

**Bang for the Buck:
How People with Parkinson's Can Make the
Most of Visits to the Neurologist**

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■ General

- Be aware of the time allotted by the MD/nurse for the visit.
- Arrive early enough to complete billing paperwork before the appointment time
- For initial visit
 - Bring all records relevant to PD
 - Previous doctors' office notes
 - Especially important is info on previous drugs tried and their
 - Maximum dosages reached
 - Benefits
 - Side effects
 - Lab/test reports
 - Films or CDs of brain imaging (MRI, CAT scans), not just radiologists' reports

- Bring a family member to:
 - Help with history and other info MD requires
 - Help remember info provided

- For followup visits

- Bring interim records from other doctors relevant to PD
 - Office notes
 - Test results

- Provide information
 - Current list of all medications
 - Prescription
 - Over-the-counter
 - Supplements
 - As-needed meds for:
 - Pain
 - Anxiety
 - Insomnia
 - Constipation
 - Order the list by medication name, not by time of day.
 - Include medication changes instituted and discarded since previous visit.
 - Specify if you are taking the brand name or generic.

- Address PD issues as a “problem list”
 - For each problem known to the MD, list
 - Current status
 - Response to medication changes
 - Mention any new problems before the physical exam starts. State:
 - When it began
 - What time of day it tends to occur
 - Relationship, if any, to dose times of medication (especially levo/carb)
 - Include possible medication side effects.

- To what extent is the PD affecting your daily activities?
 - More time required? (Express as a percent increase.)
 - Do you need help with some things?
 - Getting out of deep chair or car
 - Putting on heavy coat
 - Buttons or other fine manual skills

- Fluctuations
 - Early-morning offs
 - End-of-dose wearing-off
 - Unpredictable offs
 - Sudden, over a few seconds
 - Wearing-off over an hour or so
 - Time of day?
 - If variable, "average" several days' observations
 - Relation to time since:
 - previous levodopa dose
 - previous meal

- Any gastrointestinal issues?
 - Drug side effects
 - Dopaminergic drugs
 - Loss of appetite or nausea
 - Diarrhea
 - Constipation
 - Anticholinergics (amantadine, trihexyphenidyl, etc.)
 - Constipation
 - Dry mouth
 - COMT inhibitors
 - Nausea
 - Abdominal pain
 - Diarrhea
 - Stalevo includes the COMT inhibitor entacapone

- Caused by PD
 - Constipation
 - Reflux symptoms
 - Weight loss without loss of appetite

- Important updates to non-PD health issues
 - Be very brief
 - List one problem at a time
 - By diagnosis, if possible, not by symptom
 - Changes in meds tried and discarded
- What time was my last levodopa dose?
(Helpful in evaluating exam result)

- Problems that a family member or caregiver may have to describe
 - Memory loss, confusion
 - Compulsive behavior, as from dopamine agonists
 - Gambling, including not just casinos but also
 - Lottery tickets
 - Internet gambling
 - Sports betting
 - Re-checking lights, gas, locks
 - Sexual aggressiveness
 - Eating
 - Medication non-compliance
 - Subtle dyskinesia
 - Typically starts with head or shoulder movement
 - Often mistaken for tremor
 - Rapid-eye-movement behavioral disorder with violent movement

- Questions to ask the neurologist after the exam
 - Is the diagnosis of PD still certain?
 - Did my PD Scale score change?
 - When is it time to:
 - Start medication
 - Start carbidopa/levodopa
 - Increase dosage size or frequency
 - Add medication to extend doses of carbidopa/levodopa
 - Substitute a different medication in the same class
 - Dopamine agonists
 - Pramipexole, Ropinirole
 - COMT inhibitors
 - Entacapone, Tolcapone
 - MAO-B inhibitors
 - Selegiline: Oral vs. Sublingual
 - Rasagiline
 - Levodopa
 - Regular
 - Long-acting
 - Orally dissolvable

- Generic vs. brand
 - Can any generics be safely substituted for any brand-name drugs I'm taking?
 - Would brand-name work better than any generics I'm taking?

- What non-drug measures are advisable?
 - Exercise
 - Aerobic
 - Stretching
 - Weight training
 - Is permission from primary care or cardiologist needed?
 - Would a course of formal physical therapy be advisable?
 - Do I need an evaluation by a:
 - Speech/swallowing therapist?
 - Neuropsychologist?
 - Dietary changes needed?
 - High-fiber
 - More fluids
 - Avoid salt restriction
 - Protein manipulation
 - Higher intake to blunt levodopa side effects
 - Lower intake to speed up onset of levodopa action

- What are current recommendations for deep-brain stimulation surgery?
 - Patient selection criteria
 - Am I a candidate?
 - If not, could I be a candidate in the future?
 - Keep in mind:
 - The surgery improves with time.
 - The types of surgery available change.
 - The risks and adverse effects lessen with time
 - The risk increases with advancing
 - Patient age
 - Stage of PD
 - But the available medication alternatives improve, too
 - Having surgery may disqualify you from participating in clinical trials

- Anything new?
 - Recently approved prescription medications?
 - Non-prescription medications found helpful?
 - Experimental drug trials available for you?
 - At neurologist's institution
 - Elsewhere (accessible to frequent study visits)
 - New drugs in literature?
 - New (possibly effective) uses for old drugs?
Examples:
 - Pyridostigmine (for myasthenia gravis) for low blood pressure of PD
 - Mirtazepine (for depression) for tremor of PD
 - Gabapentin (for epilepsy) for muscle pain of PD
 - Creatine (for bodybuilding) as experimental neuroprotective agent for PD

- Paperwork

- At the start, not the end, of the visit, give the MD or nurse
 - a list of prescription to be refilled
 - disability forms to be completed
 - request for handicapped parking form
 - request for work excuse