

Professional in-home care: Where to start and what to ask



An educational resource for family care partners

When living with progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) or multiple system atrophy (MSA), one of the trickiest and often more overwhelming challenges is knowing how proactive to be around implementing new or different strategies for managing care. Many individuals and families consider hiring professional care to attend to someone's evolving and increasing symptoms and care needs over time. Professional in-home care can help someone maintain independence, safety and engagement as well as provide care partners with the extra support and assistance they need throughout their journey.

Knowing where to start the process of hiring professional care, figuring out what home care could look like for you and how to go about researching care options can feel daunting or confusing. In this document, we have compiled common questions and advice people share about in-home care. We also provide information to help clarify the process, breaking it down into steps. It is our hope that this resource that will allow you to better understand in-home care services so that you can find the right care support for you and your family.

CurePSP is dedicated to the support, awareness, care and cure of PSP, CBD and MSA. Please contact us at info@curepsp.org or 1-800-457-4777 if you have any questions or if we can be of further support or assistance. You can also visit www.curepsp.org for more information and resources.

Step 1: Understand in-home care.

What is in-home care?

In-home care provides professional (paid, as opposed to family) caregivers for additional support and assistance. This can be in your home or even for additional one-on-one services for those who are living in long-term care facilities. In-home care can offer companionship and mental stimulation for the care recipient, monitoring with safety, assistance with ambulation, hands-on personal care and help with household tasks. It can be just one or all of these care tasks. Family care partners frequently utilize in-home care to be able to step away for some time, or “respite,” with the peace of mind that their loved one is being cared for. Even hiring minimal in-home care, such as two or three times per week for a few hours, can make a world of difference. There is always the option to increase hours of care over time as needed, if it is financially feasible. For many, in-home care can prevent burnout for families and becomes an important aspect of the support system, and ultimately enhances safety, quality of life and the ability to stay in the home for longer.

How do I know it is the right time to consider or hire in-home care?

PSP, CBD and MSA are challenging diseases to manage without help, but when to hire in-home care is not always clear and is a very individual decision. In the earlier stage of disease, it is possible for your loved one to function independently. However, as the disease progresses, you may notice increasing difficulty with performing basic functions without help or safety risks. Many families will hire someone in the earlier stages of the diagnosis for companionship or just a little help in order to establish a relationship with an agency or caregiver and start getting used to professional care. You may want to start the process by asking your neurologist and/or social worker for their input and advice so that you can better understand the level of care required at various stages of disease progression. It is also important to consider not just the care support you need now but also what you may need down the road. Take into account how in-home care may help with the prevention of complications like a big fall or care partner burnout. Once they hire in-home care, many people report that they could have utilized the services earlier.

Factors to consider regarding the right time for professional in-home care:

- The age and physical health of the primary family care partner
- If you are the sole person providing care and if you have support from other family members or friends
- Other responsibilities you may have, such as work or other family members to attend to
- How much of your day is spent on caregiving tasks and responsibilities
- If you are finding that you are sleeping less or experiencing increased fatigue, more anxious or easily irritated, feeling hopeless or less interested in activities you used to enjoy, or not attending to your own health (e.g., missing medications or appointments)
- What time you have for yourself—to attend to your mental and physical health; spend time with your friends and other loved ones; do something enjoyable, relaxing or energizing
- Your comfort with your loved one's safety while you run errands or leave them alone for any length of time
- Your home setup for the person's care needs now and in the future, including ease of navigating the home space and availability of safety and adaptive equipment such as grab bars and a shower bench
- If your loved one, friends, family members or healthcare providers have shared their concerns about your health and needs
- Why you are considering professional in-home care at this time

We recognize that pursuing professional in-home care is often a big step. Trusting your care to an outside person, and having someone else in your personal space and part of your routine, is definitely a transition. It takes a great deal of courage and openness to consider bringing on additional support services.

It can be helpful to keep in mind that any in-home care services you hire do not have to be set in stone and you have the right to advocate for your care needs. This could be increasing, decreasing or stopping services altogether; asking for caregivers to do or not do certain tasks while they are working for you (e.g., being more proactive); and finding a different caregiver if someone is not the right fit.

Not all people with PSP, CBD or MSA have a clearly defined family care partner or one who lives with them or is able to help. Many diagnosed people who live alone, or who want to support their family, will initiate hiring professional care services.

Step 2: Identify your home care needs.

Most in-home care is “non-medical,” meaning they are usually not doing things like wound care, tube feeding, tracheostomy or ventilator care, suctioning, placing catheters or distributing medications (they can do medication reminders). They also often cannot cut nails.

Some in-home care agencies or caregivers are able to perform these tasks, but they may require special licensing, the involvement of a nurse and be more expensive. Below we describe the most common non-medical in-home care services.

Home helper services

- **Transportation and errands:** Medical appointments, grocery shopping, picking up prescriptions
- **Meal planning and preparation**
- **Light housekeeping:** Vacuuming, laundry, changing bed linens, cleaning and putting away dishes

Companionship and monitoring

- **Socialization and activity:** Gardening, playing games, crafting, prompting exercise, going out to a park/movie/mall/museum, taking a walk
- **Respite:** A break from the caregiving role for the family care partner to attend to their own physical and mental well-being

Personal care services

- **Mobility:** Helping to get up and down from a chair; support and safety for walking; reminders to use cane or walker; pushing in wheelchair
- **Bathing/showering:** Safety monitoring, washing, drying off, assistance with getting in/out of shower or bath
- **Grooming:** Shaving, brushing teeth, drying hair, applying lotion
- **Eating and drinking:** Feeding, cutting food, observing for safety or swallowing issues, reminders to slow down or to take sips of liquid between bites
- **Toileting:** Helping to get on/off toilet, pulling up/down pants, wiping

How do I determine the quantity and kind of in-home care we need?

Take time to reflect on	Comments
What assistance with tasks, activities or ambulation does the person require? What safety challenges to they have?	
What type of engagement would my loved one benefit from? <ul style="list-style-type: none"> • What activities do they enjoy? • What do they not enjoy? • Are there places they like to go? • Do they need prompting or monitoring for exercise? 	

Take time to reflect on	Comments
What time(s) of day or night do we need the most assistance? <ul style="list-style-type: none"> • Getting up and ready in the morning • Certain time of day when my loved one would otherwise be alone • Certain time of day when my loved one has particular difficulty getting around • Getting ready for bed • Over night • At mealtimes • Weekdays • Weekends • Other 	
Am I able to easily transport my loved one to doctor's appointments, etc.?	
What tasks around the house would I benefit from assistance with?	
How would I spend my time while a professional caregiver is there?	
Other care tasks or thoughts on professional in-home care:	

In addition, reflect on how to get started with in-home care or how to get used to the idea. Here are a few pointers:

- Start slow, if possible, and build up hours as your comfort level increases.
- Acknowledge and validate some of the normal concerns and emotions that can arise when embarking on the decision to hire professional care.
- Realize that employing in-home help should increase safety, decrease stress and likely prolong the person's ability to live at home.

As a family care partner, how do I spend my time when the professional caregiver is here?

We often hear care partners voice comments like, "It's been so long since I've had any time to myself, I can't imagine what I would do with it." For these reasons and others, we believe it is important for the family care partner to plan ahead as to how they will utilize their break or respite time. Write down an "appointment" with yourself to read, take a walk, make a phone call, see a friend or go shopping. Likewise, you can schedule time to go to the hairdresser, doctor, massage or an exercise class. Once you have made your plan, be sure to follow through with it. The idea here is for the family member to think in terms of taking care of themselves for this period of time. After having a break, family care partners often return feeling refreshed and rejuvenated.

Step 3: Understand the options.

Generally, professional caregivers are either self-employed ("private duty" or "independent") or are employed by an agency. Many families explore both options, considering the general pros and cons of both. No matter what, it is important that you find the care that you feel is right for your unique care, financial and family situation and needs.

In-home care agencies**Many in-home care agencies:**

- Will come up with an individualized plan of care and try to match a caregiver accordingly.
- Have a registered nurse on staff to supervise care services.
- Provide standardized training in dementia, personal care and first aid (and sometimes more) to their caregivers.
- Insure against in-home accidents, car accidents and injury of the clients and caregivers.
- Perform background checks, reference checks, Tuberculosis (TB) tests and drug tests.
- Will try to fill in with another caregiver if yours has to cancel (for example, if they are sick).
- Comply with HIPAA rules around privacy and confidentiality.
- Are regulated by local governing bodies.
- Are available via phone 24/7.
- Will try to replace a caregiver if you do not have good chemistry with that individual.

Some patients and families have shared that downsides of in-home care agencies can include:

- Tend to be more expensive than paying someone privately.
- May have minimum shifts by hours per day and/or days per week.
- May not always have the caregivers available to meet your requested shifts.
- May charge if you cancel a shift without enough notice or you have the caregiver leave earlier than their shift was scheduled to end.
- A non-medical in-home care company may not be able to work with someone with more complex medical interventions, such as a feeding tube, tracheostomy or ventilator, or they may be significantly more expensive.

Private duty/independent caregivers:

These caregivers are self-employed and do not work for an in-home care agency. Independent caregivers may have worked for an in-home care agency or long-term care facility, are retired, are in school (maybe even to go into health or nursing care) or perhaps were a family care partner themselves. They generally tend to be less expensive than agencies, and sometimes their fees may be flexible/negotiable.

Some patients and families have shared that downsides of independent caregivers can include:

- There is often no one to replace them if they have to call out.
- There may be no formal background/reference checks, or TB or drug testing. Or these are the responsibility of the family to pursue.
- They may have not had any formal care or first aid training.
- They may not be insured if they or the care recipient were to be injured during services.
- Interviewing, coordination, supervision, payroll and taxes are the responsibility of the family.

Step 4: Understand the costs.

Note: This particular section of this resource primarily pertains to people residing in the United States. If you live outside of the U.S., coverage and cost of in-home care may be different and it will be helpful to explore the specific options available in your area.

If I am paying out-of-pocket for in-home care, how much does it cost?

The large majority of non-medical in-home care is paid for privately, out-of-pocket. How much this costs varies greatly depending on where you live, as well as what kinds of services they are providing—for example, companionship and home helper services versus personal care; care during the day versus overnight. Another factor is whether you are hiring a caregiving agency versus a private duty/independent (not through an agency) caregiver. It can be \$15-\$40 per hour. Or more or less! Again, it varies greatly. Generally and unfortunately, the cost of professional care has been increasing in recent years.

Will my insurance cover in-home care?

- **Medicare and private health insurance:**

Medicare and most private health insurance typically do not cover in-home care.

Medicare and private health insurance will, however, cover “Home Health.” Home Health includes skilled nursing services and rehabilitation (physical, occupational, speech therapy) in the home. Home Health requires a referral from a doctor or advanced practice provider (physician assistant, nurse practitioner). Someone may be referred to Home Health while recovering from a hospitalization, illness or injury. It is also common to refer to Home Health if a person would benefit from rehabilitation therapies but would have too much difficulty getting to an outpatient clinic and is in need of therapies in the home. To qualify, the person must be felt to be “homebound,” meaning that it takes considerable effort and special assistance to leave the house. While someone is getting Home Health, they may also qualify for an in-home aide, but this is often only for personal care (bathing a couple of times per week), and they will usually not be able to offer respite or home helper services. This is temporary, until the person is discharged from Home Health.

There is a tendency to hear the terms “home health” and “in-home care” used interchangeably, which leads to the frequent misconception that insurance covers home care. It is also common to hear people refer to in-home care as a “nurse” or “nursing service,” when most in-home care is not skilled nursing care. Unfortunately, insurance representatives are also sometimes not clear on the differences in terms and may mistakenly tell someone that their insurance covers in-home care, when they are in fact referring to Home Health.

- **Medicaid:**

Medicaid can often cover in-home care. This can include such programs as Personal Care Services (PCS), CAP in-home, or Special Assistance. Talk to your Medicaid worker about what programs are available in your area and what you may be eligible for. If you do not have Medicaid, contact your county’s Department of Social Services to see if you may be eligible and how to apply.

- **Long-term care insurance:**

Long-term care insurance does cover in-home care services. If you have paid into long-term care insurance, how much care will be covered and for how long will depend on your individual plan. You will have to contact your long-term care insurance company/agent to inquire about how and when to activate services and what your coverage will look like.

Are there other programs that cover or offer in-home care?

- **Hospice:**

For people under the care of hospice, the hospice agency can often offer a nursing assistant for baths a few times each week. They may also have a volunteer program where a volunteer can sit with someone and provide companionship for a couple of hours. Many families will still hire in-home care services when under hospice care.

- **Veteran's benefits:**

The Veteran's Administration (VA) may be able to cover or provide in-home care services to eligible veterans or dependents. If you or your partner/family member served in the military, talk to the VA service officer in your area about your benefits, what additional services you may be eligible for and the application process.

- **Government-supported programs:**

In the United States, the National Family Caregiver Support Program funds an array of programs to support older adults and their family care partners. Many states and counties will use these funds to support "respite" or "in-home aide" programs, which often provide a few hours per week of in-home care. Sometimes these programs have waiting lists, depending on their funding and availability at any given time. They may also have eligibility criteria based on care needs, income and whether or not someone has a family care partner. States or counties may also offer "respite vouchers" where you may qualify for a one-time voucher to help pay for respite care services. You can contact your local Department/Council on Aging, Senior Center, Department of Social Services and/or Area Agency on Aging to see what may be available in your area.

- **Nonprofit organizations:**

If you or your loved one lives with a specific medical diagnosis, there may be nonprofit organizations that offer in-home care programs or funding. These are not extremely common and may take some research to find them. They often have eligibility criteria around income or level of care needs. Additionally, they are often limited (by amount of respite support offered and/or timeframe to use it by) and may have strict criteria for how the funds can be used. CurePSP is proud to offer the Quality of Life Respite Grant - learn more by visiting www.psp.org/ineedsupport/respitegrant

While not in-home care, adult day care centers can also be an excellent option for an additional layer of care for families. Adult day care are centers where a person will go for a half-day or whole day one to five times per week for social engagement activities, meals and exercise. Some adult day care centers are able to offer medical or personal care, as well as transportation. Adult day care is often less expensive, for the same number of hours, compared to professional in-home care. Many people will utilize a combination of adult day care and in-home care to provide them with the comprehensive care and respite they need.

Step 5: Explore the options available in your area.

Where do I start?

If you are looking for an in-home care agency, you may find that there are a lot or very few, depending on where you live. There are small privately-owned agencies and there are franchises of nationwide agencies.

Utilize different resources at your disposal to explore options:

- Ask family, friends, support group members or your religious/spiritual community if they have had a positive experience with certain agencies or caregivers.
- Ask your doctor, social worker or other members of your healthcare team if they could suggest in-home care agencies with strong reputations.
- Sometimes people will use care locator websites, examples of which can be found at the end of this resource. Be aware that privately-paid-for care locators may not always represent a variety of objective opinions or reviews.
- Your local senior center or Area Agency on Aging or Department on Aging may maintain a list of local in-home care agencies and/or independent caregivers.

Remember that the same care is not right for everyone and people can have very different experiences with and perceptions of the same caregiver or agency. It is important to get a thorough idea of care services, fees, training, etc., to find the agency and/or caregiver that will best fit your care needs, personality, schedule and budget.

TIP: Once you decide to go the route of an in-home care agency or independent caregiver, if you have the time and energy, it can be helpful to contact at least two of them to schedule a consultation session.

Step 5: Consider these questions to help find the right care.

Are there questions I should ask when hiring an *in-home care agency*?

About their business	Comments
How do they sound over the phone? Hopefully they sound professional, organized, passionate and not too sales-y.	
How long have they been in business?	
Are they privately owned or are they a franchise of a national company?	
Do they have a current license to practice in the state? Are they certified by an accrediting body?	
How extensive are their reference checks, background checks and drug screenings?	
How many caregivers do they employ?	
What is their turnover of staff?	

Integrity of their care practices	Comments
What trainings do they provide their caregivers?	
How do they match their caregivers and clients?	
Do they offer their clients a “Patient’s Bill of Rights” that describes the rights and responsibilities of both the agency and the person being cared for?	
What procedures do they follow for ensuring patient confidentiality?	
Do they write a plan of care and update the plan as necessary?	

Oversight of care	Comments
Do they have their caregivers keep a log of what they did during their shift?	
How do they oversee care to ensure quality?	
Are staff members available on call around the clock, seven days a week, if necessary?	
Do they have a nursing supervisor available to provide assistance?	
What is their protocol for replacement if a caregiver cannot come when scheduled?	
What is their insurance process in the event that the caregiver or client is injured? Or if there is a situation where the caregiver steals or damages property?	

Provision and cost of care	Comments
What are their fees? Does this vary by time of day (e.g., day versus overnight, weekday versus weekend) or based on care services provided (companionship or home helper versus personal care)?	
What is their billing process?	
Do they have minimum days and/or hours for caregiving shifts?	
Do they accept long-term care insurance? Will they provide assistance with filing a claim?	
Will they work with people at end of life/under hospice care?	
Will they work with someone with complex medical interventions—feeding tube, tracheostomy, ventilator? Are their fees higher in these cases?	

Are there questions I should ask when hiring a *private duty/independent caregiver*?

Question to ask	Comments
Do they present themselves professionally?	
How long have they been a caregiver?	
Why did they become a caregiver?	
What formal training have they had as a caregiver?	
Do they know basic first aid? CPR? Heimlich?	
How many references can they provide?	
What do they charge?	
What days and hours are they available?	
How will they document their hours?	
Are they insured in the event that they or the client are injured?	
How will they notify you if they are running late or have to call out?	
Are they willing to run errands or offer transportation? Will they use their own car or your car for this? Do they have a valid driver's license? Do they have car insurance?	
How will you pay them? What is needed to document and track their income for tax purposes?	

What other factors can I consider to find and advocate for the right in-home care?

- Likes and dislikes (e.g., food, TV shows to watch, activities to do) of the person with PSP/CBD/MSA
- When medication reminders are needed
- Use of assistive devices like glasses, hearing aids, canes, walkers, grab bars, etc.
- Possible behavioral or cognitive challenges and how best to respond to them
- Mobility challenges (e.g., getting in or out of a chair, use of a gait belt for walking)
- Special diets or nutritional needs
- Exercises the caregiver can prompt or even do them with the care recipient
- Your household rules concerning:
 - Smoking
 - Caregiver's use of TV, telephone, small appliances, etc.
 - Can the caregiver eat your food or should they bring their own?
 - If the shift is overnight, will the caregiver be sleeping while on duty or awake? Where will they sleep?
 - COVID-19 - Consider comfort and policies around vaccination, mask-wearing, washing hands, testing and calling out for sickness

Note:

Because of the rarity of the diseases, it is not very common to come across an in-home care agency or caregiver that has had experience working with PSP, CBD or MSA. Familiarity with Parkinson's disease and other neurodegenerative diseases is helpful, but there are unique care needs to be mindful of with PSP, CBD or MSA. Explain the diagnosis to the caregiver(s), including the person's symptoms and care needs associated with the disease, such as blood pressure regulation, swallowing safety, impulsivity, vision issues, urinary function or use of ambulatory equipment. You can provide them with resources from CurePSP for additional education, which you can find at www.psp.org/resources

Check In

What are my three main takeaways from reading this resource?

1.

2.

3.

What questions do I have about in-home care at this point?

How do I define quality of care for myself and my loved one?

What are my priority needs at this time?

What three next steps do I need to take at this point?

1.

2.

3.

Additional Resources

Agencies and Associations

Aging Life Care Association: www.aginglifecare.org, 520-881-8008

ARCH National Respite Network and Resource Center: www.archrespite.org

www.care.com

www.caregiver.com

www.carewell.com

Caregiver Action Network: www.caregiveraction.org, 855-227-3640

Eldercare Locator: www.eldercare.acl.gov, 800-677-1116

Family Caregiver Alliance: www.caregiver.org

www.homecare.com, 800-445-8106

National Alliance for Caregiving: www.caregiving.org/resources

National Association of Area Agencies on Aging: www.usaging.org, 202-872-0888

National Council on Aging: www.ncoa.org

National Institute on Aging: www.nia.nih.gov, 800-222-2225

Publications

AVOIDING Attendants From HELL: A Practical Guide to Finding, Hiring and Keeping Personal Care Attendants, by June Price

Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (Or Your Loved One!), by Alfred H. DeGraff

Dressing Tips and Clothing Resources for Making Life Easier, by Shelley P. Schwarz.

Hire a Private Caregiver: Step-by-Step Guide, by Danielle Foley

How to Hire a Caregiver for Your Senior: Your Complete Guide to Finding, Employing, and Retaining In-Home Help, by Guy Maddalone

How to Choose a Home Care Agency: A Consumer's Guide, through the National Association for Home Care and Hospice: www.nahc.org

The Comfort of Home: A Complete Guide for Caregivers, by Maria M. Meyer and Paula Derr

The Resourceful Caregiver: Helping Family Caregivers Help Themselves, by National Family Caregivers Association

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