



Care Partner Guide for Daily Care

Tips and Tools for Medical Visits, Healthcare Planning & Decision-Making

Medical visits and healthcare decisions are pivotal moments in Parkinson's care. Appointments are often brief, information-dense, and emotionally charged. Care partners play a critical role in ensuring concerns are heard, information is shared accurately, and care decisions reflect both medical needs and personal values.

This guide offers practical tools to help care partners prepare for visits, advocate effectively, and participate confidently in healthcare planning—while honoring the voice and autonomy of the person with Parkinson's.

The Care Partner's Role in Medical Visits

Care partners are often the most consistent observers of day-to-day changes and patterns.

Key caregiver contributions include:

- Observing symptom changes over time
- Noting medication effectiveness and side effects
- Identifying safety, cognitive, or behavioral concerns
- Supporting accurate recall during appointments
- Helping interpret and reinforce care plans after visits

Medical visits are not just about test results or prescriptions—they are about understanding how Parkinson's is affecting daily life. Care partners help bridge the gap between clinic-based care and what happens at home by sharing real-world observations clearly and respectfully.

Preparing for Appointments

Preparation improves the quality and efficiency of medical visits.

Helpful preparation tips:

- Write down concerns ahead of time
- Prioritize the top 2–3 issues for the visit
- Bring an updated medication list (including supplements)
- Note recent changes in mobility, cognition, mood, sleep, or hallucinations
- Bring WPA contraindicated medication cards

Appointments move quickly. Written notes prevent important issues from being overlooked—especially when stress, fatigue, or cognitive changes are present. Encourage the person with Parkinson’s to identify what matters most to *them* so their priorities guide the discussion.

During the Medical Visit

Care partners support communication without speaking *over* the individual with Parkinson’s.

Effective in-visit strategies:

- Allow the person with Parkinson’s to speak first
- Add observations respectfully when needed
- Ask for clarification when information is unclear
- Take notes or request written instructions
- Share WPA contraindicated medication cards with providers

Allowing time for the person with Parkinson’s to express themselves preserves autonomy and confidence. When adding caregiver observations, framing them as neutral patterns rather than judgments helps maintain trust.

Providing the **WPA contraindicated medication cards** during visits is an important safety step. It helps remind providers—especially those unfamiliar with Parkinson’s—of medications that may worsen cognition, hallucinations, or motor symptoms. These are located on our website wiparkinson.org for downloading.

Shared Decision-Making & Care Planning

Parkinson's care involves ongoing decisions related to medications, therapies, safety, and future planning.

Core principles of shared decision-making include:

- Respecting personal values and preferences
- Balancing symptom management with quality of life
- Revisiting decisions as needs change
- Including care partners appropriately
- Clearly documenting decisions

There is rarely a single “right” choice in Parkinson's care. Decisions evolve and should reflect what matters most to the individual—independence, comfort, safety, or participation in meaningful activities. Care partners help ensure these values remain central as care becomes more complex.

Advance Care Planning & Healthcare Preferences

Planning ahead reduces uncertainty during urgent or stressful situations.

Key planning topics to address early:

- Healthcare power of attorney
- Advance directives or living wills
- Preferences for hospitalization or life-sustaining treatments
- Emergency contact information
- Medication safety considerations

Advance care planning is not about loss of hope—it is about clarity. Care partners often help initiate, document, and revisit these conversations so wishes are understood and respected over time.

Emergency Care, Hospitalization & Medication Safety

Emergency and hospital settings pose unique risks for individuals with Parkinson's, particularly related to medication timing and contraindicated drugs.

Critical caregiver advocacy steps:

- Clearly state the Parkinson's diagnosis on arrival
- Emphasize that medication timing is essential
- Provide an up-to-date medication list
- **Present the WPA contraindicated medication card immediately**
- Repeat this information at every care transition

In emergency or inpatient settings, providers may be unfamiliar with Parkinson's-specific medication risks. Certain commonly used medications—for nausea, agitation, sleep, bladder symptoms, or pain—can significantly worsen confusion, hallucinations, or motor symptoms.

Care partners should **actively provide the WPA contraindicated medication card** to emergency staff, hospital teams, pharmacists, and consulting providers. This simple step can prevent serious complications and serves as a powerful layer of protection during vulnerable moments.

Tools That Support Healthcare Engagement

Helpful tools include:

- Appointment preparation worksheets
- Medication and symptom tracking logs
- A shared medical binder or digital folder
- Emergency information cards
- WPA contraindicated medication cards (kept in wallet or bag)

Organized, accessible information reduces stress and improves continuity of care. Many families find that keeping medication cards and documents easily visible allows them to advocate quickly and confidently when it matters most.

When to Ask for Additional Support

Seek additional guidance if:

- Medical information feels overwhelming
- Appointments feel rushed or unclear
- Healthcare decisions become emotionally difficult
- Care responsibilities increase significantly

Social workers, care coordinators, and patient navigators can help families navigate complex systems and decision-making.

A Final Thought for Care Partners

Being present at medical visits and during healthcare decisions is a powerful act of advocacy. Your preparation, observations, and willingness to speak up help ensure safer, more coordinated care.

Carrying and sharing our **WPA contraindicated medication cards** is one of the simplest—and most effective—ways to protect the person you care for. Your role matters deeply.

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