

LIVING INDEPENDENTLY WITH PARKINSON'S DISEASE

Coping effectively with Parkinson's disease (PD) can be challenging for anyone, even those living with close, supportive family or friends. While some people prefer to live alone and thrive on the independence, for a person with Parkinson's, living alone may cause additional worries and challenges. Along with the physical and mental changes brought about by normal aging, PD can make it harder to remain socially connected and safe in your own home. Despite these challenges, many people living alone with PD manage well.

Staying Connected

One of the most important strategies for successful independent living with PD is to maintain social connections. Isolating yourself may lead to depression and a worsening of your symptoms, so it is important to find ways to interact with other people in a way that works best for you.

A supportive network of friends and family is usually viewed as ideal, but for many people, and for a variety of reasons, this is not always available. Consider using the internet as a way of staying connected through email, messaging, video chat, social media and online forums. Attending a support group meeting can be another way of meeting other people in similar situations.

Home Safety

People with PD are at greater risk of falling, so it is crucial to ensure that your home is safe for you. Making your house a safer place can help you feel more comfortable and can decrease some concerns that you, and those who care about you, may have. Here are some suggestions for improving home safety and avoiding falls:

- Install brighter lighting inside and outside your home.
- Add bed rails, and install grab rails to your stairs, and bath or shower.
- Rearrange furniture so you have clear pathways through your living space.
- Remove all rugs or mats that are not affixed firmly to the floor, along with any other tripping hazards.
- Secure or eliminate loose wires or cords to avoid tripping or getting caught on them.
- Consider installing an alarm system that connects to emergency responders.

Getting Organized

Another important aspect to living well on your own is to be organized. Activities of daily living, such as cooking, laundry, and personal care can be tiresome and overwhelming. A good way of keeping yourself organized is to create a to-do list and detailed schedule as a constant reminder. You may also want to consider home delivery services for your groceries, or for prepared meals. Ask your pharmacist about home delivery, and be sure to request bubble wrapping of your medications for safety. In addition to these day-to-day activities, a financial planner can help you organize your future income and resources.

Managing Medication

Managing PD medications can be difficult without a full-time or live-in carepartner. Here are some strategies for easier medication management:

- Create a chart of all your medications with detailed information, including the name and type of medication, dosages, and schedule. Post your chart on the door of your refrigerator so it is easy for you to use, and for other people to locate if necessary.
- Consider purchasing a pill timer. These are available for purchase online, and in some pharmacies.

- Keep a Medication Card up-to-date with current medication, and always carry it with you.
- Keep a medication and symptom diary, and take it with you to medical appointments. Write down changes in symptoms, how closely you followed your medication schedule, what you ate with your medications and anything new you may be concerned about.

Home and Community Care programs

If living alone is becoming too difficult for you, but you would like to remain independent, there are options for you. Each Health Authority has a Home and Community Care program that can help you to remain independent. These programs vary, and some may be subsidized based on income. The first step in finding out what your home support options might be is to arrange for an in-home safety and individual needs assessment. You will need to contact the Home and Community Care office in your area. You do not need a medical referral to do this. Contact information is on all Health Authorities' websites or, if you do not use the internet, contact Parkinson Society British Columbia for help.

Technology

It is recommended that you have a cordless phone to carry with you around your home, and a cell phone for use outside of your home. There are also phones available with special features, such as a large key pads and enhanced audio, and all smartphones can be adapted with built-in accessibility features and downloadable applications. Be sure your family, friends and support team have your phone numbers, and consider adding emergency contact numbers to your phone's speed dial function.

Asking for Help

Even if you find it hard to do so, ask for help when you need it. Many people are happy to help when they understand your needs. Make your requests specific (e.g. Could we have coffee together more than once a month?), practical (e.g., Could you drive me to an appointment?), and provide as much notice as possible (e.g. My appointment is at the end of next week. Can you drive me there?). You may be pleasantly surprised by some of the responses.

Additional Resources

In-Home Safety Check | Parkinson Society BC | bit.ly/pdhomesafetycheck

Symptom Tracking Checklist | Parkinson Society BC | bit.ly/pdsymptomchecklist

Medical Appointment Preparation Sheet | Parkinson Society BC | bit.ly/pdmedication

Parkinson's Medication Helpsheet | Parkinson Society BC | bit.ly/pdmedication

Aware in Care Kit | Parkinson Society BC | bit.ly/awareincarekitcontents

Home and Community Care Services | Government of BC | bit.ly/homeandcommunitycare