programs for cognitively or functionally limited adults who require supervision, socialization, structure, and some personal assistance.
   *Include:* exercise, socialization, recreational activities.
   *May include:* transportation, meal and snack, incontinence care, nurse oversight, medication reminders, social work services.
   Features and fees vary from program to program, and state to state.
   Can provide much-needed respite for full-time family caregivers.

2. Medical/Rehabilitation Services: Physical, Occupational, and Speech Therapies
   In-patient Rehabilitation: Intense rehabilitation stays in an institute or unit dedicated for such purpose.
   *Day Rehabilitation Programs:* Community-based, day rehabilitation treatment programs.
   *Outpatient Therapy:* Rehabilitation therapy in a community clinic.
   *Home Health Care:* Skilled Care (Registered Nurse) and Therapies for patients designated as “home-bound.”
   Medicare or insurance covers the above, subject to initial evaluation and periodic re-evaluations.

3. Non-medical or Personal Home Care
   Assistance with activities of daily living such as bathing, grooming, dressing.
   Provided by in-home care providers referred to by various terms: home health aide, companion, personal caregiver, homemaker.
   Offered through an agency or by private individuals.

Not covered by Medicare. These are private pay services although some may be covered by one’s long-term care insurance. In addition, some states offer subsidized personal care services for individuals with limited financial means.

4. Independent Living: Senior Apartments, Active Senior Communities, Retirement Homes
   Age-restricted (e.g. 55 or over) residences that are not licensed to provide personal care or nursing.
   Some are federally or state subsidized; most are private-pay.
   Basic services may include a certain number of meals (per day, week, or month), housekeeping and, or laundry (laundry of only linens, or also personal clothing?), social activities, well-being checks, transportation to doctors and outings.
   Personal care assistance can be purchased, on-site or from an outside home care company, for an additional cost.

5. Assisted Living
   A building, a specified unit of a building, or a part of a Continuing Care Retirement Community (CCRC) that is licensed to provide personal care for activities of daily living for 24 hours a day, in addition to the basic services of meal, housekeeping, and social programs. States differ regarding which, or how many, services come with “assisted living,” and which can be purchased for additional cost.
   Does not provide skilled medical or nursing (RN) care such as wound care or administration of medications.

6. Supportive Living
   State-funded facilities – in some states – for seniors who need assistance with daily living (as in Assisted Living, above).

7. Skilled Nursing Facilities (SNF’s) or Nursing Homes
   Licensed and regulated by State and Federal governments to provide room and board, daily care, supervision, medical care and oversight. 24-hour registered nurses (RNs) and certified nurses’ aides (CNAs).
   Certified for Medicare and/or Medicaid coverage, for a certain number of beds. Note: Medicare certification allows for short-term rehabilitation stays only. Otherwise, private pay and/or long-term care insurance.

Types of Care Available in Skilled Facilities:

1. Custodial or Basic Care: Assistance with personal care, ambulation, safety, supervision, medication dispensing.
2. Skilled Care: Treatments or procedures (such as wound care), intravenous medications or feedings, managing of machinery such as respirator or ventilator.
3. Sub-Acute: Rehabilitation from an acute illness, injury, or exacerbation of a disease process; covered by Medicare and supplemental insurance.
4. Respite Care: Short-term or trial stays; “vacation stays” while family caregiver takes a break; private pay or occasionally through state or private grants.

8. Continuing Care Retirement Communities (CCRC’s)
   Residential communities that offer a range of care options (e.g. independent living, assisted living, skilled nursing) on a single campus.
   Not all CCRC’s provide all levels of care.
   CCRC’s require monthly payments in addition to an upfront investment of some sort.

9. Special Care Units (SCU’s) and Memory Care Units (MCU’s)
   Some states license, and thereby recognize the designation of, these special units that exist within facilities that are already licensed to give care.
   For example, “memory care assisted living” or “memory care skilled nursing.”