



Understanding and living with a Parkinson's diagnosis can be a difficult and emotional journey. Knowing what to expect provides an opportunity to plan for possible adjustments at work, home, and in relationships.

Although everyone's path is different, know you are not alone.

# REGAINING CONTROL

3 A . 8 0/6 4

To me, hope is informed optimism.

Michael J. Fox

# WHAT IS PARKINSON'S AND WHAT CAUSES IT?

Parkinson's disease (PD) is a type of movement disorder that occurs when the brain cells that make dopamine, a chemical critical to movement, experience a decrease in function.<sup>1</sup>

The experience of living with Parkinson's is unique to each person. Even though some similarities are observed among individuals with PD, not every experience is the same.<sup>2</sup>

Researchers believe that in most people, Parkinson's is caused by a combination of genetic and environmental factors.<sup>3</sup>



90,000

people in the U.S. are diagnosed with Parkinson's each year.<sup>4</sup>

# Symptoms of Parkinson's

Early symptoms, which may be mild and go unnoticed, often start on one side of the body. As they progress, the symptoms typically get more severe on that side, persisting even as they start to affect the limbs on both sides.<sup>5</sup>

The main movement-related (motor) symptoms of Parkinson's are<sup>6</sup>:



Slow movements

(bradykinesia)



Involuntary shaking of particular parts of the body when relaxed

(resting tremor)



Stiff and inflexible muscles

(rigidity)

However, people with Parkinson's can also experience a wide range of other physical and psychological symptoms (collectively called non-motor symptoms) that can occur before the movement symptoms develop. We will expand on these symptoms in a later section.

# HOW IS PARKINSON'S DIAGNOSED?

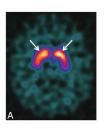
The diagnosis is based on medical history, clinical observation, and physical examination. No laboratory test is currently available to confirm a Parkinson's diagnosis; therefore, neurologists use a combination of contributing factors and supporting tests.<sup>8</sup>

# Contributing Factors 9,10

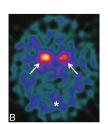
- Presence of 2 out of 3 primary symptoms (bradykinesia, resting tremor, rigidity)
- Absence of other neurological signs on examination
- Rule out other conditions mimicking these symptoms, including certain medications
- Responsiveness to Parkinson's medications, such as Levodopa

# Supporting Test<sup>10</sup>

A commonly used supportive test known as a DaTscan, a non-invasive nuclear medicine test that looks at the function of dopamine active transporters (DaT) in the brain. It is often used to distinguish Parkinson's from essential tremor.



DATSCAN
OF NORMAL
PATIENT



DATSCAN OF PATIENT WITH PARKINSONIAN SYNDROME

# HOWIS PARKINSON'S EVALUATED?

To measure Parkinson's progression or response to treatment, doctors use a set of tests and questions, called the Unified Parkinson's Disease Rating Scale published by the Movement Disorders Society (MDS-UPDRS).

Some of the tests in the evaluation may be familiar to you:



**FINGER TAP TEST** 



# Important things to do after diagnosis

Assemble a care team: Seeing a movement disorder specialist (MDS) along with your primary physician and/or neurologist can be helpful and valuable, especially when you are initially diagnosed with Parkinson's. MDS doctors specialize in creating a treatment plan and are aware of the latest treatment options available.



### Learn more

Knowledge is power, and when you and your care partner know more about the disease and available treatment options, evaluating your own symptoms can be easier.



# Build a support network<sup>11</sup>

Usually a mix of family, friends, and your care team make up your trusted support system. They are the people you can rely on during your Parkinson's journey.



# Exercise regularly<sup>11</sup>

Exercise helps sustain mobility and motivation while helping to improve overall well-being and quality of life.



### Eat well<sup>11</sup>

To complement regular exercise, doctors encourage a diet rich in vegetables, fruits, and healthy fats (found in nuts, avocado, and olive oil).

# Finding your support network

Joining a Parkinson's support group offers a sense of community and can provide insights about the condition and treatment options. These groups can be a safe space for open discussions, helping you navigate the everyday challenges of living with Parkinson's.

For a list of support groups and helpful resources, scan the QR code.

# MONITORINGYO

# Helpful tips to make the most of your appointment:

1

# Keep a Journal:

- Maintaining a journal, or completing PD-specific questionnaires regularly, can help organize symptoms impacting your quality of life.
- Explore digital apps designed for Parkinson's by searching 'Parkinson's apps' on search engines or app stores.

2

## Create a Medication List:

- Include current and past medications, with details on dosage and times of intake.
- Note any side effects or reasons you want your neurologist to review specific medications.

# UR CONDITION:

3

# Gather Medical Reports:

- Include results
   from past tests
   and investigations.
- Prepare a list of questions to discuss with your doctor.

4

# Maximize Your Time:

 Come prepared to each doctors visit with a clear focus on the reason you are there. Before your appointment, ask yourself: "What is the ideal outcome of today's doctors visit?" 5

# Consider Bringing Support:

 Think about asking someone you trust to accompany you. They can provide additional information about your medical history and offer support during and after the visit.

Feel empowered during your visit by following these simple steps to get the most out of your doctors visits.

# How is Parkinson's treated?

# Dealing with the motor symptoms of Parkinson's 12-14

As mentioned earlier, the loss of dopamine, a brain chemical that regulates movement and emotions, plays a key role in the progression of Parkinson's.¹ To address this, the primary treatment involves replacing dopamine (ie: carbidopa/levodopa) or using drugs that intend to mimic its effects (ie: dopamine agonists). These medications, which have been on the market for years, can significantly improve both motor and some non-motor symptoms.

Carbidopa/levodopa or dopamine agonists are often combined with other drug classes, including **MAO-B** and/or **COMT** inhibitors. These combinations aim to make more levodopa available by slowing

its breakdown. Other options include fast-acting or slow-release tablets, transdermal skin patches and other compounds tailored to specific motor symptoms, like anticholinergics for tremor, or amantadine for *dyskinesias*, which are involuntary movements that occur from complications with your medication levels.

It's important to remember everyone's experience with Parkinson's is unique, and treatment should be tailored to your needs. Based on your symptoms and lifestyle, your doctor will choose a treatment path that will likely be adjusted as the disease progresses.

Non-motor symptoms may be present early in the disease progression and may precede the onset of motor symptoms.<sup>15</sup> While these may improve with dopamine therapy, more symptom-specific therapies may be needed.

# Examples of non-motor symptoms include:

- Constipation: can affect the way your medication is absorbed and may be alleviated by changes in lifestyle and diet i.e. fiber-rich foods, increased fluid intake, prune juice, and scheduled toileting after meals.<sup>12</sup>
- Loss of bladder control: i.e. urinary frequency and urgency. Medications that work to block or reduce bladder overactivity can be useful.<sup>14</sup>
- Problems sleeping (insomnia, vivid dreams, daytime sleepiness): different sleep-related symptoms may occur with PD as dopamine plays an essential role in the sleep-wake cycle.<sup>16</sup>
- Low mood (depression) and anxiety: antidepressants may be prescribed to deal with mood-related symptoms.

# Building support beyond your neurologist

Your movement disorders specialist or neurologist may be the primary contact for other specialists. For specific problems, consulting physicians from other subspecialties (for example, a psychiatrist, urologist, or GIT specialist) may be helpful in a holistic approach.

Allied healthcare providers, like physiotherapists, speech therapists, and occupational therapists, can help with additional strategies.

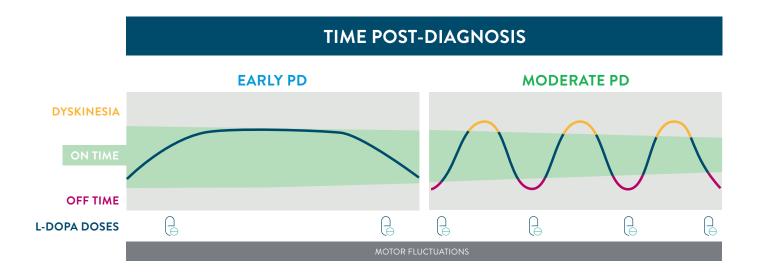


In the early stages, Parkinson's tends to respond well to dopamine replacement-based treatments. However, as PD progresses, medications can become less effective at controlling symptoms adequately, requiring increased amounts of dopamine in the form of higher doses given at more frequent intervals.

# AS PARKINSON'S PROGRESSES

Developing fluctuations in motor symptoms as your medication wears off can become more noticeable and movement can become more tedious. This is commonly referred to as "off-time".<sup>17</sup>

Others may experience involuntary movements (dyskinesia), which occur when medication levels peak.

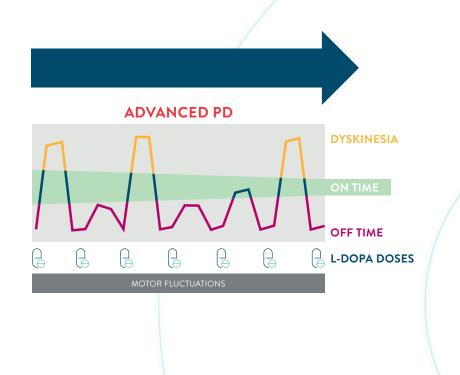


The figure above shows how the frequency of "off-time" and dyskinesias increases, while the amount of "on-time" decreases as Parkinson's progresses.

The occurrence and severity of motor complications or fluctuations can vary from person to person. However, once they occur, careful adjustment of treatment or advanced therapies may be required. Developing fluctuations in motor symptoms as your medication wears off can become more noticeable and movement can become more tedious. This is commonly referred to as "off-time".<sup>17</sup>

# As Parkinson's progresses over time, levodopa treatments tend to become less responsive.

Despite increases in dosage and intake frequency of levodopa, patients with moderate to advanced Parkinson's experience longer periods of reduced mobility, "off-time", and increased episodes of dyskinesias. These motor fluctuations and increased periods of "off-time" can be associated with disability and a dramatically reduced quality of life.<sup>17</sup>





# Advanced treatment options

When medication or skin patches are not enough or side effects cannot be well controlled, your doctor may discuss advanced treatment options with you. While not a cure for Parkinson's there are options available to treat symptoms.

# Pump Therapies 18,19 Alternative to oral medication. Designed to provide continuous medication delivery via portable pump inserted during a surgical procedure where a small tube is placed directly into the small intestine for medication delivery. Description Requires daily placement of the infusion needle. · Despite its efficacy, a proportion of patients reported experiencing adverse events ranging from mild to moderate, including procedural pain and infection. Common side effects include skin reactions that may require discontinuing treatment.

## Alternative Procedures<sup>20</sup>

### Surgical Lesioning:

- Irreversible procedure involving selective destruction of targeted brain tissue to interrupt disruptive networks within the brain.
- Become less common over the years with the introduction of levodopa in 1960s and again in 1990s because of DBS.

### Focused Ultrasound:

- Utilizes high-intensity ultrasound waves to destroy cells using thermal ablation.
- Irreversible procedure, with no ability to adjust therapy settings if symptoms change.
- Option for select group of PD patients.<sup>21</sup>

# Deep Brain Stimulation (DBS)

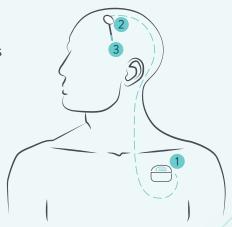
- Long-term safety and effectiveness data for individuals experiencing disabling tremors, rigidity, slowness of movement, or medication-induced dyskinesias.<sup>22</sup>
- Research shows DBS recipients can take fewer medications, enjoy extended hours
  of symptom control (on-time) and achieve better management of symptoms during
  medication gaps (off-time).<sup>23</sup>
- Offering adjustable therapy, DBS allows for personalized treatment adjustments to optimize the balance between therapeutic benefits and unwanted side effects.<sup>24</sup>

As with any surgery or therapy, DBS has risks and complications:\*

- Surgical risks: most side effects from DBS surgery are temporary and correct themselves over time. Risks may include infection, bleeding, and/or serious complications.
- Stimulation-related risks: Potential for neurological side effects such as mood changes, cognitive impacts, depression, loss of coordination, or other symptoms.
   These can usually be managed by adjusting device settings.

# How DBS Therapy Works

- The DBS battery sends energy pulses through thin wires called leads, like a pacemaker for the brain.
- The leads target the specific areas of the brain responsible for movement disorder symptoms.
- 3 The pulses of energy helps to relieve symptoms.





### SCAN THE QR CODE

To take a short assessment and speak over the phone with our education team to find out if DBS could be right for you.

\*Risk Information: There is no cure for Parkinson's disease (PD) and essential tremor (ET), but there are options available to treat symptoms. The first-line therapy is medication. Surgical treatments are also available. It's important to discuss with your doctor what's right for you along with the risks and side effects of each option, such as motor fluctuations or permanent neurological impairment. As with any surgery or therapy, DBS has risks and complications. Loss of coordination is a potential side effect of DBS therapy. Patients should exercise reasonable caution when participating in activities requiring coordination, including those that were done before receiving therapy (for example, swimming). Patients should also exercise reasonable caution when bathing. New onset or worsening depression, which may be temporary or permanent, is a risk that has been reported with DBS therapy. Suicidal ideation, suicide attempts, and suicide are events that have also been reported. Most side effects of DBS surgery are temporary and correct themselves over time. Some people may experience lasting, stroke-like symptoms, such as weakness, numbness, problems with vision or slurred speech. In the event that the side effects are intolerable, or you are not satisfied with the therapy, the DBS system can be turned off or surgically removed. Risks of brain surgery include serious complications such as coma, bleeding inside the brain, paralysis, seizures and infection. Some of these may be fatal.

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