


What I Wish I Knew

For Newly Diagnosed Individuals

Questions

1. Is there a cure for PD?
2. Is a PD diagnosis fatal?
3. How long can I expect to live?
4. Should I tell my family and friends?
5. Does everyone with PD have a tremor?
6. What are lesser known PD symptoms?
7. Can I still work (travel/volunteer) with PD?
8. Can I feel disinterested in hobbies/social activities?
9. What can I do now to look after my health?
10. Why does my healthcare team push exercise so much?
11. Is medication timing that important?
12. Is it better to delay medication or start now?
13. Why would I consider joining a support group?
14. Why would I call PSBC with my questions?
15. What's inspiring about the PD community?

Question 1

- Is there a cure for PD?
 - No
 - Treatment:
 - Levodopa/Carbidopa 
 - Prolopa[®]: Levodopa/benserazide (lighter option)
 - Azilect[®]: Rasagiline (stretches dopamine curve to prevent wear off)
 - Exercise
 - Other...

Question 2

- Is a PD diagnosis fatal?
 - No
 - PD is chronic and progressive
 - Rate of progression varies
 - Each person is unique
 - Important to exercise/take meds on time

Question 3

- How long can I expect to live?
 - Many people live years/decades with PD
 - About what you do now
 - Lifestyle choices and self-care plan are key



Question 4

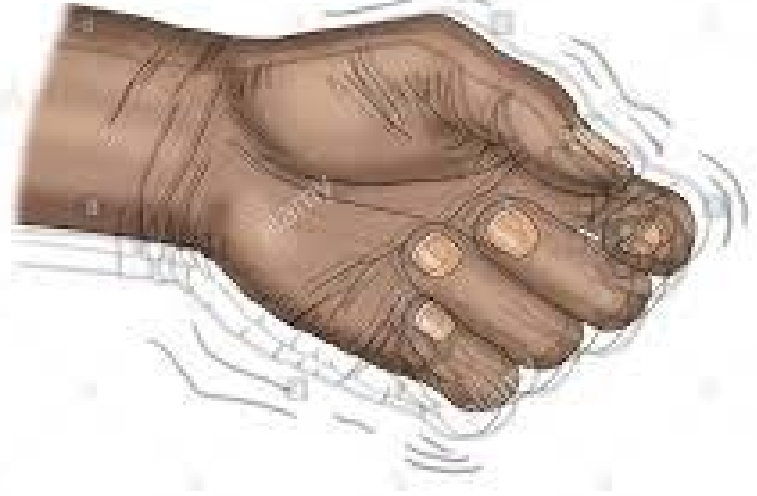
- Should I tell my family and friends?
 - Up to you...
 - Get informed about PD
 - Formulate your own PD language
 - Share with family and friends for SUPPORT
 - Disclosure to Employer/Colleagues (if wanted/needed)
 - Not required under law
 - Consider risks/benefits



Question 5

- Does everyone with PD have a tremor?
 - No
 - Up to 30% of individuals with PD don't have a tremor
 - Tremor can be a good sign
 - neurons working!
 - Symptoms are divided into 2 categories
 - Motor Symptoms
 - Non-Motor Symptoms

Parkinson's Hand Tremor



Question 7

- Can I still work (travel/volunteer) with PD?
 - Yes - keep doing what you love!
 - Work/Volunteer
 - If needed, talk with your employer for accommodations. Required by law. Get legal advice!
 - Travel
 - Don't delay!
 - Research appropriate insurance
 - Factor in rest time for jet lag & exercise time

Question 6

- What are some common lesser known PD symptoms?
 - Constipation/Incontinence
 - Vision issues (double vision)
 - Over/under sweating
 - Blood pressure changes from changed position (orthostatic hypotension)
 - Slowed thinking (bradyphrenia)
 - Fatigue

Question 8

- Can I feel disinterested in hobbies/social activities?
 - Yes
 - Bio-social impacts
 - Biological = chemical difference in your brain
 - Social = stigma of disease

Question 9

- What can I do now to look after my health?
 - EXERCISE!
 - At least 30min a day, 5X/week
 - Healthy baseline (nutrition, stress, sleep)
 - Be social!
 - Stay busy but don't overextend yourself
 - Create a weekly routine



Question 10

- Why does my healthcare team push exercise so much?
 - Exercise has shown to slow down progression, mitigate symptoms, create stronger bodies, strengthen mind-body connection and reduce stress.

Question 11

- Is medication timing that important?
 - YES
 - Medication on time helps reduce motor fluctuations (e.g., “ON” & “OFF” periods).



Question 12

- Is it better to delay medication or start now?
 - No evidence that says delaying medication is better for long run.
 - Some delay medication because their overall quality of life isn't affected by symptoms.
 - Over time, they may choose to start medication for PD.
- Modalities: naturopathy, acupuncture, etc.
 - Supplement, not replace medication

Question 13

- Why would I consider joining a support group?
 - Social support from people who “get it”
 - Build sense of community
 - Individualized support group
 - Informal group (no meetings), like-minded people
 - Education/information – understand the science, make informed decisions
 - Stay informed about what PD community is doing
 - Events, workshops, research

Question 14

- Why would I call PSBC with my questions?
 - Can answer and support your PD related question
 - Disclosure: PSBC staff are not medical staff
 - Brainstorm action plan to get back on track
 - Connect you with support groups, exercise classes, events/workshops, and PD healthcare professionals

Question 15

- What's inspiring about the PD community?
 - Taking control
 - Research
 - Advocacy
 - Access to information helps you make informed decisions about your health & life



TRUST THE CURRENT.

WHEN YOU RELAX AND
GO WITH IT, IT'S EASY.

- KAMAL RAVIKANT

That's all folks...

THANK YOU!