PARKINSON INFORMATION

Parkinson Society Canada
Société Parkinson Canada

PROGRESSION OF PARKINSON'S DISEASE

This document has been prepared to help you become more informed about Parkinson's. It is designed to answer questions about Parkinson's and how it might progress. Included are some suggestions on how to prepare for the Parkinson's journey.

What is Parkinson's?

Parkinson's is a disorder of the brain. Movement is controlled by dopamine, a chemical that carries signals between nerves in the brain. When cells that produce dopamine die or are damaged, Parkinson's symptoms appear. Parkinson's is a complex condition.

What are the symptoms of Parkinson's?

The loss of dopamine can cause a variety of *motor* (movement) symptoms, including:

- Tremor (shaking)
- Muscle stiffness (rigidity)
- Slowness of movement
- Impaired balance

Other symptoms may also occur:

- Small handwriting
- Soft speech
- Stooped posture
- Reduced facial expression
- Shuffling when walking
- Muscle pain

In addition to the motor symptoms, you might notice *non-motor* symptoms, including:

- Constipation
- Sleep disturbance
- Bladder urgency and frequency
- Dizziness on standing
- Fatigue
- Depression: feeling sad, having less energy or losing interest in activities
- Memory problems

Individuals with advanced Parkinson's may experience other symptoms that are due to a combination of the disease process and medications used to treat Parkinson's. The most common symptoms are hallucinations (seeing things that are not really there, including animals or people). Very occasionally, some people experience delusions (having thoughts that are not real).

If you experience symptoms associated with Parkinson's, take action and contact your doctor. Early assessment and diagnosis can help you manage Parkinson's or identify other conditions that may be causing the symptoms.

Is Parkinson's the same for everyone?

No. Each person with Parkinson's is unique and each person may experience different symptoms. However, since Parkinson's is a progressive condition, symptoms will worsen over time and new ones may appear. It is difficult to estimate how quickly or slowly Parkinson's will progress in each person. It may progress more quickly in people who are older when the symptoms first begin. Parkinson's may progress less quickly when the main symptom is tremor, especially when it starts on one side.

How is Parkinson's treated?

Currently, there is no cure for Parkinson's. However, many of the motor symptoms can be treated with medications. Medications used to treat the symptoms either replace the lost dopamine or mimic the action of dopamine in the brain. Medications can alleviate the symptoms, but do not slow the progression of Parkinson's. As the symptoms change, medications will need to be adjusted.

Non-motor symptoms may be treated by other types of medications. Parkinson's can be challenging to manage because some treatments for non-motor symptoms can worsen the motor symptoms. It is important to discuss treatment options with your neurologist.

Some people with Parkinson's may benefit from brain surgery (often known as deep brain stimulation or DBS). Surgical treatment for Parkinson's can be beneficial for some people. Surgery is not a standard treatment for everyone; but can be considered after drug therapy has been tried. Procedures involve inserting a probe into the brain and targeting specific areas that may control tremor or involuntary movements. Talk with your neurologist to determine whether you might be a candidate for surgery. A comprehensive assessment will need to be done before a decision is made.

Physiotherapy and exercise can improve one's flexibility, reduce stiffness and alleviate stress.

How will I know when Parkinson's has progressed?

Although everyone is different, there are signs that Parkinson's is progressing. You may find that it takes longer or more effort to perform daily activities such as getting dressed. Tremor on one side of your body may now appear on both sides. You may notice significant changes in the way you walk, from slowness to a shuffle. Symptoms may be worse one day and not the next. You may notice that you need to take your medications more frequently. Higher doses or a combination of medications may be necessary to control symptoms.

It is important to be aware of changes and tell your doctor when you notice them. Ask your care partner or family if they have noticed changes, such as difficulty hearing you talk. Involve health care professionals, such as speech pathologists or home care workers to help you manage the daily challenges of Parkinson's.

How long will I live with Parkinson's?

Depending upon your age of onset, how you manage the symptoms, and your general health, you can live an active life with Parkinson's. In most cases, one's life is not shortened. However, as you age and as the disease progresses, there will be increased risks. For example, impaired balance can lead to falls; swallowing problems, if not managed, can lead to pneumonia. Parkinson's is known as a chronic (long term) condition that will require ongoing monitoring and management to maintain one's quality of life.

What about other health conditions?

Parkinson's will not exclude you from the possibility of developing other health concerns. Distinguishing between normal aging, Parkinson's symptoms and those of another condition can be challenging. For example, memory or concentration changes can be a side effect of medications, a non-motor symptom of Parkinson's or a separate condition. Ensure you are working with health care professionals who are knowledgeable about Parkinson's, especially with the need to follow your medication routine. It is important to maintain a healthy lifestyle (e.g., good nutrition, exercise, staying active and socially engaged).

What approach can I take?

Learn as much as you can about Parkinson's. Your local Parkinson Society has many resources to help you manage the condition.

Reducing stress in your life will make a difference. Join a Parkinson support group. Some people find yoga and tai chi helpful. Humour can also be a great stress reducer. Staying as active as possible and maintaining a positive attitude is important. Many people find that a creative activity such as painting, singing, playing an instrument, dancing or writing poetry helps. *Even if Parkinson's affects your balance, you can still have a balanced life!*

What do I need to know to plan my life?

Take stock of your life and communicate with those who are close to you (care partner, family, friends).

Work options. Discuss options with your employer, such as adaptive technology or reduced work load. If it becomes necessary, find out if retiring early is an option. Many people who reduce their workloads find they are able to focus on managing their Parkinson's (i.e., more time to keep physically fit).

Finances. Will your benefit/medical plan cover drugs and other expenses, such as speech therapy? Do you have a retirement and/or pension plan? Do you qualify for disability insurance or the disability tax credit? Contact disability professionals before reducing your work hours, to determine if this will affect the amount of eligible funding.

Legal and health planning issues. Discuss power of attorney and advance care planning with your family now. Discuss what quality of life means for you. By talking about these issues now, you can impact your care in the future. (*Information on advance care planning varies from province to province. Contact your local Parkinson Society for appropriate resources.)

Care issues. Seek the care of a neurologist or movement disorder specialist. Together you can develop a care plan that will meet your needs. Monitor your symptoms and communicate any changes so adjustments to medications can be made.

Personal choices. As Parkinson's progresses, you will be faced with making choices about your life. Symptoms and medications can affect your ability to drive safely. Knowing this may happen and planning for it can make the decision easier. You may choose to stop driving.

What do care partners need to know?

If you are a care partner or family member, Parkinson's will affect your life, too. Learn as much as you can. Care partners often believe they will remain healthy and always be able to provide care. However, care partners often burn out and become ill.

Take care of yourself: Continue to enjoy your own interests; take time to relax; maintain a healthy lifestyle including exercise and good nutrition; and consider using services, such as home care. Have an "emergency plan" in case you become ill. Build a network of support. Contact your local Parkinson Society for information about Parkinson's and referral to a support group.

How do I begin the Parkinson's Journey?

The Parkinson's journey will be different for everyone. To help you stay the course, think about what is important to you. Some things to consider may include:

- How you will manage your Parkinson's symptoms
- How you will minimize side effects of medications
- How you will maintain your emotional well-being
- How to ensure you continue your work or hobbies
- How you will maintain relationships with family and friends
- How you will maintain your independence

Whatever you choose, maintaining your quality of life on a daily basis is important.

Where can I find information?

Contact your regional Parkinson Society or visit www.parkinson.ca.

References:

AAN Guideline Summary for Patients and their families: Diagnosis, prognosis, and treatments for newly diagnosed Parkinson Disease.
AAN Guideline Summary for Patients and their families: Screening and treatment for depression, dementia, and psychosis with Parkinson disease.

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