W H I T E P A P E R

Parkinson's Disease

Understanding a Progressive Neurological Cause of Dependency

Motor Symptoms · Cognitive Changes · Progression Stages · New Therapies · Care Realities

A Complete Guide for Patients, Families, and Caregivers

Diagnosis · Medications · Clinical Trials · Care Costs · Caregiver Support

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Sources: Michael J. Fox Foundation, Parkinson's Foundation, Stanford Medicine, NIH ClinicalTrials.gov, FDA

> *This white paper is for educational purposes only and does not constitute medical or financial advice. Consult qualified medical and financial professionals for personal guidance.*

1. EXECUTIVE SUMMARY

Parkinson's disease (PD) is the second most common neurodegenerative disorder in the United States, affecting approximately 1.2 million Americans — a number projected to reach 1.6 million by 2037. It is a chronic, progressive disease of the nervous system that gradually erodes motor control, cognitive function, and independence over time.

Unlike many conditions, Parkinson's has no cure and no proven treatment that slows its progression. Current therapies manage symptoms effectively for years — sometimes decades — but the disease ultimately advances. That progression drives increasing care needs, rising medical costs, and a heavy caregiver burden that few families fully anticipate.

> *Parkinson's disease cost the United States $82.2 billion in 2024 — a figure projected to surpass $112 billion by 2045. More than 90% of direct medical costs are covered by Medicare and Medicaid. The remaining burden falls on patients and families, often without warning. Source: Michael J. Fox Foundation / Parkinson's Foundation, March 2026.*

This white paper is designed to give patients, family members, and caregivers a clear, honest picture of Parkinson's disease — from diagnosis through advanced stages. It covers:

- What Parkinson's is and how it progresses
- How it is diagnosed and staged
- Every major current maintenance medication and what it does
- The most promising clinical trials underway in 2026
- The real cost of care at each stage
- The critical importance of early recognition and functional planning
- Caregiver burden and the support networks that make it survivable

2. UNDERSTANDING PARKINSON'S DISEASE

What Is Parkinson's Disease?

Parkinson's disease is a progressive neurological disorder caused by the loss of dopamine-producing neurons in a region of the brain called the substantia nigra. Dopamine is the chemical messenger that coordinates smooth, controlled movement. As these neurons die, dopamine levels drop, and the brain's ability to regulate movement deteriorates.

The disease was first described by English physician Dr. James Parkinson in 1817 in his landmark Essay on the Shaking Palsy. More than 200 years later, it remains one of medicine's most complex challenges — treatable but not curable.

How Common Is Parkinson's Disease?

~1.2 million Americans currently living with Parkinson's disease

90,000+ New U.S. diagnoses each year

60 Average age at diagnosis (10–15% are diagnosed before 50)

1.5x Men more likely than women to develop PD

$82.2 billion Total U.S. economic cost of PD in 2024

What Causes Parkinson's Disease?

The exact cause of Parkinson's remains unknown in most cases. Research points to a combination of genetic and environmental factors.

Genetic Factors

- Mutations in genes such as LRRK2, PINK1, PRKN, SNCA, and GBA increase risk
- About 10–15% of PD cases are directly linked to an inherited gene mutation
- The LRRK2 mutation is the most common known genetic cause, found in 1–2% of all PD patients and up to 20% of Ashkenazi Jewish patients

Environmental Factors

- Long-term exposure to pesticides, herbicides, and industrial chemicals
- Head trauma history
- Rural living and well water consumption (possibly linked to pesticide exposure)
- Manganese or other heavy metal exposure in occupational settings

The Role of Alpha-Synuclein

A protein called alpha-synuclein plays a central role in most forms of PD. In people with Parkinson's, alpha-synuclein misfolds and clumps together, forming toxic aggregates called Lewy bodies inside neurons. These Lewy bodies spread through the brain, damaging dopamine-producing cells. Alpha-synuclein is now a primary target of the most promising new clinical trials.

Symptoms of Parkinson's Disease

Parkinson's symptoms are divided into two categories: motor symptoms (affecting movement) and non-motor symptoms (affecting everything else). Both categories worsen over time and eventually drive care needs.

Motor Symptoms (The Classic Four)

- **Tremor —** Rhythmic shaking, most commonly in the hands at rest; the hallmark symptom
- **Bradykinesia —** Slowness of movement; reduced arm swing, smaller steps, masked facial expression
- **Rigidity —** Muscle stiffness and resistance to movement, often causing pain
- **Postural instability —** Loss of balance and coordination; major fall risk in later stages

Non-Motor Symptoms (Often Underestimated)

- Cognitive decline and dementia (affects up to 80% of patients over time)
- Depression and anxiety (occur in 40–60% of patients)
- Sleep disorders, including REM sleep behavior disorder (acting out dreams)
- Autonomic dysfunction: constipation, urinary problems, low blood pressure on standing
- Loss of smell (often one of the earliest signs, occurring years before motor symptoms)
- Fatigue and pain
- Speech and swallowing difficulties

> *Non-motor symptoms — particularly cognitive decline, depression, and swallowing problems — are often the most disabling aspects of advanced Parkinson's and the primary drivers of nursing home placement.*

How Does Parkinson's Progress? The Five Stages

Stage (Hoehn & Yahr)	Description	Care Impact
Stage 1 — Mild	Tremor, stiffness, or slowness on one side of the body only. Symptoms are noticeable but do not interfere with daily life.	Independent. Little to no care needed.

Stage (Hoehn & Yahr)	Description	Care Impact
Stage 2 — Moderate	Both sides of the body affected. Balance is normal. Some difficulty with daily tasks.	Still independent. Some assistance may be helpful.
Stage 3 — Mid-Stage	Balance problems emerge. Falls begin. Daily tasks take longer. Still lives independently.	Part-time assistance. Home safety modifications needed.
Stage 4 — Advanced	Severe disability. Cannot live alone safely. Able to walk with assistance but very limited.	Significant daily care required. Home health aide or assisted living.
Stage 5 — Late	Wheelchair-bound or bedridden. Around-the-clock care required. Possible dementia.	Memory care facility or skilled nursing. 24-hour professional care.

On average, a person lives 10–20 years after a Parkinson's diagnosis. The rate of progression varies widely — some individuals remain at Stage 2 for many years; others progress more rapidly. The uncertainty of progression makes early recognition and proactive care planning especially critical.

3. DIAGNOSIS

There is no definitive blood test or brain scan that confirms Parkinson's disease with certainty. Diagnosis is based on a neurological examination and medical history. A movement disorder specialist — a neurologist with specialized training in Parkinson's — provides the most accurate diagnosis.

Diagnostic Criteria

Doctors use the United Kingdom Parkinson's Disease Society Brain Bank Criteria. A diagnosis requires:

- Bradykinesia (slowness of movement) — required in all cases
- Plus at least one of: muscle rigidity, resting tremor, or postural instability
- Absence of features that suggest another condition (called 'red flags')
- At least three 'supporting criteria' such as excellent response to levodopa, rest tremor, and progressive course

Diagnostic Tools

- **Neurological examination —** The primary diagnostic tool
- **DaTscan (Dopamine Transporter Scan) —** Nuclear imaging that shows dopamine activity in the brain; helps distinguish PD from similar conditions
- **MRI and CT scans —** Used to rule out other causes such as stroke or tumors
- **Genetic testing —** Recommended for patients with family history or early onset (before age 50)
- **Skin biopsy for alpha-synuclein —** A newer test that detects misfolded alpha-synuclein in nerve fibers of the skin; being adopted as an objective biomarker

> *A new skin biopsy test (marketed as SYNTap by Amprion) can now detect abnormal alpha-synuclein with high accuracy, representing a major step toward objective, biological confirmation of Parkinson's disease — similar to amyloid PET for Alzheimer's.*

4. CURRENT MAINTENANCE MEDICATIONS

As of 2026, there are no medications proven to slow, stop, or reverse Parkinson's disease progression. All approved treatments are symptomatic — they manage the effects of dopamine deficiency but do not address the underlying disease process. However, these medications are highly effective at controlling symptoms, often for many years.

> *Important distinction: All current PD medications are symptomatic treatments. The quest for a disease-modifying therapy — one that actually slows progression — is the central focus of every major clinical trial described in Section 5.*

Class 1: Levodopa / Carbidopa — The Gold Standard

Levodopa, first introduced in the 1960s, remains the most effective medication for Parkinson's disease after more than 60 years. It is a precursor to dopamine that crosses the blood-brain barrier and is converted into dopamine in the brain. Carbidopa is combined with levodopa to prevent it from being metabolized before reaching the brain, reducing side effects.

The 'On/Off' Problem

With long-term use (typically 5–10 years), levodopa's effectiveness becomes unpredictable. Patients experience 'on' periods when the medication works and 'off' periods when it wears off and symptoms return. Managing these fluctuations is a central challenge of advanced Parkinson's care. Several newer formulations and delivery systems address this problem.

Brand Name	Generic Name	FDA Approval	What It Does
Sinemet (original)	Carbidopa / levodopa (IR)	1975	Standard oral tablet; multiple daily doses; foundation of PD treatment for 50+ years
Sinemet CR	Carbidopa / levodopa (CR)	1991	Extended-release; fewer daily doses; smoother coverage
Rytary	Carbidopa / levodopa (ER capsule)	2015	Dual-layer release for more sustained and predictable on-time
Crexont	Carbidopa / levodopa (novel ER capsule)	2024	Newest oral formulation; more consistent plasma levels
Inbrija	Levodopa inhalation	2018	Inhaled rescue during

Brand Name	Generic Name	FDA Approval	What It Does
	powder		sudden OFF episodes; rapid onset within minutes
Duopa	Carbidopa / levodopa intestinal gel	2015	Continuous pump delivery into the small intestine; for advanced PD with severe fluctuations
Vyalev	Foslevodopa / foscarbidopa subcutaneous infusion	2024	24-hour under-the-skin infusion; newest delivery system; avoids on/off swings

Class 2: Dopamine Agonists

Dopamine agonists mimic the effect of dopamine in the brain by directly stimulating dopamine receptors. They are less powerful than levodopa but cause fewer motor fluctuations. Side effects can include impulse control disorders (compulsive gambling, shopping, or eating), hallucinations, and excessive daytime sleepiness.

Brand Name	Generic Name	Approval	Notes
Mirapex / Mirapex ER	Pramipexole	1997	Oral; widely used first-line agent
Requip / Requip XL	Ropinirole	1997	Oral; available in extended release
Neupro	Rotigotine transdermal patch	2007 / 2012	24-hour skin patch; useful for patients with swallowing problems
Apokyn	Apomorphine injection (SC)	2004	Rapid-acting rescue injection for sudden OFF episodes; acts within 10 minutes
Onapgo	Apomorphine SC infusion	2025	Continuous 24-hour pump; newest approval; reduces OFF time in advanced PD

Class 3: MAO-B Inhibitors

Monoamine oxidase-B (MAO-B) inhibitors block an enzyme that breaks down dopamine in the brain, extending the effect of naturally produced and supplemental dopamine. Often used as initial monotherapy in early PD or as add-on therapy.

Brand Name	Generic Name	Approval	Notes
Eldepryl / Zelapar	Selegiline	1989	First MAO-B inhibitor approved for PD; used as add-on to levodopa
Azilect	Rasagiline	2006	Once-daily tablet; mild symptomatic benefit
Xadago	Safinamide	2017	Add-on to levodopa; also has glutamate-modulating effects that may reduce dyskinesia

Class 4: COMT Inhibitors

Catechol-O-methyltransferase (COMT) inhibitors block another enzyme that breaks down levodopa and dopamine, extending the duration of each levodopa dose. Used exclusively as add-on therapy to levodopa to reduce 'wearing off.'

Brand Name	Generic Name	Approval	Notes
Comtan	Entacapone	1999	Taken with every levodopa dose; also available as Stalevo (combined)
Tasmar	Tolcapone	1998	More potent than entacapone; requires liver monitoring; reserved for difficult cases
Ongentys	Opicapone	2020	Once-daily capsule; taken at bedtime separate from levodopa

Class 5: Amantadine

Amantadine was originally an antiviral drug discovered to improve PD symptoms. It blocks glutamate receptors and has mild dopaminergic effects. Its primary use is to reduce levodopa-induced dyskinesia (involuntary movements), a major quality-of-life problem in advanced PD.

Brand Name	Generic Name	Approval	Notes
Symmetrel	Amantadine (IR)	1973	Early adjunctive therapy; older formulation
Gocovri	Amantadine (ER)	2017 / 2021	FDA approved for dyskinesia (2017) and OFF episodes (2021); once at bedtime
Osmolex ER	Amantadine (ER)	2018	Taken once in the morning; also for drug-induced movement disorders

Class 6: Adenosine A2A Receptor Antagonist

Brand Name	Generic Name	Approval	Notes
Nourianz	Istradefylline	2019	Non-dopaminergic mechanism; add-on to levodopa; different side effect profile

Class 7: Anticholinergics (Older, Limited Use)

Anticholinergic medications were among the earliest PD treatments. They block acetylcholine to rebalance it against dopamine. Used rarely today — primarily for younger patients with predominant tremor — because they cause confusion, memory problems, and constipation, making them risky for older adults.

- Trihexyphenidyl (Artane) — Still used selectively for tremor in younger patients
- Benztropine (Cogentin) — Similar use; also treats drug-induced parkinsonism

Surgical Treatment: Deep Brain Stimulation (DBS)

Deep Brain Stimulation is not a medication, but it is a well-established treatment for appropriate candidates with advanced PD and medication-refractory motor fluctuations. Electrodes are surgically implanted in specific brain targets (subthalamic nucleus or globus pallidus) and connected to a pacemaker-like device in the chest that delivers continuous electrical stimulation.

- Reduces tremor, rigidity, and OFF time significantly in well-selected candidates
- Allows most patients to reduce levodopa dose, reducing dyskinesia
- Does not slow disease progression or treat non-motor symptoms
- Best candidates: Younger patients with good cognitive function and clear levodopa benefit
- Adaptive DBS (aDBS) received FDA approval in early 2025 — a 'closed loop' system that senses brain activity and automatically adjusts stimulation (Medtronic Percept with BrainSense)

Focused Ultrasound

FDA-approved MRI-guided focused ultrasound (MRgFUS) uses concentrated ultrasound energy to create a precise lesion in a brain target — noninvasively, with no incision. Approved for essential tremor (2016) and unilateral PD tremor (2021). It provides immediate, dramatic tremor relief on the treated side but cannot address other symptoms or be repeated. Research into bilateral treatment is ongoing.

5. PROMISING CLINICAL TRIALS — 2026 UPDATE

2025–2026 represents the most active period in the history of Parkinson's research. For the first time, multiple trials are testing drugs that may actually slow or stop the disease — not just manage its symptoms. These are called disease-modifying therapies (DMTs). No DMT has yet been proven effective, but several are showing strong signals.

> *The central challenge: Because Parkinson's progresses slowly over decades, clinical trials must run for years and enroll hundreds of patients to detect whether a drug is truly slowing the disease versus just managing symptoms. This is why breakthrough therapies take so long — even when the science looks promising.*

Category A: Targeting Alpha-Synuclein (The Root Cause)

Alpha-synuclein is the protein that misfolds and aggregates in Parkinson's neurons. Clearing or preventing these aggregates is considered the most direct way to slow or stop the disease. Multiple approaches are being tested simultaneously.

Prasinezumab (Roche / Prothena)

- Type: Monoclonal antibody (infusion) targeting and clearing aggregated alpha-synuclein
- Trial: Phase 3 planned after promising Phase 2b (PADOVA) results showing slower progression in patients on stable levodopa
- Status: Phase 3 trial design underway; Stanford is expected to be a site
- Why it matters: First antibody-based alpha-synuclein therapy to show a statistically significant signal in a Phase 2 subgroup — a meaningful first for the field

ABL301 (AbbVie)

- Type: Monoclonal antibody with a 'Trojan horse' mechanism to cross the blood-brain barrier more effectively
- Trial: Phase 1 completed (safe and well-tolerated); Phase 2 in planning
- Why it matters: Better brain penetration has been the limitation of previous anti-synuclein antibodies

ACI-7104.056 — The Alpha-Synuclein Vaccine (AC Immune)

- Type: First-ever active vaccine against alpha-synuclein — stimulates the patient's own immune system
- Trial: Phase 2 (VacSyn trial); interim data showed clear antibody formation and good tolerability
- Why it matters: A vaccine approach would be far simpler and cheaper than regular infusions; could be given once or twice a year

Category B: LRRK2 Inhibitors

LRRK2 (Leucine-rich repeat kinase 2) is a protein that becomes hyperactive in some forms of Parkinson's, damaging dopamine neurons. Blocking LRRK2 is most relevant for patients with LRRK2 mutations — but researchers believe it may benefit all patients since LRRK2 is elevated in many PD cases.

BIIB122 / DNL151 (Biogen / Denali Therapeutics)

- Type: Small molecule oral LRRK2 inhibitor
- Trial: Phase 2b (LUMA trial); results expected in late 2026
- Enrolling: Patients with and without LRRK2 mutations at multiple sites including UCSF
- Why it matters: If effective across all PD patients, this would be a major breakthrough

ARV-102 (Arvinas)

- Type: Protein degrader (PROTAC) targeting LRRK2 — degrades the protein entirely rather than blocking it
- Trial: Phase 1/2 early results showed safe brain penetration and reduction in LRRK2 protein levels

Category C: Targeting Neuroinflammation

Chronic low-level inflammation in the brain accelerates neuron death in Parkinson's. Multiple trials are testing anti-inflammatory approaches.

BHV-8000 (Biohaven)

- Type: Oral drug inhibiting TYK2 and JAK1 enzymes to reduce brain inflammation
- Trial: Phase 2/3 enrolling up to 550 patients aged 40–85 with early-stage PD
- Duration: 48 weeks; primary goal is to slow functional decline

VENT-02 (Ventus Therapeutics)

- Type: Oral drug inhibiting the NLRP3 inflammasome — a key driver of brain inflammation in PD
- Trial: Phase 2a; actively enrolling ~30 participants with mild to moderate PD

Dapansutrile — DAPA-PD Trial

- Type: Anti-inflammatory drug targeting NLRP3 inflammasome (different approach from VENT-02)
- Trial: Phase 2; recruitment beginning early 2026 (Cure Parkinson's / Van Andel Institute)

Category D: Gene Therapy

Gene therapy delivers a working copy of a gene directly into brain cells using a viral vector. Unlike medications taken daily, gene therapy potentially requires only a single treatment.

AB-1005 / AAV-GDNF (AskBio / Bayer) — REGENERATE-PD Trial

- Type: Gene therapy delivering the GDNF gene into the brain to protect and restore dopamine neurons
- FDA Status: Received Regenerative Medicine Advanced Therapy (RMAT) designation February 2025
- Trial: Phase 2 (REGENERATE-PD) — randomized, double-blind, sham surgery-controlled; ~87 patients
- Why it matters: GDNF is one of the most potent known factors for dopamine neuron survival

ISM8969 (Insilico Medicine) — AI-Designed Therapy

- Type: Oral anti-inflammatory therapy designed entirely by artificial intelligence — first AI-developed PD drug to reach human trials
- Status: FDA application (IND) filed late 2025 to begin Phase 1 human trials

Category E: Stem Cell Therapies

Stem cell therapies aim to physically replace the dopamine-producing neurons that have died — rebuilding the brain's capacity rather than just compensating for its loss. This approach is the most complex and is still in early-stage clinical testing.

Bemdaneprocel (BlueRock Therapeutics / Bayer)

- Type: Off-the-shelf allogeneic dopaminergic neuron precursors derived from human embryonic stem cells
- Phase 1 result: Safe and well-tolerated; PET scan confirmed transplanted cells survived; high-dose patients gained 2.7 additional hours of ON time per day
- Trial: Phase 3 (exPDite-2); ~102 participants; first patient treated September 2025

ANPD001 (Aspen Neuroscience)

- Type: Personalized, patient-specific (autologous) dopamine neuron precursors grown from the patient's own skin cells — no need for immunosuppressants
- Trial: Phase 1/2a (ASPIRO); third cohort now receiving treatment

Category F: Established Drugs Being Repurposed

Ambroxol — ASPro-PD Trial (Phase 3)

- What it is: An over-the-counter cough medication used for decades in Europe
- Mechanism: Increases GCase enzyme activity in brain cells, helping clear protein waste including alpha-synuclein
- Trial: Phase 3 (ASPro-PD); 330 patients; 2 years; especially relevant for GBA1 mutation carriers

Risvodeninib (Sun Pharma / TransThera) — c-Abl Kinase Inhibitor

- Type: Oral capsule blocking c-Abl kinase, an enzyme that damages dopamine neurons when overactive
- Phase 2 result: Significant improvement in MDS-UPDRS symptom score vs. placebo — one of the most encouraging Phase 2 results in recent years
- Status: Phase 3 design being planned with FDA input

Category G: New Symptomatic Therapies

Tavapadon (AbbVie) — Under FDA Review 2026

- Type: Once-daily oral dopamine D1/D5 receptor agonist — novel mechanism vs. existing agonists
- Trials: Three Phase 3 trials (TEMPO program) all showed significant improvement in motor symptoms
- Key result: In advanced PD as add-on to levodopa, patients gained 1.1 extra hours of ON time per day without troublesome dyskinesia
- Status: New Drug Application submitted to FDA September 2025; decision expected 2026

Solengepras (Cerevel/AbbVie) — ARISE Trial (Phase 3)

- Type: Non-dopaminergic oral drug targeting GPR6 receptor to rebalance motor circuits
- Trial: Phase 3 (ARISE); topline data expected H1 2026

EJS ACT-PD — The World's Largest Parkinson's Trial

> *Launched in 2025 by Cure Parkinson's (UK), the Edmond J. Safra Accelerating Clinical Trials for Parkinson's Disease (EJS ACT-PD) trial is the largest clinical trial ever conducted for Parkinson's disease. Led by University College London and Newcastle University, it will evaluate multiple potential disease-modifying treatments simultaneously in 1,600+ participants — dramatically accelerating the search for therapies that can slow or stop the disease.*

Trial Summary Table

Drug / Therapy	Target	Phase	Expected Data
Prasinezumab	Alpha-synuclein	Phase 3	2027–2028
ABL301	Alpha-synuclein	Phase 2	TBD
ACI-7104 (vaccine)	Alpha-synuclein	Phase 2	2026–2027
BIIB122 / LUMA	LRRK2	Phase 2b	Late 2026

Drug / Therapy	Target	Phase	Expected Data
ARV-102	LRRK2 (degrader)	Phase 1/2	2026
BHV-8000	Neuroinflammation	Phase 2/3	2027
Risvodeninib	c-Abl kinase	Phase 3	2027–2028
Ambroxol / ASPro-PD	GCase enzyme	Phase 3	2027
AB-1005 Gene Therapy	GDNF / neurotrophic	Phase 2	2026–2027
Bemdaneprocel	Cell replacement	Phase 3	2028
Tavapadon	D1/D5 receptor	FDA Review	2026
Solengepras / ARISE	GPR6 receptor	Phase 3	H1 2026
ISM8969 (AI-designed)	Neuroinflammation	Phase 1	2027

6. THE REAL COST OF PARKINSON'S CARE

The financial impact of Parkinson's disease is severe and often underestimated. According to a March 2026 report from the Michael J. Fox Foundation and the Parkinson's Foundation, the total U.S. cost of Parkinson's disease in 2024 was $82.2 billion — projected to exceed $112 billion by 2045.

Cost Category	Annual Amount (2024)	Who Pays
Direct medical costs (total)	$23.8 billion	90%+ covered by Medicare/Medicaid
Hospitalizations & outpatient care	Included above	Medicare / private insurance
Medications	Included above	Medicare Part D / private / out-of-pocket
Lost patient income	Included in $58.4B indirect	Patient / family
Unpaid caregiver time	Included in $58.4B indirect	Family / spouses
Caregiver productivity loss	$8+ billion	Caregivers / employers

Cost of Care by Stage and Setting

Care Setting	PD Stage Typically Needed	Average Annual Cost (2025)	Notes
Home — self-managed with medications	Stage 1–2	$5,000–$15,000	Medications, neurologist visits, PT, OT
Home — with part-time paid caregiver	Stage 2–3	$25,000–$50,000	20–30 hrs/week home health aide at ~$30/hr
Home — with full-time paid caregiver	Stage 3–4	$65,000–$100,000+	Full-time 40+ hrs/week; specialized PD care
Assisted Living Facility (memory care)	Stage 3–5	$54,000–$72,000/yr	Median $4,500–$6,000/month; varies by state
Skilled Nursing Facility (private room)	Stage 4–5	$90,000–$110,000/yr	Median $8,000–$9,500/month; 24-hour care
Total lifetime care cost (avg. 10–15 yrs)	All stages	$300,000–$1,000,000+	Highly variable; depends on progression and

Care Setting	PD Stage Typically Needed	Average Annual Cost (2025)	Notes
			setting

A person with Parkinson's who lives 15 years after diagnosis and progresses to Stage 4 or 5 in the final 5 years may easily accumulate $500,000–$800,000 in total care costs. The majority of this comes in the advanced stages — precisely when cognitive decline makes planning most difficult.

What Medicare Covers — and What It Does Not

- **Medicare DOES cover:** Physician visits, hospitalizations, medications (Part D), physical therapy, occupational therapy, speech therapy, home health visits (when skilled care is needed), and hospice
- **Medicare DOES NOT cover:** Custodial care — help with bathing, dressing, eating, and mobility when no skilled nursing is needed. This is the care most Parkinson's patients need for the longest time.
- **Medicare limits:** Covers only short-term skilled nursing care after hospitalization (up to 100 days; full coverage for only 20 days). Does NOT pay for long-term nursing home stays.

The care gap is critical: Parkinson's patients may need 5–10 years of custodial care that Medicare does not cover. This is the funding gap families must plan for.

7. THE CAREGIVER BURDEN

Parkinson's disease is a family disease. As symptoms progress, family members — most often spouses and adult children — take on increasing caregiving responsibilities. The physical, emotional, and financial toll on caregivers is severe and often underrecognized.

40% of Parkinson's caregivers report symptoms of clinical depression

$8+ billion in caregiver productivity was lost to the U.S. economy in 2024

50+ hours/week is the caregiving load for family members in advanced PD cases

40% of spousal caregivers predecease their PD partner due to caregiver stress

What Caregivers Need to Know

- Caregiver burnout is not a sign of failure — it is a predictable outcome of an impossible burden sustained too long without support
- Respite care — temporary relief for caregivers — is available through community programs and some Medicaid waiver programs
- Adult day programs provide structured daytime care for PD patients while caregivers continue to work or recover
- Home health aides — whether paid privately or through community programs — dramatically reduce caregiver strain and delay nursing home placement
- Support groups for both patients and caregivers are available through the Parkinson's Foundation (parkinson.org) and local hospital systems

8. KEY ORGANIZATIONS AND RESOURCES

Organization	What They Offer	Website
Parkinson's Foundation	Education, helpline (1-800-4PD-INFO), care centers, caregiver resources	parkinson.org
Michael J. Fox Foundation	Research funding, clinical trial finder (Fox Trial Finder), patient community	michaeljfox.org
American Parkinson Disease Association	Local chapters, support groups, patient education	apdaparkinson.org
NIH ClinicalTrials.gov	Database of all active U.S. clinical trials; searchable by location	clinicaltrials.gov
Eldercare Locator	Federal helpline for local aging services and caregiver support	1-800-677-1116
AARP	Caregiver resources, Medicare guidance	aarp.org

9. NEXT STEPS FOR PATIENTS AND FAMILIES

> *Parkinson's disease is a marathon, not a sprint. The families who navigate it best are those who recognize the trajectory early — before the caregiving burden becomes a crisis. You do not have to figure this out alone.*

If you or a loved one has been diagnosed with Parkinson's disease, or if you are concerned about future risk, the following steps can protect your family:

Step 1 — Connect with a Movement Disorder Specialist

A neurologist who specializes in Parkinson's and movement disorders will provide the most accurate diagnosis, the most current medication management, and can refer you to clinical trials. The Parkinson's Foundation offers a helpline and referral service: 1-800-4PD-INFO.

Step 2 — Ask About Current Medication Options

The medication landscape has changed significantly with recent approvals (Crexont 2024, Vyalev 2024, Onapgo 2025). If your diagnosis pre-dates these approvals, ask your specialist whether any of them could improve your ON time or reduce fluctuations.

Step 3 — Explore Clinical Trials

Clinical trials offer access to potential breakthrough therapies — often at no cost — while contributing to research that benefits all Parkinson's patients. The Michael J. Fox Foundation's Fox Trial Finder at foxtrialfinder.org is the best starting point.

Step 4 — Plan for Care Costs Ahead of Time

Because Medicare does not cover custodial care, families should understand the funding gap early. Estimate the potential 5–10 year cost of custodial care based on your local rates, and know what resources (savings, home equity, community programs, veteran benefits) are available. Documenting a clear advance directive while cognitive status is clearly intact is critical.

Step 5 — Build Your Support Network

Contact the Parkinson's Foundation at parkinson.org for local support groups, care center referrals, and caregiver resources. Connection with others facing the same journey is consistently cited by patients and families as one of the most valuable resources available.

> *The most preventable tragedy in Parkinson's disease is the family that treated the diagnosis as a private matter and waited too long to build a support network. The diagnosis is not the end of independence — but it is the beginning of a decade-plus journey that no one should walk alone.*

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> *DISCLAIMER: This white paper is provided for educational purposes only. It does not constitute medical or financial advice. Information about clinical trials, medications, and costs is current as of July 2026 and may change. Consult qualified medical and financial professionals for guidance specific to your situation.*

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