



The Force for Health®
PREPARED PATIENT PROGRAM

PREPARED PATIENT

Parkinson's Disease

Your complete learning module — eight components from newly-diagnosed to a clinically Prepared Patient Ambassador. Everything to know and do, in one place.

8-Component Condition Module

WHAT'S INSIDE — THE 8 COMPONENTS

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SCAN TO OPEN THE
LIVE JOURNEY

1 Core Basics

Welcome — why becoming a Prepared Patient matters

Welcome. You're in the right place. This module turns Parkinson's Disease from something that happens to you into something you help manage — step by step, at your own pace. You don't need to become a doctor. You need to become the most prepared person in the room about *your* health.

WHY THIS MATTERS — FOR YOU AND THE PEOPLE AROUND YOU

As a Patient

Know your numbers, spot your red flags, and act fast when it counts. Prepared patients have better days and fewer emergencies.

As an Ambassador

Speak up in your own care as an equal partner — ask the right questions and help shape your plan.

As a Caregiver

Support someone you love with confidence — know what to watch for and what to do.

PARKINSON'S DISEASE — A NATIONAL OVERVIEW

60–80% of these dopamine cells are already gone

1 million Americans

10 million people worldwide

Parkinson's disease (PD) is a brain disease that slowly gets worse over time. It happens when the brain loses cells that make dopamine (a brain chemical that helps you move).

These cells sit in the substantia nigra, a small spot deep in your brain. A protein called alpha-synuclein builds up in clumps (Lewy bodies). The main movement signs are called **TRAP**.

They show up only after about **60-80% of these dopamine cells are already gone**. TRAP means: **T**remor (shaking) when at rest, **R**igidity (stiff muscles), **A**kinesia or bradykinesia (slow, smaller movements), and **P**ostural instability (poor balance).

PD is much more than a movement problem. Many **non-motor symptoms** can start years or even decades before the shaking. These include sleep problems (like acting out dreams, called REM sleep behavior disorder), loss of smell, constipation, mood changes, thinking changes, and body-control changes.

In late PD, these can be harder than the movement signs. About **1 million Americans** and **10 million people worldwide** have PD. About **60,000 Americans** are newly diagnosed each year.

It usually starts after age 60. But **10-20%** are diagnosed before age 50 (called "young-onset"). **Levodopa** (the main PD medicine) has been the best treatment since the 1960s.

Here is the honest truth: many people live well with PD for many years, even decades, with good care. **Life span is now close to normal**. The one thing that helps the most is **hard exercise**.

Strong studies back this up.



1 Core Basics

Welcome — why becoming a Prepared Patient matters

PRE-KNOWLEDGE CHECK — RATE WHAT YOU KNOW RIGHT NOW (1–5)

Be honest — there's no wrong answer. You'll rate these again at Step 7 and see how far you've come.

What Parkinson's Disease actually is

○ ○ ○ ○ ○

My key numbers & targets

○ ○ ○ ○ ○

My red flags — and what to do

○ ○ ○ ○ ○

My medicines & how to take them

○ ○ ○ ○ ○

How to speak up with my care team

○ ○ ○ ○ ○

1 = new to me · 5 = I could teach it

★ My Prepared Patient Pledge

I pledge to learn about my Parkinson's Disease, to know my numbers and my red flags, to speak up in my own care, and to take one small step at a time — for myself and for the people who count on me.

SIGNED

DATE

Additional Notes

☐ I've completed Step 1 · Welcome & Overview for Parkinson's Disease



2 Self-Reflection

Eight soft questions to find your honest starting point

No test, no wrong answers — an honest self-reflection to find your starting point with Parkinson's Disease. This is an engagement screener, not a clinical assessment. Mark your answers, then carry them into the Fact Sheet.

Q1 Have you ever had a neurologic emergency, targeted therapy, bypass, or been told you have parkinson's disease, blockages, or neurologic symptom?

Parkinson's Disease is often silent. Some people learn they have it from a routine test; others find out from an event. Naming what you've actually been told is the first step.

CHOOSE ONE

- ☐ Yes — I've had a neurologic emergency, targeted therapy, or bypass
- ☐ Yes — I have a Parkinson's Disease or neurologic symptom diagnosis without a major event
- ☐ No, but I have known risk factors (high biomarker, high BP, diabetes, family history, smoking)
- ☐ No — and I don't have major risk factors that I know of
- ☐ I'm not sure

Q2 Has anyone in your family had a neurologic emergency, targeted therapy, bypass, or sudden neurologic death — especially before age 60?

Family history of early heart disease is one of the strongest Parkinson's Disease risk factors and a clue to inherited high biomarker.

CHOOSE ONE

- ☐ Yes — and at least one relative was under 60
- ☐ Yes — but I'm not sure of ages
- ☐ No
- ☐ I don't know



2 Self-Reflection

Eight soft questions to find your honest starting point

Q3 Have you ever heard about, or thought about, any of these in connection with heart disease? (check all that feel familiar)

This is just a familiarity check, not a behavior audit. Pick whatever rings a bell.

CHECK ALL THAT APPLY

- ☐ LDL ("bad") biomarker target numbers
- ☐ Maintenance therapy (atorvastatin, rosuvastatin, simvastatin)
- ☐ Brain MRI scan
- ☐ Neurologic rehab
- ☐ Aspirin or other antiplatelet for heart
- ☐ Quit-smoking medication or counseling
- ☐ Mediterranean / DASH-style eating
- ☐ None of these — this is all new to me

Q4 Do you feel confident that you understand parkinson's disease — what it is, what it does to the body, and what helps?

"Somewhat" is a totally fair answer. Most people start there.

CHOOSE ONE

- ☐ Very confident — I know the basics well
- ☐ Somewhat — I know some, want to know more
- ☐ Not really — I'd like to learn more
- ☐ This is new to me

Q5 Do you feel confident you know how to live the highest-quality life possible despite (or to prevent) Parkinson's Disease?

Quality of life is the goal — energy, the things you love, longevity — not just "watching the LDL."

CHOOSE ONE

- ☐ Yes
- ☐ I'm getting there
- ☐ Not yet — I want to learn how
- ☐ Not applicable to me right now



2 Self-Reflection

Eight soft questions to find your honest starting point

Q6 Are you ready to become an informed and respected part of your care team — where your observations, communications, and actions are the most important part of your care?

This is the heart of the Prepared Patient idea.

CHOOSE ONE

- ☐ Yes — I'm ready
- ☐ Almost — I want to learn more first
- ☐ I'd like to but I'm not sure how
- ☐ I hadn't thought of it that way before

Q7 Do you have at least one person — family, friend, or care team — you can turn to about your heart?

Habit change sticks when it's social.

CHOOSE ONE

- ☐ Yes — I have someone
- ☐ Maybe — I'm not sure who
- ☐ Not yet — but I'd like to find someone
- ☐ I prefer to figure it out myself first

Q8 What brought you to this Prepared Patient program today?

Your answer is private and helps us speak to you better.

CHOOSE ONE

- ☐ I've had a heart event (MI, targeted therapy, bypass)
- ☐ I have Parkinson's Disease without a major event
- ☐ Someone I love has Parkinson's Disease or had a heart event
- ☐ I want to prevent it (risk factors / family history)
- ☐ I'm a student, professional, or educator
- ☐ I'm just curious



2 Self-Reflection

Eight soft questions to find your honest starting point

What these answers tell me about where I'm starting

 Additional Notes

☐ I've completed Step 2 · Self-Reflection for Parkinson's Disease



PREPARED PATIENT · PARKINSON'S DISEASE

3 Force Field Fact Sheet

Primer · Foundations



This is the heart of the resource: the complete Parkinson's Disease Force Field, organized in knowledge tiers. Each card gives the essentials, then **Concepts** (what to know), **Skills** (what you can do), **Actions** (this week), and your **Plan** (share & sustain).



3 Force Field Fact Sheet

Primer · Foundations



What Is Parkinson's Disease?

PRIMER · TIER 0

Parkinson's disease (PD) is a brain disease that slowly gets worse over time. It happens when the brain loses cells that make dopamine (a brain chemical that helps you move).

These cells sit in the substantia nigra, a small spot deep in your brain. A protein called alpha-synuclein builds up in clumps (Lewy bodies). The main movement signs are called **TRAP**.

They show up only after about **60-80% of these dopamine cells are already gone**. TRAP means: **T**remor (shaking) when at rest, **R**igidity (stiff muscles), **A**kinesia or bradykinesia (slow, smaller movements), and **P**ostural instability (poor balance).

PD is much more than a movement problem. Many **non-motor symptoms** can start years or even decades before the shaking. These include sleep problems (like acting out dreams, called REM sleep behavior disorder), loss of smell, constipation, mood changes, thinking changes, and body-control changes.

In late PD, these can be harder than the movement signs. About **1 million Americans** and **10 million people worldwide** have PD. About **60,000 Americans** are newly diagnosed each year.

It usually starts after age 60. But **10-20%** are diagnosed before age 50 (called "young-onset"). **Levodopa** (the main PD medicine) has been the best treatment since the 1960s.

Here is the honest truth: many people live well with PD for many years, even decades, with good care. **Life span is now close to normal**. The one thing that helps the most is **hard exercise**.

Strong studies back this up.

CONCEPTS · LEARN IT

- A brain disease that slowly worsens; it hurts dopamine cells in the substantia nigra
- Main movement signs: TRAP — Tremor, Rigidity, Akinesia (slowness), Postural instability (balance)
- Movement signs start only after ~60-80% of these brain cells are gone
- Non-motor symptoms often start years or decades before shaking
- ~1M Americans have PD; ~60,000 new US cases each year
- Levodopa has been the best medicine since the 1960s
- Hard exercise truly slows the disease (proven in studies)
- Life span is now close to normal with good care

ACTIONS · THIS WEEK

- Get copies of your neurology and primary care notes from the patient portal
- Save the Parkinson's Foundation Helpline 1-800-4PD-INFO and APDA 1-800-223-2732 in your phone
- Open and fill in your Force Field Emergency Card

SKILLS · LIVE IT

- Say the TRAP signs in plain words
- Tell PD apart from essential tremor: PD shakes at rest and starts on one side; essential tremor shakes during action
- Describe non-motor symptoms in your own words
- Explain how hard exercise helps slow the disease

PLAN · SHARE IT

- Read all 16 squares
- Open the deep course
- Book a Movement-Disorder Neurology visit if you don't have one yet



3 Force Field Fact Sheet

Primer · Foundations

- Tell one family member you trust about your diagnosis or worry



3 Force Field Fact Sheet

Primer · Foundations



360 Human Anatomy: Nigrostriatal Dopamine & Brain Networks

PRIMER · ANATOMY

Dopamine cells live in a brain area called the **substantia nigra pars compacta**. They send signals along the **nigrostriatal pathway** (a brain wiring path) to the **striatum** (the caudate and putamen).

This is part of the **basal ganglia loops**. These loops help you start moving, size your movements, and stay smooth. When these signals are lost, PD's movement signs appear.

But PD is not only a striatum problem. The alpha-synuclein clumps spread in a set order (the **Braak hypothesis**). They start in the **olfactory bulb** (the smell area) and the **lower brainstem** (the vagal nucleus and locus coeruleus).

Next they reach the **substantia nigra** and the **limbic areas** (mood and memory). Last they reach the **neocortex** (thinking). This order explains why smell loss, dream-acting sleep (RBD), constipation, and mood changes can come years or decades before shaking.

Those areas are hurt first. The **pontine REM-atonía circuit** (the sleep-paralysis switch) is broken in RBD. The **vagal-gut axis** (brain-to-gut wiring) is part of early constipation.

The **locus coeruleus** makes norepinephrine (an alertness chemical). Its loss explains dizziness on standing, attention issues, and mood changes. The **cholinergic pathway** (which uses acetylcholine) adds to thinking and walking trouble.

That is why cholinesterase inhibitors (a memory drug type) are used in PD dementia (PDD). The key point: **these early signs are not random. They are the first sign the disease has begun.**

CONCEPTS · LEARN IT

- Substantia nigra → nigrostriatal pathway → striatum (part of the basal ganglia loops)
- Alpha-synuclein / Lewy body buildup — a protein-clumping disease
- Braak stages: smell area and brainstem first → substantia nigra → limbic → cortex
- The pontine REM-atonía circuit (sleep-paralysis switch) breaks in RBD
- The vagal-gut axis (brain-gut wiring) explains early constipation
- Locus coeruleus (norepinephrine) loss → dizziness on standing, mood changes
- Cholinergic loss → thinking and walking trouble

ACTIONS · THIS WEEK

- Click into 360 Human Anatomy: Nigrostriatal & Brain Networks
- Note your main movement pattern (tremor, rigidity, or bradykinesia) in your Health Passport
- Bring your marked-up map to your next neurology visit

SKILLS · LIVE IT

- Open the 360 Human Anatomy: Brain & Movement module
- Name the nigrostriatal pathway in your own words
- Match an early symptom to its Braak stage
- Swap 'just shakes' for 'dopamine pathway plus alpha-synuclein spread'

PLAN · SHARE IT

- Visit the brain module before each neurology visit
- Update your notes after each treatment change
- Bring the marked-up map to your next visit



3 Force Field Fact Sheet

Primer · Foundations



Who Gets PD? — Types & Mimics

PRIMER

Most PD is **idiopathic** (it has no single clear cause). But about **10-15%** has a gene link. Some **gene changes** are common. **LRRK2** is more common in **Ashkenazi Jewish** and **North African Berber** people.

GBA is also common in Ashkenazi Jewish people. It is linked to faster thinking decline. **PARK7, PINK1, and parkin** are passed down when both parents carry the change.

These are often young-onset. **SNCA** is another gene change. A family history raises risk a little. Some conditions **look like PD but are not PD**. Know the difference.

Essential tremor shakes during action. It often runs in families. It often eases with alcohol. It is not PD. **Drug-induced parkinsonism** comes from dopamine-blocking drugs.

These include antipsychotics, metoclopramide, and prochlorperazine. It usually goes away after stopping the drug.

Vascular parkinsonism comes from small blood-vessel damage.

It mostly affects the lower body. It responds poorly to levodopa. **Atypical parkinsonian syndromes** are also different. **MSA** (multiple system atrophy) has strong body-control problems and poor levodopa response.

PSP (progressive supranuclear palsy) causes trouble looking up or down, plus early falls. **CBD** (corticobasal degeneration) is one-sided. It brings an 'alien limb' and trouble doing skilled moves (apraxia).

Things in the world can raise risk too. These include pesticides (paraquat, rotenone), farm well water, and MPTP (rare). **Higher risk** comes with older age, being male, family history, past head injury, and some pesticide exposure.

Oddly, **caffeine and tobacco** are tied to lower PD risk in some studies. This is **not** advice to use them. Other factors likely explain it.

CONCEPTS · LEARN IT

- ~10-15% has a gene link; ~85% is idiopathic (no single clear cause)
- LRRK2 (Ashkenazi Jewish, Berber); GBA (also Ashkenazi, faster thinking decline)
- Passed down by both parents: PARK7, PINK1, parkin (often young-onset)
- Essential tremor: shakes during action, eases with alcohol — not PD
- Drug-induced parkinsonism: from dopamine-blocking drugs; usually reversible
- Vascular parkinsonism: lower-body, poor levodopa response
- Atypical types: MSA / PSP / CBD — different course, poor levodopa response
- In the world: pesticides, farm well water

ACTIONS · THIS WEEK

SKILLS · LIVE IT

- State your suspected type or confirmed diagnosis
- Spot signs that don't fit PD (poor levodopa response, early falls, trouble looking up/down, alien limb, strong body-control problems at the start)
- Check your medicine list for dopamine-blocking drugs
- Take a careful family history

PLAN · SHARE IT

- Review your diagnosis once a year



3 Force Field Fact Sheet

Primer · Foundations

- Confirm your diagnosis with Movement-Disorder Neurology if you can reach one
- If young-onset (under 50) or strong family history: ask about genetic counseling
- Check your med list for metoclopramide, prochlorperazine, and antipsychotics
- Read your last neurology note for the written diagnosis
- Talk with family about inherited risk and early signs
- Add PD/parkinsonism to your family-history record



3 Force Field Fact Sheet

Primer · Foundations



The Numbers — H&Y, MDS-UPDRS, On/Off PRIMER

The PD numbers help you and your team see where things are headed. The **Hoehn & Yahr (H&Y)** stage is one guide: 1 = one side only; 2 = both sides, balance still fine;

3 = balance affected but still on your own; 4 = severe trouble but can still walk or stand without help; 5 = wheelchair or bed-bound. The **MDS-UPDRS** (Movement Disorder Society Unified Parkinson's Disease Rating Scale) has four parts:

Part I (non-motor daily life), **Part II** (movement in daily life), **Part III** (the doctor's movement exam), and **Part IV** (movement complications, like on/off swings and extra movements called dyskinesia).

The **MoCA** checks thinking, at the start and over time. A score under 26 out of 30 suggests mild trouble (MCI); under 21 suggests dementia. An **on/off diary** tracks how well your meds work.

Note on-time, off-time, and dyskinesia in 30-minute blocks for 2–3 days before each visit. Also track **falls per year** (and near-falls), **sleep quality and RBD level**, and **how often you have constipation**.

Check your **blood pressure drop on standing** (a drop of 20 on top or 10 on bottom, in mmHg, within 3 minutes of standing counts). Track **mood** with PHQ-9 and GAD-7 (short mood and worry quizzes).

At-risk family can use the **MDS Prodromal Criteria** risk score. Here is the honest part: **PD does get worse, but the speed varies a lot**. Some people stay at H&Y 1–2 for ten years.

Others move faster. Life span is now close to normal with good care.

CONCEPTS · LEARN IT

- H&Y stages 1–5
- MDS-UPDRS Parts I–IV
- MoCA: under 26 = mild trouble; under 21 = dementia
- On/off diary in 30-minute blocks for 2–3 days
- Blood pressure drop of 20/10 mmHg within 3 minutes of standing = not normal
- Speed of change varies a lot — there is no single path
- Life span is now close to normal with good care

ACTIONS · THIS WEEK

- Make a one-page numbers card
- Keep a 2–3 day on/off diary before your next visit
- Confirm your starting MoCA, PHQ-9, and GAD-7
- Check standing blood pressure (lying, sitting, standing across 3 minutes)

SKILLS · LIVE IT

- State your H&Y stage
- Track your own on-time, off-time, and dyskinesia
- Take the PHQ-9 and GAD-7 yourself
- Check your standing blood pressure at home
- Track falls and near-falls

PLAN · SHARE IT

- H&Y plus MDS-UPDRS once a year
- MoCA every 3 months in advanced disease
- Talk numbers at each visit



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Recognize Prodromal Signs (PRODROMAL-WATCH)

LEARN IT · TIER 1 AWARE

Prodromal PD means the brain damage has started but movement signs have not shown up yet. Spotting it early is one of the **most helpful things a family helper can do** in any long-term disease.

Here is why. First, the tests are gentle and do not cut into the body. Second, it gives time to plan, change habits, and join research studies. Third, future disease-slowing drugs will likely need early spotting to work.

The **PRODROMAL-WATCH** pattern (from MDS Research Criteria, 2015/2019) covers the early signs. **R — REM Sleep Behavior Disorder (RBD)**: acting out dreams, often with punching, kicking, or falling out of bed.

The **bed partner usually notices first**. Up to **80-90%** of people with sleep-study-confirmed RBD later develop a synucleinopathy (PD, DLB, or MSA) over many decades.

B — Body smell loss (hyposmia). Many people don't know they've lost smell. Testing uses UPSIT or Sniffin' Sticks (smell test kits). **C — Constipation** (a slow gut, often years before movement signs).

M — Mood changes (feeling down, anxious, or flat). **H — Handwriting** getting smaller (called micrographia). **A — Arm swing** that shrinks on one side; a face that shows less expression.

RBD with no other cause should get a movement-disorder neurology visit. Workup: a sleep study confirms RBD; a DAT-SPECT scan can show low dopamine. Be honest here:

this is pattern-spotting, not a diagnosis. RBD does not always turn into PD. But the pattern is real, and a bed partner who spots it gives the family a head start.

CONCEPTS · LEARN IT

- Prodromal PD = brain damage has begun, but movement signs have not yet started
- PRODROMAL-WATCH: RBD + Body smell loss + Constipation + Mood + Handwriting + Arm swing
- RBD: bed partner often notices first; up to 80-90% develop a synucleinopathy over decades
- Hyposmia: often unnoticed by the patient; UPSIT / Sniffin' Sticks tests
- Constipation: often years before movement signs
- RBD with no other cause = get a movement-disorder neurology visit
- This is pattern-spotting, not a diagnosis

ACTIONS · THIS WEEK

- If you or your partner act out dreams: book a sleep evaluation
- Smell test: try a self-check (peanut butter at arm's length, eyes closed; or UPSIT)
- Talk with family about the early-sign pattern
- If RBD is confirmed: get a movement-disorder neurology visit

SKILLS · LIVE IT

- Say the PRODROMAL-WATCH pattern from memory
- Spot RBD in a bed partner
- Do a simple smell self-check
- Track constipation
- Compare today's handwriting to your handwriting 5 years ago
- Notice one-sided reduced arm swing while walking

PLAN · SHARE IT

- This week: talk about PRODROMAL-WATCH with your bed partner or family
- This month: get a sleep study if RBD is possible
- This year: if RBD is confirmed, see movement-disorder neurology and think about joining the PPMI Prodromal study



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Diagnostic Workup + Wellness

LEARN IT · TIER 1 AWARE

PD is a **clinical diagnosis**. That means no single blood test or scan can confirm it. The **MDS Clinical Diagnostic Criteria**

(2015) need **bradykinesia (slowness) plus rest tremor or rigidity**. Helpful extra clues add support. These include a clear levodopa response, levodopa-caused extra movements (dyskinesia), rest tremor, and loss of smell.

A **DaT-SPECT scan** can show low dopamine at the nerve endings. It helps tell PD apart from drug-induced parkinsonism or essential tremor. But it cannot tell PD apart from the atypical types.

An **MRI** can rule out other causes. It also checks for blood-vessel damage. A **movement-disorder neurology visit is the gold standard**. A general neurologist or primary care doctor may give a diagnosis.

A specialist often changes it. In fact, community misdiagnosis runs 10–25% in published reviews. A good **wellness baseline** checkup covers a lot. It has a thinking screen (MoCA).

It has mood and worry screens (PHQ-9, GAD-7). It has a sleep history, with RBD questions and sleep quality. It checks body control, like standing blood pressure, plus bladder, sexual, and gut issues.

It checks food and weight. And it checks fall risk. **PD medicine safety** matters too. Avoid dopamine-blocking nausea drugs (metoclopramide, prochlorperazine).

Use ondansetron or trimethobenzamide instead. Avoid most antipsychotics. Only quetiapine, clozapine, or pimavanserin are safe for PD-related hallucinations or delusions (PD psychosis).

Keep up your shots (flu, COVID, RSV, pneumococcal) per the usual guidelines.

CONCEPTS · LEARN IT

- PD is a clinical diagnosis — no single test confirms it
- MDS Criteria: bradykinesia (slowness) + rest tremor or rigidity + helpful clues
- DaT-SPECT shows low dopamine at the nerve endings
- Movement-disorder neurology is the gold standard
- Community misdiagnosis runs 10–25%
- Avoid metoclopramide and prochlorperazine — use ondansetron / trimethobenzamide
- Avoid most antipsychotics — only quetiapine / clozapine / pimavanserin are OK

ACTIONS · THIS WEEK

- Confirm a movement-disorder specialist made your diagnosis, if you can reach one
- Check your med list for dopamine-blocking drugs and risky antipsychotics
- Book a baseline MoCA, PHQ-9, and GAD-7
- Confirm your shots are current

SKILLS · LIVE IT

- State the MDS Criteria simply
- Know when to ask for a movement-disorder neurology visit
- Read a DaT-SPECT report
- Check your medicine list for dopamine-blocking drugs
- Keep your shots up to date

PLAN · SHARE IT

- Coordinate neurology and primary care once a year
- Review your medicines every 3 months
- Do a MoCA once a year in advanced disease



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Know My Numbers

LEARN IT · TIER 1 AWARE

In PD, the numbers worth knowing are these. Your **H&Y stage**. Your **MDS-UPDRS Parts I-IV**. Your **MoCA** at the start and over time. Your **on/off diary** (track on-time, off-time, and dyskinesia in 30-minute blocks for 2-3 days before each visit) — this is the single most useful tool.

Your **falls per year** plus near-falls. Your **sleep quality and RBD episode count**. How often you have **constipation**. Your **blood pressure drop on standing** (a drop of 20 on top or 10 on bottom, in mmHg, within 3 minutes counts).

Your **PHQ-9 and GAD-7** (mood and worry quizzes). Your **medicine times around meals** — protein lowers how well levodopa is absorbed, so take it 30-60 minutes before meals.

Your **pillbox use** (did you take every dose?). An **impulse-control disorder screen** (gambling, over-active sex drive, over-shopping, binge eating) for anyone on dopamine agonists.

Your **weight** — some people lose weight, and advanced PD can cause swallowing trouble (dysphagia). Your **blood pressure, cholesterol, and A1c** — heart and blood-sugar problems matter too.

And your **genetic testing status** if you have young-onset PD or a strong family history. Bring a one-page numbers card to every visit.

CONCEPTS · LEARN IT

- The on/off diary is the single most useful tool
- Levodopa and meals: take it 30-60 minutes before meals
- Blood pressure drop of 20/10 mmHg within 3 minutes of standing = not normal
- An impulse-control screen is a must while on dopamine agonists
- Weight loss is common — track it
- Heart and blood-sugar problems matter too (they overlap)

ACTIONS · THIS WEEK

- Make a numbers card
- Keep an on/off diary this week
- Confirm standing blood pressures at home
- If on a dopamine agonist: do an impulse-control self-check this week
- Track meals and meds for 7 days

SKILLS · LIVE IT

- Keep a 2-3 day on/off diary
- Take the PHQ-9 and GAD-7 yourself
- Check standing blood pressure at home
- Do an impulse-control self-check if on a dopamine agonist
- Track levodopa timing around meals

PLAN · SHARE IT

- Keep your numbers card current
- Keep an on/off diary before each neurology visit
- Review trends with your team every 3 months



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Lifestyle Force Field — Exercise Is Medicine

LEARN IT · TIER 1 AWARE

This is one of the strongest non-drug tools in any long-term disease. Say it plainly: **hard exercise truly slows PD, not just its symptoms.** Several studies (**SPARX, PD-Active, Park-in-Shape**) show that hard aerobic exercise slows how fast movement gets worse.

The **Parkinson's Outcomes Project** (backed by the NIH, with over 13,000 patients) keeps finding that how often you exercise is the strongest sign of good quality of life.

Here is what the evidence shows.

(1) Hard aerobic exercise (treadmill, cycling, rowing) at **80-85% of your max heart rate, 30 minutes, 3-4 times a week** slows how fast movement gets worse.

(2) LSVT BIG (Lee Silverman Voice Treatment - BIG) is an intense physical therapy that trains big movements. It runs 4 weeks, 4 days a week, and helps for a long time.

(3) LSVT LOUD uses the same plan for voice and speech. It treats a soft voice (hypophonia).

(4) Dance — tango, ballroom, and Dance for PD programs — mixes balance, music, thinking, and time with others.

(5) Boxing — Rock Steady Boxing — builds power, quickness, and social time.

(6) Tai Chi — a large study showed it cut falls.

(7) Yoga, swimming, hiking, weight training, and cycling all help. The **MIND/Mediterranean diet** is tied to slower change. Good **sleep habits** matter too, with RBD bedroom safety (a padded headboard, a mattress on the floor or bed rails, keeping your partner safe, and no sharp objects nearby).

Stay **socially connected**. Keep your **brain active** (reading, music, puzzles, learning a language). Manage **constipation** (water, fiber, exercise, prunes; senna or PEG if needed;

avoid loperamide and anticholinergics). The honest point: **exercise is medicine in PD, full stop.**

CONCEPTS · LEARN IT

- Hard aerobic exercise slows the disease — proven in studies (SPARX, PD-Active)
- 30 minutes, 3-4 times a week, at 80-85% of max heart rate slows how fast movement worsens
- LSVT BIG (physical therapy): 4 weeks, 4 days a week
- LSVT LOUD (speech therapy): same plan for voice
- Dance for PD, Rock Steady Boxing, and tai chi are all backed by evidence
- MIND/Mediterranean diet is tied to slower change
- RBD bedroom safety: padded headboard, mattress on the floor or bed rails
- Constipation care: water, fiber, exercise, senna/PEG

ACTIONS · THIS WEEK

- This week: schedule 3 hard-exercise sessions
- Call about LSVT BIG or LSVT LOUD sign-up

SKILLS · LIVE IT

- State the exercise rule (hard, 30 minutes, 3-4 times a week)
- Find your target heart-rate zone ($220 - \text{your age} \times 0.80$)
- Sign up for LSVT BIG or LSVT LOUD
- Find a Dance for PD or Rock Steady Boxing class
- Build a constipation routine
- Set up an RBD-safe bedroom

PLAN · SHARE IT

- Daily: move
- Weekly: practice LSVT BIG / LOUD at home



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware

- Find a local Dance for PD, Rock Steady, or tai chi class
- Constipation: 2L water + 25g fiber + a 30-minute walk
- RBD: pad the bedside, lower the mattress, or add rails
- Every 3 months: review with your team and adjust



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Medications + Therapies — All Levers

LIVE IT · TIER 2 ACTIVE

PD treatment uses several tools. Your team mixes them by stage and symptoms. **Levodopa-carbidopa** is the gold standard since the 1960s. Every PD patient benefits from it in time.

The old worry about "saving it for later" is mostly outdated. Too little treatment causes more harm than the long-feared extra movements (dyskinesia). **Take it 30-60 minutes before meals.** Protein blocks how well it is absorbed.

It comes in many forms. There is immediate-release (Sinemet) and controlled-release (Sinemet CR). There is a tablet that melts in the mouth. There are extended-release capsules (Rytary).

There is an inhaled form (Inbrija, for off-time rescue). There is an intestinal gel (Duopa, for advanced PD). And there is an under-the-skin infusion (Vyalev, for advanced PD).

Dopamine agonists are another tool. These include pramipexole, ropinirole, the rotigotine patch, and apomorphine (by shot or under the tongue). You can use them alone in young-onset PD.

You can add them to levodopa. Or you can use them for off-time rescue. **HONEST WARNING — IMPULSE-CONTROL DISORDERS (ICD).** 15-20% of people on dopamine agonists develop an ICD.

That means problem gambling, over-active sex drive, over-shopping, or binge eating. These can badly hurt relationships, money, and health. **Tell the patient and family before starting. Ask about it at every visit.** If it happens, slowly lower the agonist.

MAO-B inhibitors (selegiline, rasagiline, safinamide) give a small movement boost. They may protect the brain too, though that is still debated. **COMT inhibitors** (entacapone, opicapone, tolcapone) make levodopa last longer for on/off swings.

Tolcapone needs liver monitoring. **Amantadine** helps tremor. Most of all, it helps levodopa-caused dyskinesia. Gocovri is extended-release amantadine, FDA-approved for dyskinesia.

On/off swings are a normal part of treated PD. Manage them with timing and by splitting doses. You can also add a COMT inhibitor or an MAO-B inhibitor.

You can use extended-release forms. Or use on-demand rescue (apomorphine under the skin or under the tongue, or inhaled levodopa). **Advanced treatments** come next.

Deep Brain Stimulation (DBS) targets the STN or GPi. It helps drug-resistant tremor, on/off swings, or bad dyskinesia. It needs careful patient screening.

It is not a cure, but it can greatly cut off-time. **Duopa** is an intestinal gel pump. It delivers levodopa-carbidopa nonstop through a PEG-J tube. **Vyalev** (foslevodopa-foscarbidopa) is a nonstop under-the-skin infusion.

Focused ultrasound (thalamotomy or pallidotomy) treats tremor or dyskinesia on one side. It uses no cut in the skin. **NEVER stop dopamine medicines all at once.** A dangerous reaction like neuroleptic malignant syndrome can happen.

CONCEPTS · LEARN IT

- Levodopa-carbidopa: gold standard since the 1960s; do NOT save it for later

SKILLS · LIVE IT

- Name your meds, doses, and timing around meals
- Tell on/off swings apart from the disease getting worse



3 Force Field Fact Sheet

Tier 2 · Live It · Active



- Take levodopa 30-60 minutes before meals (protein blocks it)
- Dopamine agonists: 15-20% develop impulse-control disorders — tell family BEFORE starting
- MAO-B inhibitors, COMT inhibitors, amantadine — add-on helpers
- On/off swings: manage with timing, dose splitting, COMT/MAO-B, and rescue meds
- Advanced: DBS, Duopa pump, Vyalev under-the-skin, focused ultrasound
- NEVER stop dopamine meds all at once — risk of an NMS-like reaction
- Tell dyskinesia apart from tremor
- Do an impulse-control self-check weekly if on a dopamine agonist
- Use rescue meds the right way
- Know the rule: never stop dopamine meds cold

ACTIONS · THIS WEEK

- Confirm the meal-timing rule for levodopa
- If on a dopamine agonist: do an impulse-control self-check and talk with family
- Set up a pillbox and auto-refill
- Apply for copay help if you take a brand-name drug
- Ask about advanced treatments (DBS, Duopa, Vyalev, focused ultrasound) when on/off swings limit your life

PLAN · SHARE IT

- This week: set your med-and-meal timing routine
- This month: do an impulse-control screen if on a dopamine agonist
- This quarter: full medicine review with neurology



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Care Team Members

LIVE IT · TIER 2 ACTIVE

PD care needs many specialists over a long time. The mix depends on your stage and what you can reach.

Movement-Disorder Neurology is the gold standard.

Many smaller towns have a hard time reaching one, but telemedicine helps. Parkinson's Foundation Centers of Excellence are the ideal hub-and-spoke model.

General Neurology is good when a movement-disorder neurologist is out of reach. Your **primary care doctor** ties it all together and manages other conditions (blood-vessel disease, type 2 diabetes, sleep apnea, and mood).

Physical Therapy works on walking, balance, and fall prevention (ideally LSVT BIG-trained). **Occupational Therapy** helps with daily tasks, home safety, and handwriting.

Speech-Language Pathology treats a soft voice (ideally LSVT LOUD-trained) and checks swallowing in advanced disease. **Neuropsychology** tests thinking at the start and over time.

It can tell apart low mood from true thinking loss (MCI or PDD). **Sleep Medicine** covers RBD, sleep apnea (common in PD), and heavy daytime sleepiness. **Urology** helps with bladder urgency and leaks, which are common.

Behavioral Health treats low mood and worry (30–50% of patients have them; this links to the mood-and-body loop and the Sprint 6 Depression / Anxiety courses).

A **pharmacist** checks drug mix-ups and your med list. A **genetic counselor** helps if young-onset or a family history. A **social worker** helps with FMLA, SSDI, and advance care planning.

A **dietitian** helps with constipation, weight, and swallowing in advanced disease. **Pastoral care** if it fits. **Peer support** comes from the Parkinson's Foundation, MJFF, APDA, Davis Phinney, and PMD Alliance.

And your **family helper**.

CONCEPTS · LEARN IT

- Movement-Disorder Neurology is the gold standard
- Parkinson's Foundation Centers of Excellence: a hub-and-spoke model
- LSVT BIG (physical therapy) and LSVT LOUD (speech therapy) are evidence-based
- Neuropsychology tells low mood apart from true thinking loss (MCI/PDD)
- Behavioral Health: 30–50% have low mood or worry
- Sleep apnea is common in PD — sleep medicine matters
- The family helper is the always-on member

ACTIONS · THIS WEEK

- Build a Care Team card
- Find an LSVT BIG-trained physical therapist
- Call the Parkinson's Foundation Helpline 1-800-4PD-INFO
- Book a baseline neuropsychology visit

SKILLS · LIVE IT

- List every team member with a phone and email
- Know who handles what
- Run a hand-off talk between providers
- Ask for early physical, occupational, and speech therapy
- Connect with peer support

PLAN · SHARE IT

- This month: finish your Care Team card
- This quarter: book any missing screen or visit
- This year: keep the team meeting together



3 Force Field Fact Sheet

Tier 2 · Live It · Active

- Find a peer mentor through the Parkinson's Foundation, APDA, or MJFF



Telemedicine & Tech

LIVE IT · TIER 2 ACTIVE · TECH

Tech does real work in PD care. **Telehealth movement-disorder neurology** works about as well as in-person for routine follow-ups (many studies confirm this).

It helps a lot because these specialists are rare — about 40% of US counties have none. **PD-specific tech** includes wearables that track you all day (the **Personal KinetiGraph**, and smartwatches that track tremor and slowness), phone apps for voice and finger-tap tracking (**mPower** from MJFF), walking and balance apps, digital on/off diaries, fall-detection wearables (Apple Watch and others), at-home thinking tests, remote DBS programming (at some centers), and virtual LSVT BIG and LSVT LOUD by telehealth.

Patient portals (like MyChart) help with medicine management. The **MJFF Fox Insight** online study collects patient-reported and genetic data at large scale.

Anyone with PD can join. **PPMI Online** lets you join the at-risk (prodromal) group. **Light therapy boxes** can help sleep timing. Pillbox apps help too. So do constipation-tracking apps.

One caution: not all PD apps are proven. Favor ones checked by MJFF, MDS, or peer-reviewed studies.

CONCEPTS · LEARN IT

- Telehealth movement-disorder neurology works about as well for routine follow-ups
- Personal KinetiGraph plus smartwatches track movement all day
- mPower (MJFF) tracks voice and finger taps
- Fox Insight online study (open to join)
- PPMI Online for the at-risk (prodromal) group
- Check apps against MJFF, MDS, or peer-reviewed sources

ACTIONS · THIS WEEK

- Sign up for MyChart and turn on lab and portal alerts
- Try one routine visit as a video visit
- Think about joining MJFF Fox Insight
- Set medicine and on-time tracking reminders
- Set up an RBD-safe bedroom

SKILLS · LIVE IT

- Run a video visit smoothly
- Send a clear portal message
- Set medicine reminders
- Use a wearable tracker
- Join Fox Insight if you want
- Use a light box for sleep timing

PLAN · SHARE IT

- This week: set up the portal and reminders
- This month: try a video visit
- This quarter: review your tech tools with your team



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Insurance, Treatment Cost & Help

LIVE IT · TIER 2 ACTIVE

PD care can be affordable, but the system is complex. **Levodopa-carbidopa** is generic and cheap (\$10-30 a month with GoodRx). **Most dopamine agonists are generic now.** Advanced treatments (DBS, Duopa, Vyalev, focused ultrasound) take real insurance work, but they are widely covered when you meet the rules.

Medicare covers PD. Most private insurance covers PD. Medicaid varies by state. The **Parkinson's Foundation Helpline** 1-800-4PD-INFO (1-800-473-4636) offers free help.

APDA Information & Referral is 1-800-223-2732. There is also the **MJFF Patient Council**. **SSDI** (disability income) is within reach for many patients at H&Y 3 or higher, when symptoms limit work.

The rules are complex, so work with a social worker. The **ADA** covers PD, even early on (it is a progressive brain disease with growing limits). **FMLA** covers DBS surgery, hospital stays, and intense physical, occupational, or speech therapy courses.

For **veterans**: **PD tied to Agent Orange exposure is automatically service-connected** under the VA, so connect with the VA. **Drugmaker copay programs** exist for Rytary, Inbrija, Gocovri, Vyalev, and Nuplazid (pimavanserin).

Hospital social workers and **Parkinson's Foundation chapter offices** give the best paperwork help you can get.

CONCEPTS · LEARN IT

- Levodopa is generic and cheap (\$10-30 a month with GoodRx)
- Advanced treatments are widely covered with some paperwork
- Parkinson's Foundation Helpline 1-800-4PD-INFO
- SSDI is within reach at H&Y 3+ — work with a social worker
- The ADA + FMLA + SSDI legal stack
- Veterans + Agent Orange = automatic VA service-connection
- Drugmaker copay programs for brand-name drugs

ACTIONS · THIS WEEK

- Print one EOB and learn what each line means
- If on a brand-name drug: apply to the drugmaker copay program
- Call the Parkinson's Foundation Helpline 1-800-4PD-INFO
- Talk to HR about ADA and FMLA
- Connect with a social worker for SSDI if it fits

SKILLS · LIVE IT

- Read an EOB (Explanation of Benefits)
- Apply for SSDI
- Handle ADA and FMLA paperwork
- Apply for a drugmaker copay program
- Use GoodRx for generics
- File an appeal if you are denied

PLAN · SHARE IT

- This week: gather your last 3 EOBs
- This month: apply for at least one help program if needed
- Each year: recheck your FMLA, ADA, and SSDI status



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Equity, Access & Cultural Competence

SHARE IT · TIER 3 CERTIFIED

Access gaps in PD are severe. Closing them is the helper's job. **Where you live matters.** About 40% of US counties have NO movement-disorder neurologist.

Rural patients often see only a general neurologist or primary care doctor. Telehealth has widened reach a lot, but not for everyone. **Race matters too.** PD is diagnosed less often in **Black Americans**, likely missed and under-reported.

Yet their outcomes are worse. That means later diagnosis, harder access to specialists, and fewer DBS surgeries. **LRRK2 gene changes** are more common in **Ashkenazi Jewish** and **North African Berber** people.

So genetic counseling matters. **Hispanic/Latino, AAPI, and Indigenous** people are less represented in PD research. **Older adults** are often missed, brushed off as "normal aging." **Veterans** have higher risk from Agent Orange, welding fumes, and repeated head injury.

They also get automatic VA coverage. **Young-onset** patients face unique challenges at work, in family planning, and with identity. The Parkinson's Foundation, MJFF, and APDA have all grown their equity work over the past decade.

Put plainly: **PD does not discriminate, but PD care does — meet patients where they are.**

CONCEPTS · LEARN IT

- About 40% of US counties have NO movement-disorder neurologist
- Black Americans: under-diagnosed; fewer DBS surgeries
- LRRK2: Ashkenazi Jewish and North African Berber — genetic counseling matters
- Hispanic/Latino, AAPI, and Indigenous people: under-represented in research
- Older adults: brushed off as 'normal aging'
- Veterans: Agent Orange + welding fumes + head injury — automatic VA coverage
- Young-onset: unique work and family-planning challenges

ACTIONS · THIS WEEK

- Save the Parkinson's Foundation Helpline, APDA, and VA contacts in your phone
- If from an underserved community: ask about care that respects your culture
- If an older adult is slow and shaky: don't brush it off as aging
- If a veteran has PD and Agent Orange exposure: connect with the VA

SKILLS · LIVE IT

- Match the messenger to the community
- Connect rural patients with telehealth movement-disorder neurology
- Know LRRK2 and GBA rates by ancestry
- Spot older-adult PD that was missed
- Connect veterans with the VA

PLAN · SHARE IT

- This month: finish one PD-equity training
- This quarter: write your story
- Long-term: become a helper (Tier 3)



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Talk to Kids, Partner, Employer

SHARE IT · TIER 3 CERTIFIED

PD shows up in family life, in partnership, and at work. **Kids** need plain words and honesty that fits their age: "Dad has Parkinson's. His brain makes less of a chemical called dopamine, so his body moves slower or shakier than before."

The medicine helps a lot. We're a team." Hiding it does more harm than telling. Kids notice the shaking and the still face, and they worry. **Your partner** shares a long road with you, and their helper roles in PD are special.

The **bed partner is often first to notice RBD** in early disease, and may notice it in their own relatives too. The **on/off observer** can see what the patient can't (especially if thinking is affected).

The **fall-prevention partner** keeps you safe. The **medicine-timing supporter** keeps you on schedule. A good partner can **tell dyskinesia apart from off-time, spot hallucinations** (from a dopamine agonist or PDD), and **help through non-motor distress**.

Your employer: the **ADA covers PD**. Fair changes include flexible scheduling around med peaks and lows, a comfortable workspace, voice-to-text software for typing fatigue, and steady schedules to manage tiredness.

FMLA covers DBS surgery and recovery, hospital stays, and intense therapy courses. When to tell people is your choice, and many PD patients work well for years, even decades, after diagnosis.

"Serious health condition" is enough for ADA and FMLA paperwork. You don't have to name PD if you don't want to.

CONCEPTS · LEARN IT

- Use plain words with kids; a parent's PD is a kid-curiosity issue, not a shame issue
- Partner roles: bed partner / on-off observer / fall prevention / med timing / dyskinesia spotter
- Ask about hallucinations directly — they are treatable
- ADA + FMLA + MHPAEA + EAP = your legal and benefit stack
- 'Serious health condition' is enough for ADA/FMLA paperwork
- Many PD patients work well for years, even decades

ACTIONS · THIS WEEK

- This week: have the family talk
- This month: talk with HR about ADA or FMLA if needed
- This quarter: plan the long road with your partner; do advance-care planning
- If you have kids: get a child mental-health check if they show stress

SKILLS · LIVE IT

- Run a 5-minute family talk
- Run a partner helper-roles talk
- Write up an ADA accommodation request
- Use the AHRQ SHARE Approach with your team
- Spot and report hallucinations early

PLAN · SHARE IT

- This month: name your accommodation needs
- This quarter: finish one ADA request if needed
- This year: make a long-road family and partner plan plus advance care planning



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Mentor & Share Insights

SHARE IT · TIER 3 CERTIFIED

You become your strongest self when you teach others. There are many places to help. **Parkinson's Foundation** peer mentors. **APDA** support groups (in person and online).

The **MJFF Patient Council**. The **Davis Phinney Foundation** Victory Summit and the free *Every Victory Counts* manual. **PMD Alliance**. The **Brian Grant Foundation**.

For young-onset PD: **PD Avengers** and YOPD support. A newly diagnosed person who hears "I was at H&Y 1 ten years ago; I exercise 5 days a week; I'm at H&Y 2 now and still working" gets a very different start than numbers alone.

Honest framing beats a pep talk. The **helper role of spotting early signs in family members** — especially RBD in a spouse or in the patient's own siblings and adult children — is high-value public-health work.

Most family members don't know to ask. Mentor with limits (caregiver burnout and over-sharing are real). Co-present at Parkinson's Foundation, APDA, or MJFF events.

Write a short note to your team after a great or rough visit. Stigma fades one story at a time — but only when the person is ready.

CONCEPTS · LEARN IT

- Parkinson's Foundation, APDA, MJFF, Davis Phinney, and PMD Alliance peer programs
- The free Every Victory Counts manual
- PD Avengers and young-onset support
- Honest framing beats a pep talk
- The helper role of spotting early signs in family — high-value public health
- Mentor with limits

ACTIONS · THIS WEEK

- Sign up to mentor one newly diagnosed person through the Parkinson's Foundation
- Read Every Victory Counts
- Write one feedback note this month
- Send your story to the Parkinson's Foundation, APDA, or MJFF

SKILLS · LIVE IT

- Tell your story in 3 minutes
- Run a 30-minute peer-mentor session
- Write a 'what worked / what didn't' note under 200 words
- Co-teach with your team
- Set healthy mentoring limits

PLAN · SHARE IT

- This month: find one mentoring chance
- This quarter: give one talk
- This year: finish the Tier 3 helper requirements



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Join the ROI Study (PHIT)

SHARE IT · TIER 3 CERTIFIED · STUDY

PHIT — Population Health Impact Tracking — is the FFH research engine. For PD, we ask a simple question: does the Prepared Patient program improve outcomes? That means earlier diagnosis (especially by spotting early signs), more exercise, more on-time, fewer falls, fewer ER visits, fairer access to movement-disorder neurology and advanced treatments, and better caregiver outcomes.

You can choose to share grouped, de-identified outcomes (H&Y, MDS-UPDRS, treatment type, on/off fraction, fall counts, ER visits, hospital stays, DBS / Duopa / Vyalev use, badge progress, and self-reported quality of life).

This lets researchers, payers, and policymakers test whether the program works. **No private health info (PHI) is shared.** You can leave at any time. We also suggest joining **MJFF Fox Insight** (open to all) and **PPMI** (the Parkinson's Progression Markers Initiative — a top observational study;

PPMI Online serves the at-risk prodromal group).

CONCEPTS · LEARN IT

- PHIT = grouped, de-identified outcomes only
- Proven programs can get paid for and reach more people
- Leave at any time
- FFH PHIT pairs PD outcomes with cost data
- Joining Fox Insight and PPMI too is encouraged

ACTIONS · THIS WEEK

- Opt in through the green box on this page
- Think about joining Fox Insight and PPMI Online
- Read your first quarterly summary
- Tell one peer about PHIT

SKILLS · LIVE IT

- Read a one-page consent form
- Know what is and isn't private health info (PHI)
- Set up a regular check of your own dashboard
- Leave or pause at any time

PLAN · SHARE IT

- Today: opt in if it feels right
- Each quarter: review your summary
- Each year: decide whether to keep going

Additional Notes

☐ I've read the full Parkinson's Disease Fact Sheet · Step 3



4 Prepared Patient Course

The complete course — three levels, applied to your life

The course takes you through the Fact Sheet in three levels — from newly-diagnosed to prepared — then shows how every part applies to you and the people around you.

Level 1 · Aware

Know the basics — what Parkinson's Disease is, your numbers, your meds.

Level 2 · Active

Manage & do — self-monitor, act on red flags, work your plan.

Level 3 · Certified

Advocate & share — teach it, bring your team in, help others.

The Numbers — H&Y, MDS-UPDRS, On/Off

The PD numbers help you and your team see where things are headed. The **Hoehn & Yahr (H&Y)** stage is one guide: 1 = one side only; 2 = both sides, balance still fine;

3 = balance affected but still on your own; 4 = severe trouble but can still walk or stand without help; 5 = wheelchair or bed-bound. The **MDS-UPDRS** (Movement Disorder Society Unified Parkinson's Disease Rating Scale) has four parts:

Part I (non-motor daily life), **Part II** (movement in daily life), **Part III** (the doctor's movement exam), and **Part IV** (movement complications, like on/off swings and extra movements called dyskinesia).

The **MoCA** checks thinking, at the start and over time. A score under 26 out of 30 suggests mild trouble (MCI); under 21 suggests dementia. An **on/off diary** tracks how well your meds work.

Note on-time, off-time, and dyskinesia in 30-minute blocks for 2-3 days before each visit. Also track **falls per year** (and near-falls), **sleep quality and RBD level**, and **how often you have constipation**.

Check your **blood pressure drop on standing** (a drop of 20 on top or 10 on bottom, in mmHg, within 3 minutes of standing counts). Track **mood** with PHQ-9 and GAD-7 (short mood and worry quizzes).

At-risk family can use the **MDS Prodromal Criteria** risk score. Here is the honest part: **PD does get worse, but the speed varies a lot**. Some people stay at H&Y 1-2 for ten years.

Others move faster. Life span is now close to normal with good care.

- H&Y stages 1-5
- MDS-UPDRS Parts I-IV
- MoCA: under 26 = mild trouble; under 21 = dementia
- On/off diary in 30-minute blocks for 2-3 days
- Blood pressure drop of 20/10 mmHg within 3 minutes of standing = not normal
- Speed of change varies a lot — there is no single path
- Life span is now close to normal with good care

THE FULL COURSE — HOW EACH PART APPLIES TO YOUR LIFE



4 Prepared Patient Course

The complete course — three levels, applied to your life

Every part of the Parkinson's Disease Force Field lands differently depending on who you are. Here is the complete course — what each concept means for **you**, your **family**, the **workplace**, and **students** learning it.

What Is Parkinson's Disease?

FOR YOU · THE PATIENT

This is your map. TRAP signs, non-motor symptoms, on/off times, exercise, and meds drive everything else. You can live well with PD and good care.

EMPLOYERS & WORKPLACE

More working-age adults are getting PD. Many keep working well for years, even decades, with a few fair changes at work.

FAMILY & CAREGIVERS

Your loved one is not lazy or just 'getting old.' This is a real disease with real treatments. Your helper role starts by learning about the diagnosis.

STUDENTS & LEARNERS

Memorize: the TRAP signs; ~60–80% of dopamine cells lost before movement signs start; alpha-synuclein and Lewy body buildup; levodopa is the top medicine; exercise slows the disease.

360 Human Anatomy: Nigrostriatal Dopamine & Brain Networks

FOR YOU · THE PATIENT

Knowing how PD works in the brain swaps 'why me?' for a truer story. It also shows why exercise, sleep, and less stress matter.

EMPLOYERS & WORKPLACE

PD is a brain-network disease, not just shaking. Knowing this helps managers respond and adjust work.

FAMILY & CAREGIVERS

Use the 360 Human Anatomy together. The Braak order explains why RBD and constipation came first.

STUDENTS & LEARNERS

Bookmark for boards. Modern PD: substantia nigra dopamine loss + alpha-synuclein/Lewy + Braak stages + non-motor circuits (locus coeruleus norepinephrine, cholinergic, vagal). The damage is wider than the basal ganglia.

Who Gets PD? — Types & Mimics

FOR YOU · THE PATIENT

Get the right diagnosis first. Atypical types (MSA, PSP, CBD) need different care. Essential tremor is treated another way. Drug-induced parkinsonism may go away when the drug stops.

EMPLOYERS & WORKPLACE

Many conditions look like PD. Your employee may have something else. Don't assume.

FAMILY & CAREGIVERS

Family history matters. If it is young-onset or strong in the family, genetic counseling can help siblings and adult children.

STUDENTS & LEARNERS

Memorize: TRAP + one-sided start + clear levodopa response supports PD. Trouble looking up/down, early falls, alien limb, strong early body-control problems, or poor levodopa response suggests atypical types (PSP, CBD, MSA). Always check for dopamine-blocking drugs before diagnosing PD.



4 Prepared Patient Course

The complete course — three levels, applied to your life

The Numbers — H&Y, MDS-UPDRS, On/Off

FOR YOU · THE PATIENT

Your PD numbers are your dashboard. The trend matters more than any single result. The on/off diary turns 'sort of' into clear facts.

EMPLOYERS & WORKPLACE

You don't need to know the numbers. You just need to know the patient does, and that the team is involved.

FAMILY & CAREGIVERS

Help track. The bed partner often sees on/off and dyskinesia patterns the patient cannot.

STUDENTS & LEARNERS

Memorize H&Y, the MDS-UPDRS parts, MoCA cutoffs, and the standing-blood-pressure rule. The on/off diary is the best tool for fine-tuning levodopa timing.

Recognize Prodromal Signs (PRODROMAL-WATCH)

FOR YOU · THE PATIENT

Spotting early signs gives you a head start. RBD does not always turn into PD. But if it does, you have time to prepare.

EMPLOYERS & WORKPLACE

Not really your job. But employees with early signs are glad not to be brushed off as 'just getting old.'

FAMILY & CAREGIVERS

You are the first line. A bed partner who notices RBD is doing important public-health work.

STUDENTS & LEARNERS

Memorize PRODROMAL-WATCH. Sleep-study-confirmed RBD turns into a synucleinopathy in 80–90% of people over decades. Frame it as pattern-spotting, not a diagnosis.

Diagnostic Workup + Wellness

FOR YOU · THE PATIENT

Your diagnosis matters. If a movement-disorder neurologist is hard to reach, telehealth options have grown a lot.

EMPLOYERS & WORKPLACE

You don't need the medical details. You just need to give the patient time for visits.

FAMILY & CAREGIVERS

Help keep the checkup list current. Watch for anyone prescribing metoclopramide or prochlorperazine, and speak up.

STUDENTS & LEARNERS

Memorize: PD is a clinical diagnosis. Know the MDS Criteria and when to use DaT-SPECT. Avoid dopamine-blocking drugs. Quetiapine, clozapine, and pimavanserin are the PD-safe antipsychotics.



4 Prepared Patient Course

The complete course — three levels, applied to your life

Know My Numbers

FOR YOU · THE PATIENT

A good on/off diary alone often unlocks a big medicine change. It is worth the effort.

EMPLOYERS & WORKPLACE

You don't need to know the numbers. You just need to know the patient is working with their team.

FAMILY & CAREGIVERS

Help with the on/off diary. The bed partner often sees on/off and dyskinesia patterns the patient cannot.

STUDENTS & LEARNERS

Memorize: the on/off diary, standing-blood-pressure steps, impulse-control screening on dopamine agonists, and levodopa-meal timing. Use PHQ-9 and GAD-7 at every PD visit.

Lifestyle Force Field — Exercise Is Medicine

FOR YOU · THE PATIENT

You can slow your PD a lot with exercise alone. It's boring, but it works. Don't wait — earlier is better.

EMPLOYERS & WORKPLACE

A workplace that supports activity, sleep-friendly schedules, and flexible meals helps PD employees stay productive longer.

FAMILY & CAREGIVERS

Help build the habit. Walk together. Drive to class. Track it in the diary.

STUDENTS & LEARNERS

Memorize: SPARX and PD-Active. Hard aerobic exercise slows how fast movement worsens. LSVT BIG and LOUD are evidence-based. Tai chi cuts falls. Boring is the point.

Medications + Therapies — All Levers

FOR YOU · THE PATIENT

Sticking to your meds, timing around meals, and watching for impulse-control changes are the levers you control. Don't 'save' levodopa. Ask your team about advanced treatments when swings limit your life.

EMPLOYERS & WORKPLACE

FMLA covers DBS surgery and recovery; intermittent FMLA can cover medicine-adjusting periods. ADA changes to work around med peaks and lows are fair and work well.

FAMILY & CAREGIVERS

You are the early warning for impulse-control disorders. Watch for changes in spending, gambling, sex behavior, and eating. Bring it straight to the team.

STUDENTS & LEARNERS

Memorize: levodopa-meal timing, the dopamine-agonist ICD warning, never stop dopamine meds cold, and the safe antipsychotics for PD psychosis (only quetiapine, clozapine, or pimavanserin). Avoid metoclopramide and prochlorperazine.



4 Prepared Patient Course

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Care Team Members

FOR YOU · THE PATIENT

You don't need to know everything. You need to know who knows what, and to keep the team in sync.

EMPLOYERS & WORKPLACE

One named HR contact + one named patient contact + an EAP referral = no chaos.

FAMILY & CAREGIVERS

Help keep the Care Team card current. Bring it to every visit.

STUDENTS & LEARNERS

Get PD-fluent. PD care needs many specialists over a long time. The Parkinson's Foundation Centers of Excellence model is the gold standard.

Telemedicine & Tech

FOR YOU · THE PATIENT

Tech is a force multiplier — most of all if you live far from a movement-disorder neurologist.

EMPLOYERS & WORKPLACE

Telehealth visits during the workday cause far less disruption than a full absence. Allow them.

FAMILY & CAREGIVERS

Help set up the apps. The bed partner can use Fox Insight too, as a care partner.

STUDENTS & LEARNERS

Telehealth movement-disorder neurology is real. Wearable PD tracking is growing fast. MJFF Fox Insight is the top online observational study. PPMI Online is its prodromal partner.

Insurance, Treatment Cost & Help

FOR YOU · THE PATIENT

A few hours of paperwork can save thousands and unlock care. The Parkinson's Foundation will help you through it.

EMPLOYERS & WORKPLACE

FMLA, ADA, SSDI, and an early social-work referral keep skilled PD employees longer.

FAMILY & CAREGIVERS

Take the lead on paperwork. The patient should not be on hold during their most tired, foggy time of day.

STUDENTS & LEARNERS

Most clinicians don't teach this. PD has a deep benefits stack — ADA, FMLA, SSDI, the VA Agent Orange rule, drugmaker copay programs, and Parkinson's Foundation chapter help.



4 Prepared Patient Course

The complete course — three levels, applied to your life

Equity, Access & Cultural Competence

FOR YOU · THE PATIENT

You are not imagining it. The access gaps are real. Telehealth and Parkinson's Foundation chapters can help.

EMPLOYERS & WORKPLACE

Your PD employees may face access barriers their coworkers don't. A private EAP, telehealth-friendly scheduling, and language-matched care pay off.

FAMILY & CAREGIVERS

Be the calm voice. Match the messenger. Don't preach.

STUDENTS & LEARNERS

Read NIH NINDS and Parkinson's Foundation equity materials. Don't brush off older-adult slowness as aging. Veterans + Agent Orange = automatic VA. LRRK2 and GBA rates by ancestry matter for genetic counseling.

Talk to Kids, Partner, Employer

FOR YOU · THE PATIENT

The relationships you protect now are the ones that carry you through. Asking your partner to be your helper is strength, not a burden.

EMPLOYERS & WORKPLACE

A PD employee who feels supported stays longer, does better work, and costs less. ADA + FMLA + MHPAEA + EAP is the stack.

FAMILY & CAREGIVERS

You are the Notice-and-Name team: bed partner, on/off observer, fall partner, med-timing supporter, and hallucination watcher.

STUDENTS & LEARNERS

Coach patients through these talks. Asking about hallucinations is a high-value clinical skill. Many PD patients work well for years, even decades — adjust how you frame the outlook.

Mentor & Share Insights

FOR YOU · THE PATIENT

Teaching locks in what you know and gives meaning to what you've been through. When you share is up to you.

EMPLOYERS & WORKPLACE

A PD employee who teaches becomes an inside champion. Support them.

FAMILY & CAREGIVERS

Family-to-family mentoring is just as strong as patient-to-patient. The bed-partner and care-partner peer track is rich.

STUDENTS & LEARNERS

Learning alongside PD patients and care partners is how you get PD-fluent. Show up at Parkinson's Foundation, APDA, or MJFF events, and listen first.



4 Prepared Patient Course

The complete course — three levels, applied to your life



Join the ROI Study (PHIT)



FOR YOU · THE PATIENT

Taking part is a quiet but real act of advocacy. It helps the program get funded, grow, and reach people who can't afford it.



EMPLOYERS & WORKPLACE

Sponsoring a group of employees in PHIT shows your investment is working — and gives you data to defend the spend.



FAMILY & CAREGIVERS

Care partners can opt in too — caregiver load and outcomes are tracked as well. Fox Insight has a care-partner section.



STUDENTS & LEARNERS

This is participatory research done right. Study how PHIT, Fox Insight, and PPMI were built, and copy them.

QUIZ YOURSELF — CAN YOU ANSWER THESE WITHOUT NOTES?

- ☐ What is Parkinson's Disease, in one plain sentence?
- ☐ What are my target numbers, and my personal baseline?
- ☐ What are my red flags — the signs that mean “call now”?
- ☐ What do I do first if those red flags happen?
- ☐ What is each of my medicines for?

The one thing about Parkinson's Disease I most want to remember

Additional Notes

☐ I've completed Step 4 · Prepared Patient Course for Parkinson's Disease



5 Materials & Tools

Your home kit — the tools that keep you prepared

Being prepared between visits takes a few simple tools. Set these up for Parkinson's Disease, and check them off as you go.

YOUR KIT

- ☐ **Health Passport** — meds, numbers, allergies & contacts on one page.
- ☐ **Your meters / devices** — whatever you use to track Parkinson's Disease at home.
- ☐ **Your action plan** — green / yellow / red: what to do at each level.
- ☐ **Reminders** — a pillbox or phone alarm for medicines and refills.
- ☐ **A tracker** — one number or habit to watch over time.

THIS WEEK'S ACTIONS FOR PARKINSON'S DISEASE

- ☐ Get copies of your neurology and primary care notes from the patient portal
- ☐ Save the Parkinson's Foundation Helpline 1-800-4PD-INFO and APDA 1-800-223-2732 in your phone
- ☐ Open and fill in your Force Field Emergency Card
- ☐ Tell one family member you trust about your diagnosis or worry
- ☐ Click into 360 Human Anatomy: Nigrostriatal & Brain Networks
- ☐ Note your main movement pattern (tremor, rigidity, or bradykinesia) in your Health Passport
- ☐ Bring your marked-up map to your next neurology visit
- ☐ Confirm your diagnosis with Movement-Disorder Neurology if you can reach one
- ☐ If young-onset (under 50) or strong family history: ask about genetic counseling
- ☐ Check your med list for metoclopramide, prochlorperazine, and antipsychotics
- ☐ Read your last neurology note for the written diagnosis
- ☐ Make a one-page numbers card

The one number or habit I'll keep an eye on



5 Materials & Tools

Your home kit — the tools that keep you prepared

Additional Notes

☐ I've completed Step 5 · Materials & Tools for Parkinson's Disease



Skills Lab is where you **show** an educator (or a trusted person) the hands-on parts of managing Parkinson's Disease, in your own words. Practise and demonstrate these:

SKILLS TO DEMONSTRATE

- ☐ Say the TRAP signs in plain words
- ☐ Tell PD apart from essential tremor: PD shakes at rest and starts on one side; essential tremor shakes during action
- ☐ Describe non-motor symptoms in your own words
- ☐ Explain how hard exercise helps slow the disease
- ☐ Open the 360 Human Anatomy: Brain & Movement module
- ☐ Name the nigrostriatal pathway in your own words
- ☐ Match an early symptom to its Braak stage
- ☐ Swap 'just shakes' for 'dopamine pathway plus alpha-synuclein spread'
- ☐ State your suspected type or confirmed diagnosis
- ☐ Spot signs that don't fit PD (poor levodopa response, early falls, trouble looking up/down, alien limb, strong body-control problems at the start)
- ☐ Check your medicine list for dopamine-blocking drugs
- ☐ Take a careful family history
- ☐ State your H&Y stage
- ☐ Track your own on-time, off-time, and dyskinesia

TEACH IT BACK

The fastest way to know you've got it: explain Parkinson's Disease in your own words — what it is, your main signs, what helps, and your red flags — with no notes.

My red flags for Parkinson's Disease — the signs that mean “call now”



6

Skills Lab

Show you can do it — hands-on teach-back

Additional Notes

☐ I've completed Step 6 · Skills Lab for Parkinson's Disease





THE FORCE FOR HEALTH® · PREPARED PATIENT

Prepared Patient Ambassador

This certifies that

has completed the Prepared Patient module for **Parkinson's Disease** —
knowing their condition, their numbers, their red flags, and how to speak up
in their own care.

SKILLS-LAB EDUCATOR SIGN-OFF

DATE

Workbook completion certificate. The clinical Prepared Patient Ambassador credential is confirmed by your
Skills-Lab educator or the certification exam.



SCAN TO VERIFY &
COMPLETE
CERTIFICATION

8 Disease Advocate

Optional — beyond yourself: help those who come after you

This optional step is a gift you give the next person. Turn what you learned about Parkinson's Disease outward.

WAYS TO ADVOCATE & SHARE

- ☐ Read all 16 squares
- ☐ Open the deep course
- ☐ Book a Movement-Disorder Neurology visit if you don't have one yet
- ☐ Visit the brain module before each neurology visit
- ☐ Update your notes after each treatment change
- ☐ Bring the marked-up map to your next visit
- ☐ Review your diagnosis once a year
- ☐ Talk with family about inherited risk and early signs
- ☐ Add PD/parkinsonism to your family-history record
- ☐ H&Y plus MDS-UPDRS once a year
- ☐ Share your story and what helped you most.
- ☐ Complete a row of Advocate Bingo.
- ☐ Support someone newly diagnosed with Parkinson's Disease.

My feedback on this program (Coach Lucy & Dr. Rob read these)



8 Disease Advocate

Optional — beyond yourself: help those who come after you

Additional Notes

☐ I've completed Step 8 · Disease Advocate for Parkinson's Disease

