

Understanding Professional Long-Term Care



It is common to require more assistance over time as people age and live with chronic or progressive health conditions. Many people diagnosed with progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) or multiple system atrophy (MSA) have partners, relatives or friends who are able to provide the necessary care to support their needs. Still, some people do not have the support system they need to offer this care. Even for those who do have care partners, many still decide that additional professional care is needed for the safety and well-being of the individual and their family.

Many of us do not think about exploring professional in-home, adult day or facility-based care (“long-term care”) until faced with the need to consider it. Services, availability and cost of professional long-term care greatly vary based on many factors, including type of care and geographic area. Exploring options for long-term care can be confusing or feel overwhelming.

Through providing brief summaries of different types of professional care, our aim is to hopefully clarify the options as you make care decisions that are right for you.

1. In-Home Care

- Services can include companionship (e.g., games), meal preparation, medication reminders, light housekeeping, assistance with walking or personal care (e.g., bathing, grooming, dressing).
- In-home care is provided through an agency or by private individuals.

2. Adult Day Services

- Community-based, daytime group programs for adults with decreased cognitive and/or physical functioning.
- Adult day care centers offer monitoring, socialization, recreational activities, exercise, meals or snacks.
- Adult day health centers can often additionally offer personal care services, such as toileting or sometimes even showering, as well as some medical or skilled care services.

3. Independent Living: Senior Apartments, Active Senior Communities, Retirement Homes

- Age-restricted (e.g., 55 and over) residences are often not licensed to provide personal or nursing care services.
- Basic services may include a certain number of meals (per day, week or month), housekeeping or laundry, social activities, wellness checks, outings and transportation for medical appointments.
- Some independent living communities offer the option to purchase à la carte in-home care or other services for an additional cost.

4. Assisted Living Facilities

- This type of facility, which may be independent or could be a part of a larger retirement community, is licensed to provide closer monitoring and assistance with daily care, such as showering, in addition to meals, housekeeping and social programs.
- Services offered by assisted living facilities may vary by geographic location and by individual facility.
- Assisted living facilities do not provide skilled nursing care such as wound care or management of life-prolonging medical interventions (e.g., feeding tube).

- Many assisted living facilities offer “respite stays,” which are short-term stays (typically a few days to a week or two) for people who otherwise do not live there. Someone may tap into this service as a trial stay or if the family care partner needs a break, goes on a trip, or is recovering from a surgery or illness.

5. Skilled Nursing Facilities

- These facilities are licensed and regulated by state and federal governments to provide room and board, daily care, supervision, medical care and oversight, 24-hour registered nurses and certified nursing assistants.
- Care available in skilled nursing facilities can include:
 - Custodial or basic care: Assistance with personal care, ambulation, safety, supervision and medication dispensing
 - Skilled care: Treatments or procedures (such as wound care), intravenous medications or feeding and management of machinery (such as respirator or ventilator)
 - Sub-acute: Rehabilitation from an acute illness, surgery or injury (meant to be temporary and is often covered by Medicare and other health insurances)
 - Respite: Short-term or trial stays for people who otherwise do not live there (similar to respite offered at assisted living facilities)

6. Continuing Care Retirement Communities (CCRCs)

- These residential communities offer a range of care options (e.g., independent living, assisted living, skilled nursing) on a single campus, although not all CCRCs provide all levels of care.
- CCRCs typically require monthly payments in addition to an upfront investment of some sort.

7. Special Care Units and Memory Care Units

- These specialized units are designed to provide care for people with moderate to significant cognitive challenges.
- These units may be standalone or may exist within an assisted living or skilled nursing facility.

A note about the cost of professional long-term care in the United States: At this time, professional long-term care is largely paid for privately by individuals and families. Medicare covers limited in-home care assistance, usually for bathing, while someone is getting Home Health rehabilitation. In addition, Medicare allows for short-term rehabilitation stays in skilled nursing facilities. Medicaid and veteran’s benefits often do cover in-home care and facility-based care, but this can depend on eligibility criteria, geographic area and availability. For those who have previously paid into it, long-term care insurance does pay for in-home, adult day and facility-based care, but how much and for how long is dependent on a person’s individual plan. Some counties or states sometimes offer subsidized care services for individuals, most often for those who meet certain financial eligibility requirements. It is important to understand and consider the cost of care when exploring these services and make the right decisions for you and your family. Social workers, elder law attorneys, geriatric care managers and financial planners may be able to assist you in this process.

Keep in mind that many people struggle with considering or pursuing professional care because of a sense of guilt or obligation. These feelings are valid and understandable. Many families will share that while the decision and transition may not have always been easy, ultimately, professional care helped support the health-related quality of life of both the person with the diagnosis and of family care partners. Professional care can provide engagement, safety and structure for the person with PSP, CBD or MSA, while also offering families an important opportunity for respite time and the peace of mind that their loved one is being cared for. It is helpful to discuss these decisions with your support system and enlist assistance in the process.



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