# Parkinson's Disease Frequently Asked Questions (FAQs)



**A Public Information Initiative** 

#### Q. 1. What is Parkinson's disease (PD)?

**Ans**. What we know today as Parkinson's disease (PD) was first described by James Parkinson in 1817 in his "Essay on the Shaking Palsy". Defining PD is difficult as it is characterized by an array of symptoms occurring together. These features can be grouped under motor symptoms and non-motor symptoms.

#### Q. 2. What are the motor symptoms in PD?

**Ans**. The four cardinal features are:

- tremor at rest
- rigidity (stiffness of limbs)
- bradykinesia (slowness of movements)
- postural instability (instability while standing or walking)

In addition, the person has difficulty in doing repetitive movements. Their speech is soft and poorly articulated. Choking, drooling, and swallowing difficulties are common. There may be disturbances in handwriting. The affected persons have a stooped posture, and while walking, they take small, shuffling steps with a tendency to fall forwards. In advanced stages, they experience freezing of movement, typically at the start of walking, in narrow corridors, or while turning around, etc.

# Q. 3. What causes the symptoms in PD?

Ans. The basal ganglia is a part of the brain which synchronizes the complex movements, e.g., walking, and is important for learning of movements to occur. Due to insufficient amount of a chemical, known as dopamine in the basal ganglia in the brain, the person starts committing more mistakes and takes longer to do a previously learnt and mastered movements, giving rise to symptoms of PD.

# Q. 4. What are the non-motor symptoms in PD?

**Ans**. The common non-motor symptoms are:

- constipation
- urinary disturbances
- sexual disturbances
- slowness in thinking
- disturbance in sense of smell
- problems with sleep
- fatique
- progressive weight loss
- visual disturbances
- dry mouth

- problems with appetite
  In advanced stages, PD can cause:
- memory disturbances
- · dementia
- emotional and behavioral disturbances
- hallucinations

# Q. 5. How will your physician diagnose PD? Is there a specific test to diagnose PD?

**Ans**. The diagnosis of PD is based on the clinical interpretation of signs, symptoms and the progression obtained through detailed history and thorough neurological examination by your neurologist. There is no single, specific, confirmatory test available for diagnosing PD yet.

# Q. 6. Why is an accurate diagnosis important in PD?

**Ans**. An accurate diagnosis will lead to early intervention which can help manage the symptoms better and lead to improved quality of life. Also, it can help avoid complications that can be caused due to wrong prescription of medications or improper dosage.

#### Q. 7. Is there a cure for PD?

Ans. To date, no intervention has been convincingly shown to slow down, arrest, or reverse the progression of PD. Though no preventive or curative treatment for PD has been discovered yet, good treatment interventions, medical and non-medical, are available to control the symptoms effectively. But they need to be followed under good professional guidance. Many new drugs and therapies are available that improve the quality of life of the patient significantly. Deep brain stimulation (DBS) is a surgical procedure which is effective in PD, when indicated by your neurologist.

#### Q. 8. What are the available medications for PD?

Ans. Ideally, the goal of treatment would be reduction of symptoms which allows the affected individuals to do activities of daily living, without risk of long-term side effects. Levodopa (in combination with Carbidopa), dopamine agonists, MAO-B inhibitors, synthetic anticholinergic drugs, COMT inhibitors, amantidine are the available drugs for symptomatic treatment of PD.

# Q. 9. How do you initiate treatment in PD?

Ans. The American Academy of Neurology practice parameter regarding the initial symptomatic treatment of PD concludes that it is appropriate to start treatment with either levodopa or dopamine agonists. An informed clinician and patient are in the best position to decide on initial treatment strategy on a case-by-case basis.

# Q.10. Which is the most widely used and the most efficacious drug for symptomatic treatment of PD?

**Ans**. Levodopa is the most widely used and the most efficacious drug for symptomatic treatment of PD. It replenishes neuronal dopamine stores and improves many of the motor features of PD. However, it

has certain side-effects such as, nausea, lowering of blood pressure upon standing/walking, hallucinations, sleepiness, and involuntary jerky movements involving the limbs, trunk, or head. Most side effects appear after prolonged usage.

#### Q.11. What is on the cards for treatment of PD in the future?

Ans. There are indicators from recent research that effective neuro-protective agents for PD may be available in the near future, as our understanding of the disease mechanisms steadily grows. Stemcell therapy and gene therapy for treatment of PD are still in early stage of research. They have not been recommended as yet.

#### Q.12. How will you quantify the disease and its progression?

**Ans**. The Hoehn and Yahr Scale is commonly used to provide gross assessment of disease progression, ranging from stage 0 (no signs of disease) to stage 5 (wheelchair-bound or bed-ridden unless assisted).

The Unified Parkinson's Disease Rating Scale (UPDRS) is the most well established scale for assessing disability and impairment.

# Q.13. Will I inherit from my parent/Will I give it to my child?

**Ans**. Less than 5-10% of patients with PD have the inheritable form of the disease. This is more likely the case when the parents have the onset of the disease in their 40's or younger (early-onset PD). Most cases of PD are sporadic. These may result due to the complex interaction between environmental and genetic factors.

#### Q.14. What are the factors associated with increased risk for PD?

# **Demographic Factors**

- · Increasing age
- Male gender
- Caucasian race
- Family history of PD
- · Lifestyle factors
- Head trauma
- Emotional stress
- Personality traits (shyness, risk-averse)

#### **Environmental Exposures**

- Pesticides
- Industrial agents
- Carbon monoxide

- Metals (manganese, mercury, iron)
- Drinking well water
- Pulp mills
- Farming
- Rural residence
- Occupation (health care, teaching, construction work)

#### Infections

- Encephalitis
- Nocardia asteroides

#### Q.15. What are the factors associated with reduced risk for PD?

Ans. There are few factors "proposed" to protect against the development of PD. Of these, the most compelling is the inverse association of cigarette smoking with PD; a clearly defined biological basis for this finding has yet to be defined. Other factors are coffee consumption, use of non-steroidal anti-inflammatory drugs (NSAIDs), early or midlife exercise.

#### Q.16. How does PD progress? What is the life expectancy and quality of life that can be expected?

**Ans**. PD is not a direct cause of death per se, although death may occur as a secondary result of severe motor dysfunction, which causes aspiration or falls in advanced Parkinson's disease.

PD is a progressive ailment, meaning that the present symptoms worsen and new symptoms may develop over time. The rate of progression of the disease is different for each individual.

PD is not a deterrent to an active, full life. Quality of life depends on the age-of-onset of the disease, the speed of progression, and how well the disease is professionally managed. Regular follow-up with your neurologist, management of the symptoms and avoiding the known complications (like falls, aspiration) is essential to maintain a good quality of life.

# Q.17. What are the lifestyle changes that will help with the management of PD?

#### **Dietary changes**

A good balanced diet which includes fruits, vegetables, whole grains is necessary. A diet rich in fiber (e.g. whole grains, greens, nuts, legumes) is important for preventing constipation. Excessive protein intake must be avoided if you are on levodopa. Water and fluid-intake must be high. Never start taking any nutritional supplements or herbal remedies without talking to your neurologist.

#### **Physiotherapy**

Physiotherapy will help with balance and maintaining your mobility. It may also help in controlling muscle freezing. Regular exercise is an important contributor to maintaining good health.

# **Occupational therapy**

Occupational therapy can help in improving/maintaining your ability to perform your everyday activities. Driving is not advisable. The person can continue to go to work as long as they can cope with the demands of the job. It is advisable to not work around heavy machinery/fire/toxic substances and chemicals or in jobs requiring shifts.

# Counseling and Psychotherapy

Stress is known to worsen the symptoms. Effective stress management is an essential lifestyle change. Seek counseling, if necessary, where you can learn techniques to manage stress and hence the disease more effectively. Anxiety and depression are common in the affected persons and caregivers who live with PD. Seek psychological help when needed. Do not give in to the stigma attached to it. When there are new symptoms, always inform your neurologist. It is important to remain cognitively stimulated and active. Do not give up on interests and things that the person is passionate about unless it is physically limiting. There are no limits to the mind.

# Q.18. What are the environmental modifications that can be done to help the patient?

Ans. Installing safety precautions at home, in the car and at work can help in the prevention of falls and increase the accessibility for the person helping them move around with ease. Hand rails in the bathroom, non-slip rubber mats near the toilet and near the bed, maintaining a clutter-free environment at home and at work, raised toilet seats; stable sofas/chairs etc. are some of the modifications that can help the patient. Canes, electric tooth brushes, wheelchairs can help people in advanced stages of the disease.

# Q.19. How can we manage problems with sleep? Is daytime napping okay?

**Ans.** Almost all patients with PD develop sleep-related problems. These have an important impact on quality of life in PD patients and their caregivers. Approximately, eight hours of sleep is required per night. A short nap in the daytime can help the patient stay refreshed.

Talk to your neurologist about any sleep disturbances experienced at night. It is important to maintain good sleep hygiene, that is, a sleep routine which will help to sleep better at night. Avoid fluids in the evening that will add to the frequent urination. Keep soft pillows on the sides that will help you maintain a good sleep posture. Sleep on a good mattress and a stable bed that the person won't fall from. Sleep in an optimally cool dark room which is silent and clutter-free.

# Q.20. Is it normal for the caregivers to feel stressed?

**Ans.** When you are caring for your loved one with Parkinson's disease, it is normal to be stressed out, feeling sad and being frustrated. It is important to consider your own personal needs and to have an active life outside of caring for your loved one.

Join a support group for Parkinson's disease. They can give practical tips for managing the disease as well help you emotionally when you meet people who understand and are going through the same things that you are going through.

Build a strong support system of friends and family who you can trust and can talk to about the disease.

### Disclaimer

This brochure is for the general information of the public and the patients. People should not self-medicate themselves with the medicines and treatments mentioned here. Before taking any of the medications mentioned in the information brochure, please consult your neurologist.

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