

10 steps to help you cope with a recent diagnosis of Parkinson's

You've just received a diagnosis of Parkinson's. You leave your doctor's office with questions, and you wonder what comes next.

The first step is to start thinking about a plan to get information and support to help make informed decisions about your future. Here are 10 steps to consider.

1. Get information from reputable sources.

All of the information out there can be overwhelming. What can you believe? To learn what resources are available in your community, start with Parkinson Canada. We have a variety of resources that can help you understand the disease and how to live from day-to-day. Call our toll-free Information and Referral Centre at 1-800-565-3000 or visit the web site at www.parkinson.ca.

2. Start talking about the diagnosis.

When you're ready, discuss your diagnosis and share information with your family and, as time passes, with good friends. Recognize that you may feel a variety of emotions: anger, denial, frustration, fear, confusion, disbelief and sadness. Proceed at your own pace. Stay connected with those close to you. Support each other, and ask for help when you need it.

3. Create a resource file.

Use a binder, folder or file box. Keep it in a convenient location (e.g., near the phone) and fill it with pertinent information such as dates, locations and phone numbers for medical appointments. Some people keep a daily journal listing symptoms and responses to medications with time of day or night.

Include articles about Parkinson's, research findings and other reference material you want to discuss with your health care providers. Include a list of your medications (prescription, over-the-counter, vitamins and supplements). Use Parkinson Canada's "I have Parkinson's Medication Card", a wallet-size card available by contacting info@parkinson.ca.

4. Get the most from your doctor's visits.

Make full use of your time at medical appointments. Write down your questions beforehand. Ask the doctor to clarify what he/she is saying in simple terms. Keep in mind that you have the right to question the treatment you're receiving, if new medications that you've heard about could help you, whether you should consider alternative therapies, or pursue a second opinion. Ask how to access your doctor's nurse or assistant between visits to answer your questions or ease your concerns.

5. Look for help and support.

Contact Parkinson Canada to find out what's available in your community. Consider joining a support group. You'll get practical advice on how to manage Parkinson's. A support group offers a safe place to talk with others who understand. Some groups provide specific help for a particular aspect of Parkinson's (e.g., newly-diagnosed or young onset). Groups for care partners are also available. Many people find support on the internet.

6. Plan for the future.

Now is the time to develop plans for the future. Avoid putting off important decisions, especially legal and estate planning. Talk to your family about your concerns. If you're working, get a good understanding of how Parkinson's may affect your ability to perform the specific tasks of your job, now and in the future. Find out what benefits are available to you.

7. Maintain an active social life.

Stay connected to family and friends so you don't become isolated. Keep in touch by phone, visits or e-mail. If you feel depressed or anxious, talk to your doctor. Continue doing the things you enjoy or find a new hobby. Think about volunteering. Parkinson Canada has many opportunities, including Parkinson SuperWalk; a fun way to connect with caring people in your community.

8. Pace yourself.

Your Parkinson's will be unique to you, so learn how to pace yourself. Many people become tired. It can be caused by the condition itself, sleep disturbances or medication side effects. Plan activities carefully, and give yourself time to complete them. Balance activity with rest periods. If fatigue becomes a serious concern, talk to your doctor.

9. Eat well.

Eating a well-balanced, healthy diet can benefit anyone, but for people with Parkinson's it takes on added importance. Your diet should include a variety of foods from all four food groups: grain products, vegetables and fruit, milk products, and meats and alternatives. Recognize that Parkinson's may present some eating-related challenges, and some dietary modification may be needed. Talk to your doctor, or consider asking for a referral to a registered dietitian.

10. Stay active and exercise regularly.

A good exercise plan can help your body cope better with Parkinson's. Regular exercise can help maintain flexibility and good posture, keep muscles strong and joints supple, and improve circulation to the heart and lungs. It can also help you to deal with day-to-day stress and give you a sense of achievement and control over your condition. Exercise could be as easy as finding a simple activity that you enjoy, such as walking, gardening or swimming and making it part of your daily routine.

SOURCES

"The Best of" Parkinson Post, Summer 2006, Volume 6, Issue 2.

Canada's Food Guide to Healthy Eating, www.hc-sc.gc.ca/fn-an/food-guide-aliment/index_e.html

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