



Caring for Parkinson's Disease



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Cover Image: Parkinsons Exercise Program, Evergreen Commons, Grand Rapids, MI. For more information related to this program and other offerings, visit the PAWM website Resource Guide.

REGARDING THIS BROCHURE

This brochure was created to provide vital information for people who live with Parkinson's disease (PD) and the families who support them. PD patients often have a complicated medical regimen and are subject to multi-system conditions that impact their quality of life. It is important to understand the motor and non-motor issues of PD and the available resources.

The first section is an overview of PD, current treatment options and potential systemic problems. For simplification, we have used "trade" names for medications instead of generic names. The second section outlines other key considerations. Hopefully, this brief brochure will be useful to you.

ABOUT PAWM

Parkinson's Association of West Michigan (PAWM) is a non-profit organization, located in Grand Rapids, MI, serving the Greater Grand Rapids area as well as the Lakeshore communities of Holland and Muskegon. PAWM is committed to helping patients and their families understand PD and learn about activities and support groups that may help with the management of PD.

PAWM is a source for PD information, support, and education. PAWM can help you establish the relationships necessary to attend meetings, feature programs on physical and speech therapy, relaxation training, and other measures that are important in learning to live with PD. You may choose to learn about home healthcare or to hear presentations by neurologists and other health professionals with PD experience and training. Please visit our website for more information.

SECTION 1 PATIENT CARE INFORMATION

WHAT IS PARKINSON'S DISEASE?

Parkinson's disease (PD) is a progressive neurological disorder that results in a loss of dopamine cells deep in the brain that are involved with control of movement and muscle tone. Primary motor symptoms include resting tremor (*shaking*), bradykinesia (*slowness*), rigidity (*stiffness*) and postural instability. Muscle power is not affected. However, people often experience a sensation of weakness due to the stiffness and slowness. Diagnosis is based on clinical examination, as there are no definitive imaging or laboratory abnormalities. If a patient has two of the primary symptoms and no other explanation is found, a presumptive diagnosis of "Parkinsonism" is made. A DaTscan (*Dopamine Transporter Scan*) may be used to differentiate between PD and similar conditions, such as an essential tremor. A DaTscan may also reveal a reduction in brain cells vulnerable in PD. An MRI of the brain may also be obtained to support a PD diagnosis.

PD is associated with the depletion of several chemical transmitters in the brain called **neurotransmitters**. Deficiency of the neurotransmitter Dopamine is associated with the motor symptoms of PD. Current therapy for motor symptoms is primarily directed at increasing dopamine in the brain.

PD is estimated to affect over 1 million (1,000,000) Americans with sixty thousand (60,000) new cases being diagnosed each year. The cause of PD is not entirely known. It is thought that a combination of genetic, environmental, and aging factors are responsible. Certain medications block dopamine in the brain and can cause symptoms that resemble PD, and in this case, PD symptoms are reversible.

TREATMENT

There are several different classes of medications that can be used to treat PD symptoms. The classes all work a little differently to achieve the same effect. Each class has “pros” and “cons” and may be used at different times in the PD course of treatment. The most effective treatment for the motor symptoms of PD is **Sinemet**. Sinemet consists of two chemicals: levodopa, also known as L-dopa, an amino acid that is converted by the brain into dopamine; and Carbidopa, which prevents the metabolism of L-dopa in the body before it reaches the brain. Therefore, Sinemet may sometimes be referred to as Carbidopa/Levodopa. Dosages of Sinemet are as follows: 10/100, 25/100, 25/250, 50/200 CR, and 25/100 CR. The top number refers to the milligram (mg) amount of Carbidopa and the bottom amount refers to the mg amount of L-dopa in each tablet. “CR” formulations are “controlled release” and may last for a longer period of time. **Parcopa** is a product that is similar pharmacologically to the short-acting Sinemet and it easily dissolves in the mouth without water. **Rytary** has the same active ingredients as Sinemet but is packaged differently to act as a combination of short- and long-acting Sinemet. It is mostly used when Sinemet is not lasting from dose to dose. **Inbrija** is an inhaled form of L-dopa without carbidopa. It is used to achieve a faster symptomatic benefit when Sinemet wears off as it is absorbed into the lungs, instead of relying on the slow absorption in the intestines. It is used as an add-on therapy, as a quick bridge or “rescue” and does not replace oral medication.

Dopamine agonists activate the same receptor in the brain as dopamine. They do not require a chemical transformation in the brain to work, and therefore, are useful when Sinemet is losing its effectiveness. They may also be the initial drug of choice depending on multiple factors that should be discussed with the treating provider.

There are four (4) oral agonists that are currently more commonly used. **Requip** and **Mirapex** are available in both short-acting and long-acting forms. **Apokyn** is an injectable agonist useful as a “rescue” agent for prolonged freezing or when oral therapy is not possible. However, it may have more pronounced side effects such as vomiting, low blood pressure. **Neupro**, a 24-hour skin patch, is also available. Cost may also be a limiting factor for some patients.

Dopamine agonists tend to have more frequent side effects than Sinemet, including drowsiness, confusion, edema, hallucinations, weight gain, and impulse-control disorders, also known as ICD’s. ICD is the failure to resist a temptation or an urge. An ICD can include compulsive behavior toward eating, gambling, shopping, sexual behavior, organizing, gaming/computer use, and others. ICD tends to happen more in people who have a history of impulse control behavior, but it can occur in anyone. Rarely, it may result in sleep attacks, sudden onset of sleep without warning.

Monoamine oxidase (MAO) inhibitors (like **Azilect**, **Eldepryl**, **Selegiline**, **Xadago**, and **Zelapar**) slow the breakdown of dopamine by inhibiting the MAO enzyme, thereby, prolonging the benefit of Sinemet. Most can be used in combination with Sinemet or alone. Xadago must be used in combination with Sinemet. There are dietary and medication restrictions with this class of medication. Therefore, it is important to speak with your doctor or pharmacist to avoid any dangerous interactions.

Catechol-O-methyltransferase (COMT) inhibitors (like **Tasmar**, **Comtan**, and **Ongentys**) prolong the benefits of Sinemet by blocking the COMT enzyme. They may also increase Sinemet side effects. Tasmar has potential liver complications and is less commonly prescribed because of the need for regular blood monitoring. Comtan has also been combined with Sinemet into one tablet called **Stalevo**. Several dosage strengths of Stalevo are available, depending on the amount of Sinemet incorporated. Ongentys is the newest of the group and has the advantage of being taken once daily.

Anticholinergics, such as **Artane**, are older medications developed before the discovery of Sinemet. They work by blocking the effects of relatively excessive acetylcholine. They may be useful for tremors in some patients but are less popular because of frequent side effects, including confusion, blurred vision, hallucinations, dry mouth, urinary retention, and constipation.

Amantadine is an anti-viral medicine (under such brand names as **Gocovri**[®], **Osmolex ER**[™], **Symadine**, and **Symmetrel**) that have value for some patients, both for symptom management and the reduction of drug-induced dyskinesias. It may produce dizziness, constipation, reversible skin spots/blotching and edema, confusion, or hallucinations.

Nourianz is a new medication developed to take with Sinemet or Rytary when the benefit of these medications is no longer lasting dose to dose. Nourianz is an adenosine receptor A2A antagonist. It may improve the amount of good treatment time without worsening dyskinesia, a side effect of involuntary movement or swaying caused by Sinemet.

Other important treatment practices to incorporate into your lifestyle include frequent exercise, good nutrition, rehabilitation therapies (i.e., physical, speech, occupational therapies), and complimentary therapies such as dance, Tai Chi, yoga, or mindfulness.

Surgical treatments are available for some people living with Parkinson's disease. These are most commonly used when Sinemet still works for symptom control but does not last dose-to-dose (i.e., medication wearing off), the medication regimen results in bothersome dyskinesia (uncontrolled, involuntary muscle movements ranging from shakes, tics and tremors to full-body movements), tremors are not responsive to medication, or medications are not tolerated. There are also symptoms that may contraindicate surgical treatments. These approaches to treatment should be undertaken in an experienced multidisciplinary Parkinson's center. Surgical treatment options include deep brain stimulation (DBS), MRI-guided focused ultrasound (FUS), and Duopa. DBS requires the placement of hardware deep in the brain and is often described as a "pacemaker for the brain." Focused ultrasound does not require hardware or incisions but rather creates a small permanent brain lesion to control symptoms. Currently this is only available in Parkinson's to treat one side of the body, limiting its use. Research is ongoing. Duopa is an intestinal infusion of Sinemet gel over 16 hours per day and involves placement of a tube that delivers medication directly to the intestine and a pump which is carried with the patient throughout the day.



Image: Dancing with Parkinson's Disease, Grand Rapids Ballet School. For more information related to this program and other offerings, visit the PAWM website Resource Guide.

CARE ISSUES

Despite many advances in treatment, there are many motor and non-motor challenges that persist. **Motor fluctuations** and “freezing” occur in advanced stages and produce dramatic, often sudden, fluctuations in PD symptoms. In part, they represent inconsistent absorption and shortened duration of the Sinemet effect. Ideally, Sinemet should be given at least thirty (30) minutes before or sixty (60) minutes after a high protein meal, to avoid competition of absorption. Patients may also require their medications at frequent intervals. If the patient is hospitalized, it is important that their medication doses follow **the same schedule** as if they were still at home. Suddenly stopping or altering a Sinemet routine may induce Neuroleptic Malignant syndrome, which is potentially fatal.

Dyskinesias and **Dystonia** are involuntary abnormal movements and muscle spasms that tend to begin in patients who have had PD for at least four (4) years and are on a form of L-dopa. These symptoms can occur when the dopamine level is high or low in the brain. More frequent dosage schedules with smaller total doses of L-dopa, amantadine, or surgical treatments may help lessen these side effects.

Falling is usually a late manifestation of the disease process, but lack of balance is inevitable. It is usually not helped with changes in PD medication. Fractures and other injuries can necessitate hospitalization and shorten life expectancy. Walkers, canes, gait training, and home safety evaluation through consultation with physical and occupational therapy, may lessen this risk. Exercise is important as well in reducing risk; however, it must be done safely and in consultation with your doctor. For those at risk of falling, a stationary recumbent (*reclining/leaning*) bicycle or supervised water activities may be best. However, limiting walking, sit-to-stand with assist only or with a wheelchair, may be necessary for high-risk patients.

Depression and **anxiety** are common symptoms of PD that specifically need to be treated and should be brought up with your neurologist. Many medication and non-medication options are available that can be very helpful.

Confusion occurs frequently in the later stages of the disease. It may occur because of frequently associated dementia, systemic illness, medication effects, or a combination of factors. The anticholinergics, dopamine agonists, and MAO inhibitors are the most likely medication offenders. However, reducing dosages to lessen confusion may sacrifice mobility.

Hallucinations may occur and can be distressing to patients and their families. Most hallucinations are visual (i.e., seeing an animal or person that is not there); however, auditory (hearing music or sounds that are not present) and tactile (feeling things that are not there) hallucinations, while less frequent, are possible. If bothersome, they may require a reduction of medication(s); elimination of sedatives, analgesics, or anticholinergics; or a trial of atypical neuroleptics such as **Seroquel**[®] (quetiapine fumarate), **Clozaril**[®] (clozapine), or **Nuplazid**[®] (pimavanserin). Sudden onset of confusion or hallucinations may be secondary to a new systemic illness such as pneumonia, urinary tract infection, or electrolyte imbalance/disturbance.

Sleep Disturbances are another common problem in PD patients. Insomnia is not only bothersome to the caregiver at night, but it also affects the patient’s well-being during the day. Medication, depression, anxiety, frequent urination, poor sleep habits, restless legs, physically acting out dreams, pain, under-treatment of motor symptoms overnight, and undiagnosed sleep apnea may contribute. Treatments may include daytime exercise, medication, cognitive behavioral therapy, and/or referral to a sleep study. Excessive daytime sleepiness and fatigue are common PD symptoms and are aggravated by medications, particularly dopamine agonists. Stimulant medication may be helpful to combat daytime fatigue.

REM Sleep Behavior Disorder is common in PD patients. Patients have vivid dreams or nightmares and act them out with physical movement. This may result in injury. Treatment options can consist of conservative measures such as using a bed rail, reduction in antidepressant medications, or adding medication such as **Melatonin** or low dose **Klonopin**.

Constipation occurs in most patients because of decreased bowel motility (*the ability of organisms and fluid to move or get around the intestines*) and medication side effects. Adequate water consumption, exercise, daily stool softeners, high fiber foods and vegetables, gentle laxatives (such as **MiraLAX**) and routine bowel habits may help. Other laxatives and enemas may be useful in a crisis. Attention must be given to bowel function as fecal impaction leading to bowel obstruction, may be life-threatening.

Increased urinary frequency, urgency, and incontinence are frequent concerns in both men and women. Medications such as **Sanctura** or **Myrbetriq**, and/or a referral to a urologist may provide relief.

Nutritional deficiency may occur. Protein intake should be separated from L-dopa to avoid poor absorption of the medication; however, protein should not be eliminated from the diet. A nutrition consult may be helpful. If the patient experiences coughing or choking when eating, a swallow evaluation should be performed with a speech therapist to learn how to lower the risk of aspiration or choking. The speech therapist may also recommend a modified diet.

Orthostatic Hypotension (*low blood pressure upon sudden standing*) is a common PD symptom and increases the risk of falls and loss of consciousness. Compression stockings, abdominal binder, adequate intake of fluids and salt, frequent small meals, and discontinuation/lowering of blood pressure-lowering medications may help. Medications to raise blood pressure, such as **Florinef**, **Midodrine**, and **Northera** (droxidopa) may be needed if conservative measures fail.



Image: Rock Steady Boxing Program, Grand Rapids, MI. For more information related to this program and other offerings, visit the PAWM website Resource Guide.

SECTION 2 INTERDISCIPLINARY CARE ISSUES FOR PD PATIENTS

INFORMATION EXCHANGE

Healthcare professionals need to consult with their patients, their family, and any caregivers involved so that a proper and effective “care plan” can be created. All PD care is supportive to improve quality of life. The healthcare professional must understand the patient’s individual goals and what is important to the patient. This requires two-way communication from everyone. Facilitate the information exchange by ensuring appropriate release of information documents for patients and those involved in their care are signed.

MEDICATIONS

The “Number One” complaint of a hospitalized PD patient is that their finely tuned, individual medication schedule is not followed. It is understood that a nursing institution or hospital cannot easily provide medication on a complicated schedule or allow the patient’s family to dispense medication at the bedside. However, a significant deviation from the patient’s schedule can create serious problems. Discuss medication timings with the patient’s advocate and consult with the patient’s neurologist if questions arise. Not all drugs are interchangeable. If the pharmacy does not carry their specific medication or dosage, see if the medication can be bought from another source, verified by the pharmacy, and dispensed by nursing staff. Be aware of contraindicated medications for the PD patient. (*A contraindication is a specific situation in which a medicine, procedure, or surgery should not be used because it may be harmful to the person.*) As noted in Section 1, adverse reactions can be severe and life-threatening.

DIETARY CONCERNS

Patients need to be monitored to be sure that meals are eaten. Patients may require help to unwrap utensils, open containers, and cut food into bite-size portions. Supplements, such as **Ensure** or **Carnation Instant Breakfast** may be offered to promote proper nutrition. Patients should be upright (60-90 degrees) for meals and should remain upright for 15-30 minutes after meals. Dysphagia (*swallowing problems*) can occur due to the loss of control of the tongue, throat, and airway muscles. Smooth solids and thick liquids are swallowed best. Tucking the chin into the chest helps prevent aspiration (*food particles going into the lungs instead of the stomach*). Referral for speech/swallowing therapy is often indicated.

REHABILITATION SERVICES

Postural instability is often present and increases the risk of falls. The use of a cane or walker can be beneficial in these instances. Frequent repositioning and range-of-motion exercises help a hospitalized PD patient to prevent contractures (*a permanent shortening of muscle, tendon, or scar tissue producing deformity or distortion*) and skin breakdown. Referral for physical therapy and/or occupational therapy can help prevent further complications from immobility and assess the need for further rehabilitation after discharge.



Image: Art Therapy for Neurological Conditions sponsored by Mercy Health, Grand Rapids, MI. For more information related to this program and other offerings, visit the PAWM website Resource Guide.

ARE THERE DRUGS THAT PARKINSON'S PATIENTS NEED TO AVOID ?

“YES” is the correct answer. Certain drugs (including some pain medications, cough medications, and anti-depressants among others) may lead to serious complications in patients taking monoamine oxidase (MAO) inhibitors. MAO inhibitor medications should be stopped two (2) weeks before any elective surgeries.

Many medications can cause reversible drug-induced Parkinsonism (referred to as ‘neuroleptic-induced Parkinsonism’) or make PD symptoms worse. They include major prescription anti-nausea medications (such as **Reglan**, **Phenergan**, and **Compazine**) and antipsychotic medications (**Haldol**, **Risperdal**, **Abilify**, etc.).

ON/OFF PHENOMENON

PD has been described as a “yo-yo” disorder. This is illustrated when a patient can perform activities of daily living and then the next hour, they are unable to move without great difficulty. Healthcare staff should be aware that PD patients can experience dramatic and sudden fluctuations in their symptoms. Therefore, patience, good communication, and timeliness with medications are vitally important. Refer to “Case Issues” with the discussion of ‘motor fluctuations’ in Section 1.

COMMUNICATION

About seventy-five percent (75%) of people with PD experience changes in speech and voice at some time. These changes usually occur gradually and can vary in intensity. Communication is further complicated when some PD patients experience slowness of facial muscles which results in the loss of expression. Referral to a speech therapist trained in Lee Silverman Voice Treatment (LSVT) for PD is often done. Patients may require more time to understand and respond to information. Patients being rushed or put under pressure can increase symptoms, anxiety, and frustration.

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CAN PAWM HELP YOU?

The Parkinson's Association of West Michigan (PAWM) is a 501-c-3 non-profit organization made possible by generous donations to provide the best information on opportunities, treatment, research, and care to people with PD, their caregivers, and their families.

Having 'understanding' is the key to living with PD. The Vision of PAWM is that every PD patient in West Michigan shall have access to quality health care and support services. Since PD affects the entire family, caregiver support is a priority.

The PAWM website is the best place to search and locate the most current information and/or events related to PD. Through the website, learn how to live a better quality of life with PD, either as the patient, family member, support partner, or caregiver. The PAWM website offers information in the following areas:

- }) Clinical Trials and Treatments
- }) Community Events
- }) Exercise Programs
- }) General PD Information
- }) Home Healthcare
- }) Physical and Speech Therapy
- }) Reading Materials
- }) Relaxation Training
- }) Support Groups

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