

CLINICAL APPOINTMENTS SUMMARY

TAKE ACTION AT YOUR HEALTHCARE APPOINTMENTS

This section is focused on helping you get the most out of your healthcare appointments. You will get more out of these appointments if you are ready for them. ***Preparing and organizing information for your wellness team is often overlooked, but is time well spent.***

A key element to taking action is having the information available that you and your wellness team will need to discuss. The worksheets that follow will help you organize your information and will need to be updated occasionally, sometimes before each visit.

Healthcare appointments are intended to encompass visits with all of the following healthcare providers on your wellness team:

- Doctor (primary care physician, neurologist, movement disorder specialist)
- Specialist (gynecologist, urologist, sleep specialist, physical therapist, speech and language pathologist, occupational therapist, recreational therapist, art therapist, music therapist)
- Alternative therapist (acupuncturist, chiropractor)
- Dentist
- Optometrist
- Social worker
- Emotional health specialist (counselor, psychologist, psychiatrist)
- Dietitian

As you update your information, file older worksheets in a specific location so that you and your wellness team can refer to them later as a measure of your progress over time.

GET THE MOST FROM YOUR APPOINTMENT

As you learn to communicate your needs and current status with the various members of your wellness team, you will help each specialist better understand what you are experiencing. When you provide detailed information, you help your team be in the best position to improve both your quality of care and your quality of life.

Many things can cause your healthcare appointments to be less than satisfying. In some instances, you might not remember important details about a visit, especially if you are anxious, are learning things for the first time or have hearing problems, multiple medical problems or memory difficulties. In addition, you may have difficulty expressing yourself, forget what you were going to say or be hesitant to ask questions. ***These are all common***



experiences, even for people who do not have Parkinson's. Utilizing the worksheets in this section will help you avoid these familiar pitfalls.

The following steps are provided to help optimize your time and enhance communication with your wellness team.

Step 1: Before Your Appointment

Write down your overarching goals for the appointment. It is very helpful to take some time and think about what is important to you. This will help you focus the appointment on your most pressing concerns.

- Complete the “Goal Summary for Doctor Visits” worksheet before your visit and bring a copy to share with your doctor.

Note specific questions and concerns before your visit. Sometimes you may forget to ask important questions during your healthcare appointment, so writing them down will remind you to ask.

- Prioritize your questions with the most important one first as you may not have the time to address everything in one visit.
- Allow space to write answers next to the question so you can refer to them later. It may also help to have your care partner or bring a friend or family member to the appointment with you to write the answers for you.
- If you are a care partner, your questions and concerns are important, too. Remember to add these to the list and be prepared to address them during the appointment.

Keep a record of any changes your doctor makes to your treatment for quick reference.

Some ways to keep good records include:

- Keeping a dedicated notebook for your healthcare visits.
- Completing the “Daily Medication Log” and showing this to all members of your wellness team before starting treatment. This will lower risk of medication interactions.
- In the “Overall Medication Log,” note how each medication you are currently taking or have taken affects you, being sure to mention any side effects you have experienced.
- Keeping copies of previous brain MRIs, CT scans and any other medical test or procedure you have had.
- Updating medical notes and contact information for current and previous healthcare providers (start by filling out the “Wellness Team Contact Information” sheet).



Step 2: Appointment Day

Maximize your time with your healthcare provider. Plan ahead, arrive early and complete forms accurately. These steps will save time for both you and your healthcare provider. Begin by asking your healthcare provider what information is needed from you. Ask questions that are important early during your appointment; don't wait until the end.


Complete the patient questionnaire forms provided by your healthcare provider. These forms can help improve communication, provide information for your record, allow your healthcare provider to spend more time on you and reduce errors and mistakes, especially when tracking your medications. Medications are a primary means of managing Parkinson's and accuracy can greatly affect how well your healthcare provider can control your symptoms.


If writing is difficult for you, ask your care partner or a family member or friend to assist you in completing the forms. In some cases, you might even be able to call and request the forms ahead of time, giving you more time to complete them at home before your appointment.

Remember these tips on the day of your appointment:

- Arrive at least 30 minutes early to complete any forms.
- Always bring a complete list of your medications (such as the "Daily Medication Log") to reduce errors that can occur from one visit to the next. Do not use statements like, "no changes," "same as last visit" or "the doctor knows what I am on." This is how errors occur!
- Visit the restroom before the start of your appointment to ensure comfort throughout the visit.
- Ask for extra copies of forms for future visits. Store them with your records and complete them at home before your next appointment.
- Schedule your appointments during your medication "on" times. This will reduce symptoms during the appointment. In some cases, it may be beneficial to schedule appointments during your "off" periods. For example, your neurologist might benefit from seeing you when your medication is "off." Talk with your doctor if you are unsure.
- Ask your doctor for permission to audio record your appointment for future reference.
- If applicable, bring your care partner with you to your appointment.

Ask questions and learn about your condition. To ensure a productive dialogue with your doctor, come prepared with questions you want to ask and note the answers. Important questions to ask include:

- What are the symptoms or problems that are related to my Parkinson's and what symptoms should I look for?
 - Do I need medication? If so, what should I expect medication to change or improve?
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- What are the most common side effects of the medication you are considering for me?
 - Are there any known drug interactions with over-the-counter medications?
 - What symptoms or side effects should be reported immediately?
 - How often should I make appointments? (Ask yourself how often you would like to see your doctor, then share this with them.)
 - Where can I find accurate and comprehensive information about my symptoms?
 - When should I see a physical therapist, occupational therapist, speech therapist, counselor or other specialist?

Step 3: After the Appointment

How often do you leave your healthcare appointment trying to remember what just happened? Do you have trouble following through with your treatment plan?

The following suggestions will help you stay on track between appointments:

- Bring a care partner, family member or friend to write down instructions and help you keep track of your next steps.
- Complete the remaining sections of the form “Goal Summary for Clinic Visits.” You are more likely to follow through with changes if you review your goals and write down the action steps needed to get you there.
- Review the information in your “Goal Summary for Clinic Visits” with the other members of your wellness team to involve them in your treatment.
- Keep a journal or a calendar of your goals for the week and steps you have taken to reach them.

Between Appointments

- Keep a list of any changes that result from calls to your doctor about new symptoms experienced between appointments.
- Keep track of medication refill needs before you run out. Provide your pharmacy with your phone number, fax number and/or address for quicker refills.
- Keep a list of prior medicines that were tried and not effective or caused side effects so that they are not used again. You can do this in the “Overall Medication Log.”
- Review your goals written in the “Goal Summary for Doctor Visits” worksheet and update on your progress.
- Ask each healthcare professional on your wellness team what information is important for you to bring to each visit so that you can work together as a team.

Appointment Checklist

The following information will be helpful to you and your wellness team over time. The worksheets referenced in this section are intended for you to use to help organize your information and maximize the usefulness of your healthcare appointments.

- ☐ Complete your doctor's patient questionnaire, or use the "Parkinson's Care Questionnaire."
- ☐ Keep a list of medications to include name, strength, timing, generic or trade name. Consider using the "Daily Medication Log."
- ☐ Keep a list of all the medications you've tried over the course of living with Parkinson's, being sure to note side effects or reasons specific medications were discontinued. Consider using the "Overall Medication Log."
- ☐ Keep a list of all your treating healthcare professionals, including name, address and fax number. Consider using the "Wellness Team Contact Information."
- ☐ Keep a list of troublesome side effects to discuss with your doctor. Consider using the "My Symptoms Worksheet."

Remember to bring the following on appointment day:

- ☐ Updated "Daily Medication Log."
- ☐ Updated "My Symptoms Worksheet."
- ☐ Updated "Goal Summary for Doctor Visits" assessment.
- ☐ Updated "Current Symptoms Summary."
- ☐ Updated "Parkinson's Care Questionnaire."
- ☐ Updated "Dental Worksheet" and "Medical Summary for Dentists" if visiting a dental provider.
- ☐ List of questions to ask before your visit.

These steps require some effort on your part. They will, however, save time in the long run and most importantly, help you obtain the greatest possible benefit from your healthcare appointments.

CURRENT SYMPTOMS SUMMARY

Name: _____ Date: _____

This document will summarize your problems or concerns, improving your team's understanding of you and your Parkinson's and helping them to effectively tailor your treatment.


I have trouble in the following areas that may be affected by my treatment, hospital stay or procedure:

Motor Problems

- ☐ Balance problems
- ☐ Communication and speech difficulties
- ☐ Dyskinesia – uncontrollable movements usually caused by medication
- ☐ Dystonia – involuntary muscle spasm, contraction leading to pain, flexion or twisting movements
- ☐ Freezing of gait or motor initiation problems (feet stuck to floor)
- ☐ “On/off” fluctuations – periods of time when my medications are “on” that I can move better and when my medications are “off” and I have difficulty moving. “Off” periods usually happen as my medication is wearing “off.” To reduce this problem, **I must have my Parkinson's medications on time.**
- ☐ Swallowing problems

Non-Motor Problems

- ☐ Anxiety
- ☐ Apathy or trouble self-initiating tasks
- ☐ Bladder problems
- ☐ Constipation
- ☐ Depression

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- ☐ Cognitive problems
 - ☐ Memory problems or mild thinking difficulties
 - ☐ Dementia
 - ☐ Hallucinations or sensitivity to hallucinations with certain medications
 - ☐ Drooling
 - ☐ Excessive sweating or chills
 - ☐ Fatigue
 - ☐ Impulsivity problems
 - ☐ Loss of smell or loss of appetite
 - ☐ Pain in these areas: _____
 - ☐ Sleep problems
 - ☐ Trouble staying asleep
 - ☐ Restless legs syndrome
 - ☐ Periodic limb movement disorder: repetitive movements, typically of the legs and feet
 - ☐ Sleep apnea
 - ☐ REM sleep behavior disorder: vivid, active, physical dreaming
 - ☐ Daytime sleepiness
 - ☐ Sensations such as tingling, aches, pain, cold hands/feet
 - ☐ Sexual dysfunction
 - ☐ Vision problems

WELLNESS TEAM CONTACT INFORMATION

Primary Care Physician

Name: _____

Address: _____

Phone: _____ Fax: _____

Neurologist

Name: _____

Address: _____

Phone: _____ Fax: _____

Other Provider _____ **Specialty:** _____

Name: _____

Address: _____

Phone: _____ Fax: _____

Other Provider _____ **Specialty:** _____

Name: _____

Address: _____

Phone: _____ Fax: _____

Other Provider _____ **Specialty:** _____

Name: _____

Address: _____

Phone: _____ Fax: _____

MEDICAL PROVIDERS

Primary Care Physician

DBS Programmer

Primary Urgent Care

Neurologist

Alternate Urgent Care

Optometrist/Ophthalmologist

Emergency

Dentist/Oral Surgeon

DBS MEDICAL HISTORY

NO: Diathermy, Lithotripsy MRI or Ultrasound. Medical Consent Required.

PATIENT HISTORY

Name: _____ DOB: _____

Address: _____

Type of Residence: _____ Phone: _____

Marital Status: _____ Work Status: _____

Occupation (if employed): _____

Activity Level: ☐ Sedentary ☐ Moderately Active ☐ Very Active

Smoker: ☐ No ☐ Yes, Current ☐ Previous

Allergies (*check for YES*):

☐ Aspirin ☐ Codeine ☐ Penicillin ☐ Local Anesthetics ☐ Acrylic ☐ Latex ☐ Metal

PATIENT PROGRAMMER

Device: _____ Manufacturer Contact: _____

Neurologist Contact: _____ Programmer Contact: _____

MEDICATIONS

NAME	DOSAGE	FREQUENCY	STRENGTH

PHYSICIANS

TYPE	DOCTOR NAME	HOSPITAL / CLINIC	ADDRESS CITY, STATE, ZIP	PHONE
Primary Care Physician				
Neurologist				
DBS Programmer				
DBS Surgeon				
Optometrist/Ophthalmologist				
Dentist				
Oral Surgeon				
OTHER				



MEDICAL INSURANCE

PRE-AUTHORIZATION

Claim #: _____

Entitled to: _____

Insurance Company: _____

Employee ID #: _____

Group Name: _____

Group Policy #: _____

Claim Inquiries: _____

EMERGENCY CONTACTS

Name: _____

Relationship: _____

Home Phone: _____

Cell Phone: _____

Name: _____

Relationship: _____

Home Phone: _____

Cell Phone: _____

Name: _____

Relationship: _____

Home Phone: _____

Cell Phone: _____

IMMUNIZATIONS AND PREVENTATIVE SCREENINGS

TYPE	DATE
Flu	
Pneumonia	
Tetanus	
Hepatitis B	
Shingles	
Gardasil	

TYPE	DATE
Colonoscopy	
EKG	
Echocardiogram	
Eye Exam	
Physical Exam	
Neurology Exam	





SURGICAL HISTORY

SURGICAL PROCEDURE	REASON FOR SURGERY	DATE	SURGEON NAME	HOSPITAL	CITY, STATE

PREPARE FOR YOUR HOSPITAL STAY

BRING THE FOLLOWING INFORMATION WITH YOU:

Make copies of your completed “Daily Medication Log” to give to your nurses and doctors. Remember to update this each time your medications are changed.

List of Medications You Should Not Have

Common anti-hallucination and anti-nausea medications can worsen movement. Both nausea and hallucinations can occur with certain medications and during illness.

Note: This is not a complete list of medications to avoid. If you have questions about other medications, ask your pharmacist or doctor.

Anti-Hallucination Medications to Avoid

Note: The anti-hallucination medications Quetiapine (Seroquel) or Clozapine (Clozaril) can be used for hallucinations and psychosis. The following should be avoided:

- Aripiprazole
- Chlorpromazine
- Haloperidol
- Molindone
- Perphenazine
- Perphenazine and amitriptyline
- Risperidone
- Thioridazine

Anti-Nausea Medications to Avoid

- Metoclopramide
- Promethazine



Medications to Avoid if You Are on Rasagiline (Azilect) or Selegiline (Eldepryl)

- Pain medications meperidine, tramadol, and methadone
- Antispasmodic medication (Flexeril)
- Dextromethorphan (cold medication) and ciprofloxacin (antibiotic)

Note: This is not a complete list of medications to avoid. If you have questions about other medications, ask your pharmacist or doctor.

If you have DBS: Bring the name and contact number for your neurologist, DBS programmer and device manufacturer, along with a document of tests, medications and procedures that require medical consent from your neurologist. Consider using the “DBS Medical History” form to collect and share this information.

Bring copies of the “Current Symptoms Summary,” as certain symptoms such as swallowing, dizziness, constipation and confusion could worsen in the hospital and these symptoms could influence your treatment decisions.

Inform Hospital Staff

- Highlight your need for medications on time.
- Discuss what you can do when the medications are “on” and when they are “off,” so that they are aware of any potential changes in your movement. This is an opportunity to reinforce the need to get your medications on time.
- Describe your dyskinesia and freezing episodes and when they occur, as these symptoms may be unfamiliar to your hospital treatment team.

What to Ask for During Your Hospitalization

- Physical therapy, occupational therapy, speech/swallowing therapy, especially if you have trouble with balance, swallowing and general mobility.
- Chaplain services or social work consult for support of you or loved ones.

What to Know or Ask Before Discharge

- Have your neurologist and primary care physician been notified of your condition while in the hospital?
- When should you see your primary care physician?
- Should you get additional rehabilitation such as physical therapy?
- What important tests, procedures or new diagnosis have you had?
- What medications have been changed and why?
- How do you get a copy of the hospital records sent to your doctor?



Advanced Directives

The following advanced directives ensure that your rights and personal wishes are respected in the event of a medical emergency or change in your health status in which you are unable to make decisions for yourself. Many options are available to help you determine these, and each document should be reviewed by your attorney to ensure your wishes are accurately recorded. Each province and territory has its own laws relating to powers of attorney, and may use slightly different terminology. You must follow the laws in the province or territory where you live.

General Power of Attorney: A legal document that gives your attorney authority to manage your finances and property on your behalf while you are mentally capable of managing your own affairs. It ends if you become mentally incapable of managing your own affairs.

Enduring or Continuing Power of Attorney: A legal document that lets your attorney continue acting for you if you become mentally incapable of managing your finances and property. It can also give your attorney authority over all or some of your property and finances.

Power of Attorney for Personal Care: A legal document that gives another person the authority to make health and other types of personal and non-financial decisions for you, if you were to become mentally incapable of doing so for yourself. Depending on where you live, these may be called powers of attorney, personal or health directives, representation agreements, or mandates.

It is a good idea to also bring a signed statement identifying a friend or family member who your doctors can talk to about your treatment.

Summary of Hospital Document Checklist

- Bring “Daily Medication Log”
- List of medications to avoid
- Bring “Current Symptoms Summary”
- Advanced directives
- Bring “DBS Medical History” (if applicable)

MEDICAL SUMMARY FOR YOUR DOCTOR APPOINTMENT

List your top three goals or concerns for your next doctor's appointment:

Note: You may wish to review the "Current Symptoms Summary" and "My Symptoms" worksheets to identify and help set these priority goals.

1. _____
2. _____
3. _____

Describe any treatment changes you have made since your last visit and how they have affected your symptoms:

List any new medical problems, allergies or hospitalizations since your last visit:

1. _____
2. _____
3. _____

Review the "Daily Medication Log" and "Overall Medication Log" to discuss any side effects of your medications.


MEDICAL SUMMARY FOR DENTISTS

Bring the following information to your dentist to inform them of Parkinson's-specific dental issues and modification tips.¹

About Parkinson's

- ☐ Parkinson's is a progressive, neurodegenerative movement disorder.
- ☐ Primary motor symptoms include rigidity, tremor, slow movement, postural instability, difficulty speaking, decreased facial expression and weakness of face and throat muscles.
- ☐ Primary non-motor symptoms include loss of smell, sleep disturbances, depression, excessive saliva, anxiety and cognitive issues.
- ☐ Parkinson's medication side effects commonly include dry mouth, low blood pressure, dizziness, confusion, nausea and an "on/off" cycle, when medication ebbs and flows in its effectiveness.

Communication

- ☐ Allow additional time for responses, as difficulty speaking and mild cognitive impairments can lead to a longer lead time in responding. Include the care partner (if present) in the discussion to ensure all information being understood is accurate.
- ☐ Collaborate with your patient to determine a signal for discomfort – for example, the patient may put his or her hand up to signal they need a break or are having trouble swallowing. Decreased facial expression can make it difficult to express discomfort in the chair.
-  **Ask your patient what medications they are currently taking to reduce the likelihood of interactions with numbing medications or anesthesia.**

Treatments

- ☐ Use more frequent suction during cleaning, as the cough reflex may not be as strong.
- ☐ Offer an intraoral rubber bite block, as Parkinson's patients may have difficulty keeping their mouth open, managing saliva or restricting head and tongue movements.
- ☐ Use an aspirator tip placed under a rubber dam and stabilized by an assistant. This will assist the patient in managing saliva and protecting airways from the higher risk of aspiration.

¹ Friedlander, A. H., Mahler, M., Norman, K. M., Ettinger, R. L. (2009). Parkinson Disease: Systemic and orofacial manifestations, medical and dental management. *The Journal of the American Dental Association*, 140(6), 658-669.

- ☐ Look for excessive loss of tooth structure; Parkinson's tremors of the orofacial musculature and the use of levodopa medication may cause bruxism.
- ☐ Utilize glass ionomers and resin-modified glass ionomers.
- ☐ Keep the dental chair at an incline of 45° or higher to enable comfortable swallowing.
- ☐ The dental chair should be raised and lowered slowly to allow the patient to adapt to the position and prevent syncope episodes.
- ☐ Help your patient in and out of the dental chair slowly to reduce the likelihood of falls. Encourage them to sit up in the chair, plant their feet on the ground, stand up slowly and walk out of the room – pausing for around 20 seconds between each transition.

❗ Ask your patient if they have had Deep Brain Stimulation surgery.

Medications and Interactions

- ☐ If a patient is taking MAO-B inhibitors (selegiline, rasagiline), avoid meperidine, tramadol, methadone, and cyclobenzaprine.
- ☐ Administer no more than 0.05mg of epinephrine per 30-minute period, with careful aspiration to avoid intravascular administration.
- ☐ Be careful when using local anesthetic agents containing epinephrine in patients being treated with levodopa and entacapone, because these patients may experience an exaggerated effect on blood pressure and heart rate.

Deep Brain Stimulation (DBS) Therapy

- ☐ Patients should have a complete dental checkup and treatment prior to DBS surgery.

❗ Ask your patient if they have had Deep Brain Stimulation surgery. If the answer is yes:

- ☐ Do not use diathermy (therapeutic ultrasound), as it is contraindicated and may lead to coma or death.
- ☐ Ultrasonic cleaning that uses air and water will not interact with the device.
- ☐ X-ray use is not contraindicated.
- ☐ Laser technology use should be reviewed with the DBS device manufacturer.
- ☐ Any electrical or magnetic device near the head, neck or chest should be approved for use by the device manufacturer.
- ☐ Device labeling does not require pre-medication with antibiotics for dental treatment.