

Parkinson's Disease Care Partner Guide: When Your Loved One is in a Senior Living Facility

Caring for a loved one with Parkinson's disease (PD) in a senior living facility, such as a nursing home or assisted living facility, can be challenging during the best of times. The COVID-19 pandemic has prompted many facilities to close their doors to visitors in order to protect their residents, which can cause family members to worry more, be more anxious, and feel helpless. This tip sheet is for family caregivers who cannot be with their loved one with Parkinson's at this time.

1. How can I manage my loved one's care when I cannot visit?

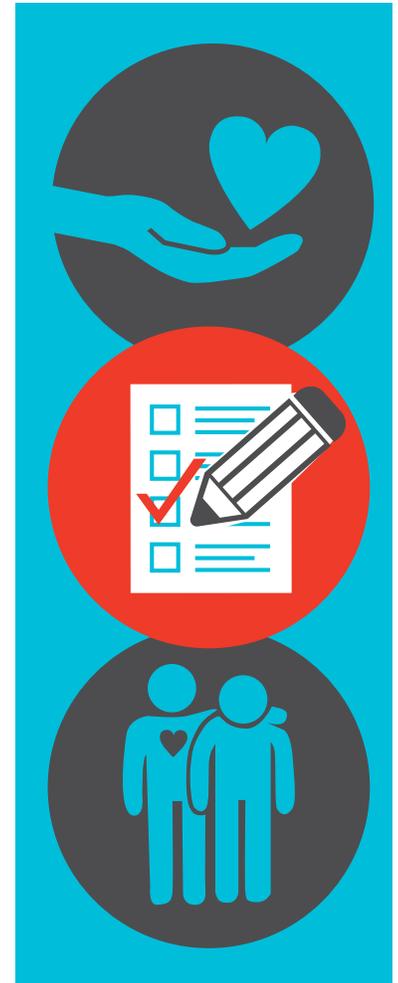
- Establish a 'point person' within the care facility. Check to ensure the facility can share information with you virtually under the HIPAA (Health Insurance Portability and Accountability) Privacy Rule.
- Confirm that you and the facility have your loved one's most recent care plan, medication list, Powers of Attorney paperwork, and their latest advanced directives to reflect preferences for hospital transportation, do-not-resuscitate (DNR) orders, or ventilator treatment. When possible, include your loved one in these conversations.

2. How can this stressful time affect my loved one's Parkinson's disease symptoms?

- Parkinson's symptoms can temporarily worsen during times of sickness, stress, and uncertainty. Talk to your facility point person about how your loved one's symptoms may change throughout the day or in between medication doses, and which symptoms may not be managed as well by medication.
- Movement symptoms including slowness, tremors, and stiffness may become worse. Remind your point person that more physical support and guidance may be needed.
- Non-movement symptoms, like depression, anxiety, and apathy are normal in PD, but can also become worse with stress. Encourage your point person to keep an eye out for mental health changes and to alert you if something seems off.
- Ask your point person to watch for other conditions like urinary tract infections, dehydration, and electrolyte imbalance. These may lead to or worsen PD symptoms like constipation, low blood pressure, and hallucinations, or cause sudden changes in mood or cognitive abilities.

3. How can I make sure my loved one's Parkinson's symptoms are being addressed?

- Medication timing is essential for managing PD symptoms. Discuss with your facility point person the importance of your loved one getting the right medications on time, every time. Encourage your loved one to use the call light to help cue a busy nurse when it's time for each medication.



RESOURCES

Find your state's Long-Term Care Ombudsman to voice concerns about care issues in a facility:

theconsumervoice.org/get_help

The Eldercare Locator is a public service of the U.S. Administration on Aging connecting you to services for older adults and their families. Call 1-800-677-1116 or visit eldercare.acl.gov

- Create a plan using the Parkinson's Foundation Aware in Care hospitalization kit. Use the Medication Form to share the dosage and timing of each medication with facility staff. Order your hospitalization kit and download the Medication Form at Parkinson.org/AwareInCare.
- Ask your primary Parkinson's doctor to sign the 'Hospitalization Letter' that highlights the impact that infections can have on Parkinson's symptoms and the importance of adherence to the Parkinson's medication schedule. Download at Parkinson.org/Letter.
- If symptoms significantly change or you are concerned your loved one may need more care, contact your loved one's neurologist immediately.
- Your loved one will most likely be alone if they need to be hospitalized. Ensure they bring their hospitalization kit, including the Medication Form, and all medications in their original bottles.

4. How can I help my loved one stay active and engaged?

- Physical therapy and exercise are critically important to managing Parkinson's symptoms. Remind staff and your loved one about the importance of getting up and moving multiple times a day.
- Create a brief list of important, more personal things staff should know like preferred name, names of important people in their life, and previous or current hobbies to place in your loved one's chart. Consider adding "red flags" that may indicate that something is wrong. Increased agitation, fatigue, or confusion could be signs of infection or depression.
- Stay connected. Schedule a regular call time and talk to the facility to see if they can help you arrange a virtual interaction. Remember that your emotions impact your loved one. Try to be optimistic in your interactions while acknowledging the challenging situation.
- If possible, help your loved one connect to online resources or ask your facility point person how they can assist your loved one with virtual programming and visits.

5. Should I bring my loved one home?

- Before you take action, talk with your facility point person and your loved one's doctor to determine if you have the capacity to care for your loved one at home. Discuss needs related to safety, mobility, toileting, activities of daily living, and non-motor PD symptoms, like hallucinations and aggressive behavior.
- Recognize that this major change could have a large impact on you, those in your home, and especially on your loved one, as everyone's daily routine will be affected.
- It is important to consider how removing a loved one from a facility may impact his/her Medicaid benefits. Contact your local department of social services to determine what the impact may be.

PARKINSON'S FOUNDATION RESOURCES

Parkinson's and COVID-19 Information

Parkinson.org/Coronavirus

Parkinson's Foundation Helpline (bilingual)

1-800-4PD-INFO (473-4636)

or email:

Helpline@Parkinson.org

PD Health @ Home (weekly online events for the PD community)

Parkinson.org/PDHealth

FREE Aware in Care Hospitalization Kit

Parkinson.org/AwareInCare

AARP'S CAREGIVING RESOURCES

AARP Nursing Homes Information

aarp.org/nursinghomes

AARP Coronavirus Information

aarp.org/coronavirus

AARP Caregiving COVID-19 Tip Sheets

aarp.org/employercaregiving

AARP Caregiving Resource Center & Family Caregiver Support Line

English: aarp.org/caregiving or call 877-333-5885

Spanish: aarp.org/cuidar or call 888-971-2013

AARP is a nonprofit, nonpartisan organization that empowers people to choose how they live as they age.

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure.