

**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