



PARKINSON'S DISEASE

PATIENT INFORMATION
BOOKLET



Lilavati Hospital and Research Centre

More than Healthcare, Human Care



Parkinson is a degenerative neurological/brain related disorder which primarily affects movement balance, and muscle control.

This disorder arises from death of specific nerve cells that secrete a chemical named dopamine.

Dopamine helps in communication between different areas of the brain, facilitating movement.

Although treatment can improve many symptoms, and also the quality of life for the patient.

There is no cure and the disease may relentlessly progress. However, in many cases, the disease has a mild and slowly progressive course over many

years or decades.

The main symptoms of Parkinson's disease are Tremors, Slowing, Stiffness in the body & imbalance that may cause sudden falls.



Additionally, if the patient is in the elderly age group, other age-related issues like small or large strokes, diabetes, blood pressure may worsen the symptoms of Parkinson's disease.

Many medicines, especially anti psychotics use in mental healthcare may result in Parkinson like symptoms and even unmask or worsen Parkinson's disease.

Extremely rarely some viral infections or repeated head trauma may cause Parkinson's disease in future.

Additionally, vascular issues such as minor strokes can contribute to the stiffness and rigidity characteristic of Parkinson's. Elevated pressure of cerebrospinal fluid (CSF) can also produce similar symptoms.

Furthermore, Parkinsonism can arise from substance toxicity or specific types of cancers.

SYMPTOMS

Symptoms start slowly, initial ones could be tremors or stiffness, usually only on one side.

Parkinsonian symptoms can be classified as below:

1. Movement related / motor symptoms

Tremor or shaking in fingers, hands or legs when at rest, patients may also rub their thumbs and forefinger back and forth which is known as the pill rolling tremor.

Slowness of movement.

Muscle stiffness and rigidity
reduced ability to perform



reflexive movements like blinking, smiling, swinging of arms during walking.

This may be misdiagnosed as frozen shoulder or disc disease.

Stooped posture.

Trouble with balance or falls
Slurred speech, speaking too quickly or softly.

Difficulty swallowing, especially with dry food.

Masked face: It appears that the patient does not display emotions on the face.

2. Non movement symptoms

Disturbances in sleep

Forgetfulness

Loss of motivation, depression

Slowness in thinking

Behavioural changes

Hallucinations/ delusions

Changes in handwriting.

3. Behavioural changes

Apathy – not feeling interest/ enthusiasm

Irritability

Disinterest in things.

TREATMENT

Parkinson's disease cannot be cured, but timely diagnosis, medicines and rehabilitation can help manage problems with walking, movement, and tremors.

Along with medication, allied rehabilitation in the following fields can significantly improve the quality of life:

1) Physiotherapy

To help with movement and balance related difficulties.





2) Speech therapy

To help with slurring of speech and swallowing related problems.

3)Psychology consult

To help with emotional, behavioural and sleep related issues and support for caretaker.

4)Neuropsychology consult

To assess and monitor decline in cognitive functioning.

WHEN TO CONSULT A DOCTOR IN ADDITION TO ROUTINE FOLLOW UPS:



- If the patient is having unusual

trouble with balance and tremors, shaking of hands or legs.

- If the patient is experiencing increased difficulty in swallowing or has been choking frequently.
- If the patient is having problems with speech.
- If the patient is experiencing problems related to sleep, such as; waking up frequently throughout the night, waking up early or feeling drowsy during the day, If the patient is having hallucinations or delusions.
- If the patient has had any injury or falls.



ADDITIONAL THINGS THAT CAN HELP



1. A balanced diet – Feel free to contact us for a diet consult.
2. Regular exercise- such as static cycling, walking, swimming, gardening, dancing, water aerobics or stretching. Be careful to avoid falls. Do not force the patient to exercise.
3. Continuing daily living activities such as dressing, eating, bathing as independently as possible.
4. Finding support groups, which are groups of people who have lived through the same difficult experiences and want to help themselves and others by sharing coping strategies.
5. Provide the patient clothes which are till knee length.

FOR THE CAREGIVER



Parkinson's disease (PD) is a progressive disease. Your role as a care partner and your level of involvement will also evolve along the way.

Remember, care is not limited to physical tasks but can also be of emotional, supportive and spiritual type.

While it can be rewarding, it can also be equally exhausting. It is important to allow time to take care of yourself and notice signs of care giver fatigue.

These include:

Feeling physically drained & mentally exhausted.

Not getting enough sleep.

Irritability & Difficulty concentrating

Withdrawal from friends, family & activities that were once enjoyable.

Changes in mood. Feelings of futility/ depression.

Suicidal thoughts

TIPS FOR THE CAREGIVER

1. Do not interpret patient's odd behaviour and condition emotionally.

2. Be mindful of the patient's emotional and physical temperament. It could happen that on some days the patient would be reluctant to follow instructions, do exercise etc. On such days, the caregiver should not force or blame the patient. You could try again later or allow a rest day.

3. Allow time for yourself. Make sure to take care of yourself to help create a productive partnership that minimizes stress and conflict. Plan things that make you happy.

4. Regular breaks from caregiving are an essential part of this balance. Take an hour daily, an

afternoon weekly or a day monthly, whatever you can manage.

These breaks from daily routines and responsibilities, often called "respite" are especially important if you are with the person you care for 24 hours a day. Counselling, adult day care, a home health aide, or any other source of help should be looked at as early interventions, not eleventh-hour alternatives.

5. Do not compare your patient to any other patient. Understand that each individual will have a unique parkinsonian problem and progression profile.

6. Find support groups for yourself which will provide a safe space to vent. The group's shared experiences allow you (caregiver) to feel less alone and isolated.

The group can introduce you (caregiver) to resources that may be able to provide some relief.



7. Feel free to seek our help in case you think you are in a low, frustrated or in a continually fatigued mood.

8. Please understand that making the patient's life better is as important as preserving your quality of life and happiness.

9. It is important to not insist upon comparing the current abilities of the patient with their past abilities.

This not only makes the patient feel bad, but also increases the negativity in your relationship with them.

Please understand and accept that the patient is a changed individual now and we must allow them their current abilities while working together to improve them as much as possible.

10. In many cases, the family or the caretaker find it difficult to cope with the stress of having to attend a patient for a long time or months or years.

For such cases, we have arranged tie-up with an institution and nursing home, where the patient can be looked after by trained nurses and caregivers while we arrange for a short or long-term holiday for the caregiver or family. Please feel free to inquire about the same.

THINGS NECESSARY FOR FOLLOW UPS OR EMERGENCIES



1. Write down your symptoms or any questions the reasons or that you have for scheduling the appointment- this aids the treatment process.

2. Make a list of the patient's past medical history which will include list of medication, investigations done so far etc. Please bring all medications if possible.

3. For emergencies- Write down your personal details, emergency contact numbers, treating doctor's emergency contact, ambulance, and primary and secondary caregiver's contact.

Patients often have nonneurological medical problems like respiratory or urinary infections, heart, problems, indications, etc. for such emergencies. You must have a general physician preferably someone with an MD medicine degree who can coordinate with us to manage such crises.



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