



Understanding and Managing Pain in Parkinson's Disease

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BASED ON TRUE STORIES

When "Leg Pain" Isn't Just Pain

A person with Parkinson's disease developed severe, persistent pain in one foot and lower leg. The pain progressively worsened, interfering with walking and daily activities over several months.

Because the pain was initially thought to be orthopedic or neuropathic in origin, the patient underwent an extensive and costly work-up: X-rays, MRI, vascular studies, nerve conduction testing, and multiple specialist assessments.

Despite this thorough evaluation, nothing adequately explained the severity or character of the pain, and the patient continued to suffer.



*Vincent van Gogh, 1890
At eternity's gate*

BASED ON TRUE STORIES

The Clue Hidden in Plain Sight

On examination in the Movement Disorders Clinic, an important clinical clue emerged that had been overlooked in every prior assessment.

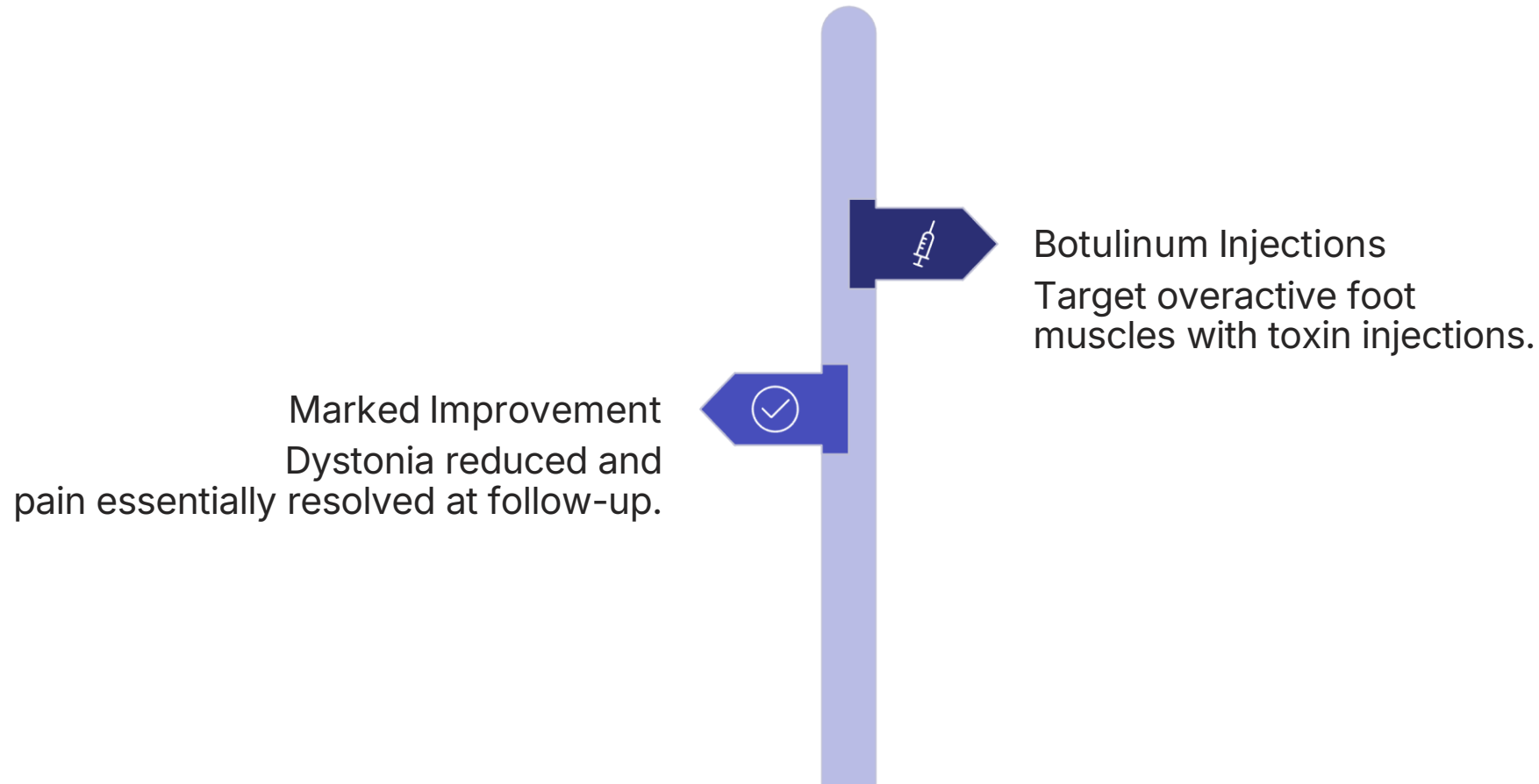
There was an abnormal sustained contraction of the foot muscles, with toe curling and abnormal fixed positioning of the foot — a characteristic and recognizable pattern.

This involuntary muscle overactivity is known as foot dystonia, and it is a well-recognized, albeit frequently missed, feature of Parkinson's disease.

❏ Dystonia-related pain is often mislabeled as musculoskeletal or neuropathic leading to years of ineffective treatment before the correct diagnosis is made.



Treatment — and Resolution



Years of suffering, numerous investigations, and multiple specialist visits had all been unnecessary once the correct underlying mechanism was recognized.

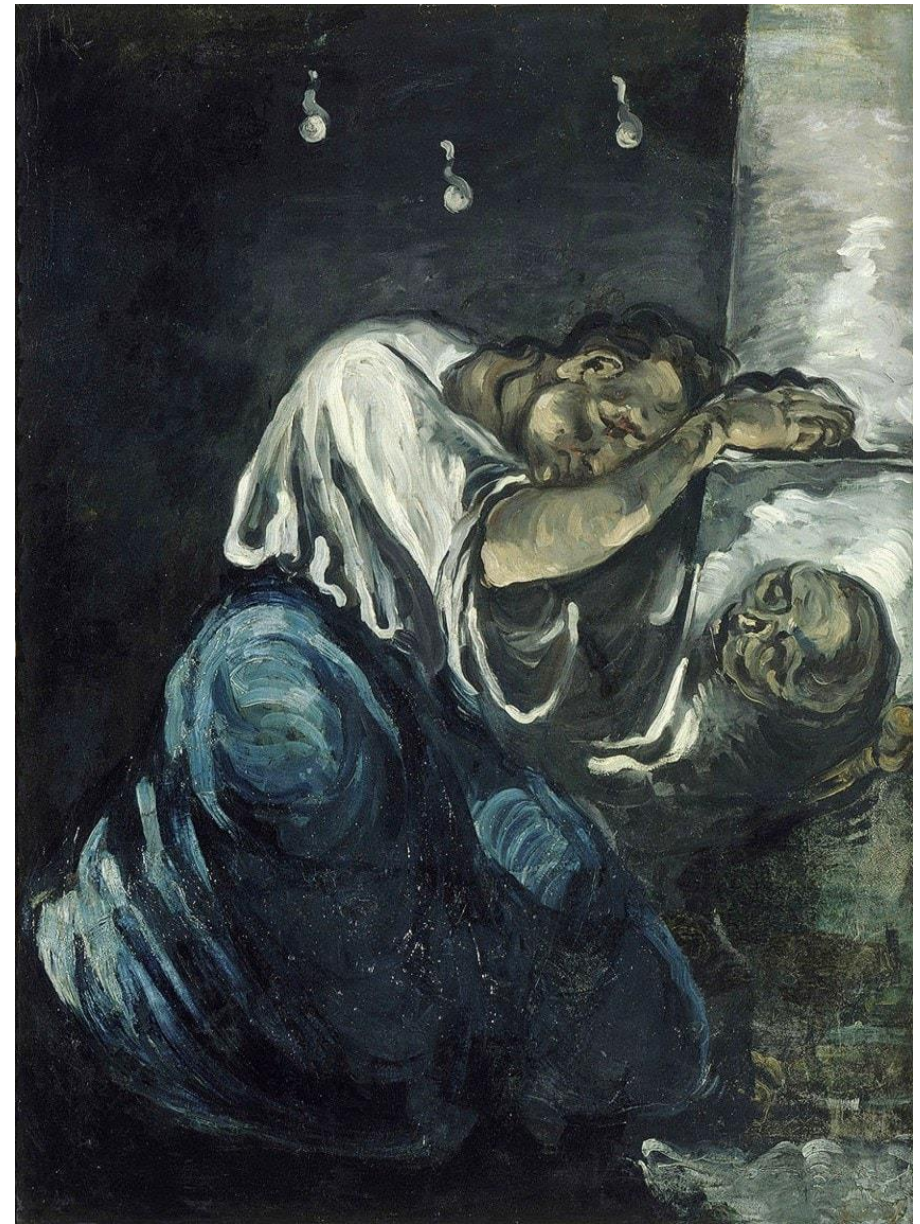
People often say
confidently, 'PD does
not hurt.'

Well, that is not true.

Every prior assessment in this patient's journey was built on a fundamental misunderstanding about Parkinson's disease.

Pain is not an anomaly in PD: it is a common feature.

Clinicians and patients alike must challenge the assumption that Parkinson's is purely a motor disorder.



La Douleur (Sorrow) (1868-1869) by Paul Cézanne

What Is Pain in the Parkinson's Context?

The IASP Definition (2020)

Pain is defined as an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.

It explicitly acknowledges both the physical and psychological dimensions of the pain experience.

Why This Matters in PD

In Parkinson's disease, this definition carries added clinical complexity.

A critical distinction must always be made: is the pain linked to rigidity, tremors, medication timing (off-period pain), or an entirely independent pathological process?

Recognizing the source of pain is not merely academic: it directly unlocks the correct treatment pathway and prevents years of misdirected management.

How Many People with PD Experience Pain?

Pain is far more prevalent across the Parkinson's disease trajectory than most clinicians and patients appreciate.

20%

At Diagnosis

Experience chronic pain at the time of their first clinical assessment, before many motor symptoms have fully developed.

Early

Before Motor Symptoms

Pain (particularly shoulder or foot pain) can emerge as a prodromal feature, predating the classic motor manifestations of PD.

80%

Over Disease Course

8/10 people are affected by clinically significant pain at some stage of their Parkinson's disease journey, making it one of the most prevalent non-motor symptoms.



Pain Does Not Exist in Isolation

In Parkinson's disease, pain rarely travels alone.

Its presence amplifies and is amplified by other burdens creating compounding cycles that erode quality of life far beyond the physical sensation itself.

Mental Health

Pain is a powerful multiplier for depression and anxiety, both of which are already highly prevalent in PD. Together they form a reinforcing cycle that is harder to break than either alone.

Motor Function

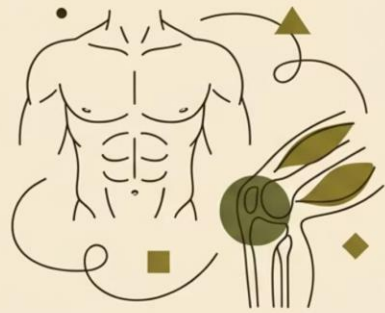
Persistent pain discourages exercise and physical activity, the very interventions most robustly supported for slowing functional decline in Parkinson's disease.

Social Identity

Diminished quality of life limits participation in social activities, eroding self-worth, identity, and meaningful relationships, hallmarks of a life well-lived.

Pain in PD Is Heterogeneous and Difficult to Characterize

One of the core clinical challenges in Parkinson's pain is that it does not conform to a single pattern. Understanding the broad mechanistic categories helps guide targeted evaluation and treatment.



Nociceptive Pain: includes musculoskeletal pain, dystonia-related pain, joint disorders.



Neuropathic Pain: includes burning sensations, electric shock-pain, pins and needles.



Nociplastic Pain: includes diffuse unexplainable sensations, restlessness and discomfort, visceral pain.

Some Pain Patterns Point to Specific PD-Related Mechanisms

🌙 Nighttime Disruptions

Nocturnal rigidity and off-period dystonia fragment sleep architecture, creating a cascade of daytime fatigue and heightened central pain sensitivity.

Optimizing evening dopamine dosing is often the first and most effective clinical lever in these patients.

Autonomic Dysfunction

Orthostatic hypotension produces a characteristic pattern known as "coat-hanger pain": a dull, aching discomfort across the neck, shoulders, and upper back that appears upon standing and resolves with recumbence.

Bladder urgency and bowel irregularity further compound systemic discomfort and significantly disrupt daily routines and sleep.

Strategies for Management

Effective pain management in Parkinson's disease requires a structured, individualized approach beginning with accurate identification of pain type and its relationship to PD pathophysiology.



Treatment Starts with Identifying the Pain

Before any intervention is selected, three foundational clinical questions must be answered. The answers shape every downstream decision from medication choice to referral pathways.

What kind of pain is it?

Classify the pain mechanistically
nociceptive (musculoskeletal, dystonic),
neuropathic (burning, electric), or
nociplastic (diffuse, centrally mediated).
Each category responds to a different
treatment approach.

Is Parkinson's disease contributing?

Determine whether the pain is directly
linked to PD pathophysiology (such as
rigidity, off-period dystonia, or central
sensitization) or whether it is incidental to
the diagnosis.

Is there a treatable trigger?

Identify reversible or modifiable
contributors: suboptimal medication
timing, untreated dystonia, postural
changes, autonomic dysfunction, or a co-
existing orthopedic or systemic condition.

The Pain Management Toolbox



Non-Pharmacological

Massage therapy, physiotherapy, occupational therapy, exercise programs, massage, TENS, acupuncture, cognitive behavioral therapy (CBT), and multidisciplinary pain clinic referral



Pharmacological

Targeted medications matched to pain mechanism (analgesics, neuropathic agents, muscle relaxants, botulinum toxin, and optimized dopaminergic therapy). Selection depends on pain classification and patient profile.



Lifestyle Modifications

Sleep optimization, dietary adjustments, structured daily activity, stress reduction, and social engagement. Lifestyle factors profoundly influence pain perception and tolerance in PD, often amplifying or diminishing pharmacological effects.

Sometimes, Optimizing Parkinson's Treatment Is Enough



ORIGINAL ARTICLE

Subcutaneous Apomorphine for OFF-related Pain in Parkinson Disease: A Randomized, Double-blind, Placebo-controlled Cross-over Pilot Trial

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When pain is directly driven by the underlying motor fluctuations of Parkinson's disease, the most effective strategy is often to treat the PD itself more aggressively rather than adding a separate analgesic.



Review Medication Timing

Reassess the frequency, dose, and timing of dopaminergic medications to ensure consistent therapeutic levels throughout the day and night.



Reduce OFF Periods

Off-period pain — including painful cramps and rigidity — often resolves dramatically when wearing-off is addressed through formulation changes or adjunct therapy.



Treat Dystonia Directly

Dystonic pain responds to targeted interventions: adjusted dopaminergic dosing, botulinum toxin injections, or in selected cases, deep brain stimulation.

RESEARCH ARTICLE

OnabotulinumtoxinA for Painful Foot Dystonia in Parkinson Disease

A Randomized, Double-Blind, Placebo-Controlled Trial

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Abstract

MORE ONLINE

Can Botulinum Toxin Reduce Pain in PD?

Yes. and this is one of the most underutilized tools in the Parkinson's pain management arsenal.

Botulinum toxin injections work by temporarily blocking the release of acetylcholine at the neuromuscular junction, reducing involuntary and sustained muscle contractions.

In PD, botulinum toxin is particularly effective for dystonia-related pain including foot dystonia, cervical dystonia, and limb dystonia.

- Botulinum toxin may also have direct analgesic effects independent of its muscle-relaxing properties, through inhibition of peripheral pain mediators.



What About Regular Analgesics?

Conventional pain medications retain an important role in Parkinson's disease particularly when pain has a component that is independent of PD pathophysiology, such as osteoarthritis, musculoskeletal strain, or post-surgical pain.

Acetaminophen

A safe first-line option for mild to moderate musculoskeletal pain. Well-tolerated in PD with minimal drug interactions.

Scheduled dosing is preferable to as-needed use for predictable analgesia.

Anti-Inflammatories (NSAIDs)

Useful for inflammatory musculoskeletal pain. Use with caution in older adults given risks of gastrointestinal bleeding, renal impairment, and cardiovascular effects. Short-term use at the lowest effective dose is preferred.

Opioids

Reserved for moderate to severe pain not responsive to other measures. Use with particular caution in PD given heightened risks of constipation, sedation, falls, and cognitive impairment. Lowest effective dose and regular reassessment are essential.

Addressing Neuropathic Pain in Parkinson's Disease

Neuropathic pain characterized by burning, electric shock-like sensations, allodynia, or pins and needles, requires a different pharmacological strategy than nociceptive pain.

The following agents have established efficacy in neuropathic pain and are commonly used in the PD context.



Gabapentin

A voltage-gated calcium channel modulator widely used for neuropathic pain. Start low and titrate slowly in PD given risk of sedation, dizziness, and falls. Also benefits comorbid restless legs and sleep disruption.



Pregabalin

Similar mechanism to gabapentin with more predictable pharmacokinetics. Effective for peripheral and central neuropathic pain. Monitor closely for somnolence and peripheral edema in older patients with PD.



Duloxetine

A serotonin-norepinephrine reuptake inhibitor (SNRI) with dual analgesic and antidepressant properties, a particularly valuable combination in PD patients where pain and depression co-exist.

When Should Pain Be Assessed Urgently?

While most pain in Parkinson's disease is chronic and manageable in the outpatient setting, certain presentations require urgent or emergent evaluation to exclude serious underlying pathology.

 Sudden Severe Pain

  Chest Pain or Shortness of Breath

 Pain After a Significant Fall

 New Weakness or Numbness

 Fever, Redness, or Swelling

  Major Unexplained Change

Key Clinical Takeaways

01

Pain Is a Core Feature of PD

Up to 80% of patients experience clinically significant pain over the disease course. It must be proactively screened for at every clinical encounter, not treated as an afterthought.

03

Optimize PD Treatment First

When pain is linked to motor fluctuations, dystonia, or off periods, optimizing dopaminergic therapy often delivers greater pain relief than adding a conventional analgesic.

02

Classification Drives Treatment

Nociceptive, neuropathic, and nociplastic pain respond to fundamentally different interventions.

Accurate mechanistic classification is the essential first step before any analgesic is prescribed.

04

Don't Miss Dystonia

Foot and limb dystonia are frequent, under-recognized causes of severe pain in PD. Examination-based recognition (not imaging) is the key to diagnosis. Botulinum toxin is highly effective.

The Multidisciplinary Team in PD Pain Management

Effective, patient-centered pain management requires coordination across disciplines.



Neurologist / Movement Disorder Specialist

Leads PD diagnosis, medication optimization, dystonia identification, and botulinum toxin therapy.



Physiotherapist

Addresses posture, gait, flexibility, and musculoskeletal contributors to pain. Designs individualized exercise programs that reduce pain and preserve function.



Occupational Therapist

Modifies daily activities and home environments to reduce pain triggers and compensate for motor limitations, preserving independence and safety.



Psychologist / Psychiatrist

Addresses the depression, anxiety, and catastrophizing that amplify pain experience.

The Role of Exercise in Pain Management

Central Pain Modulation

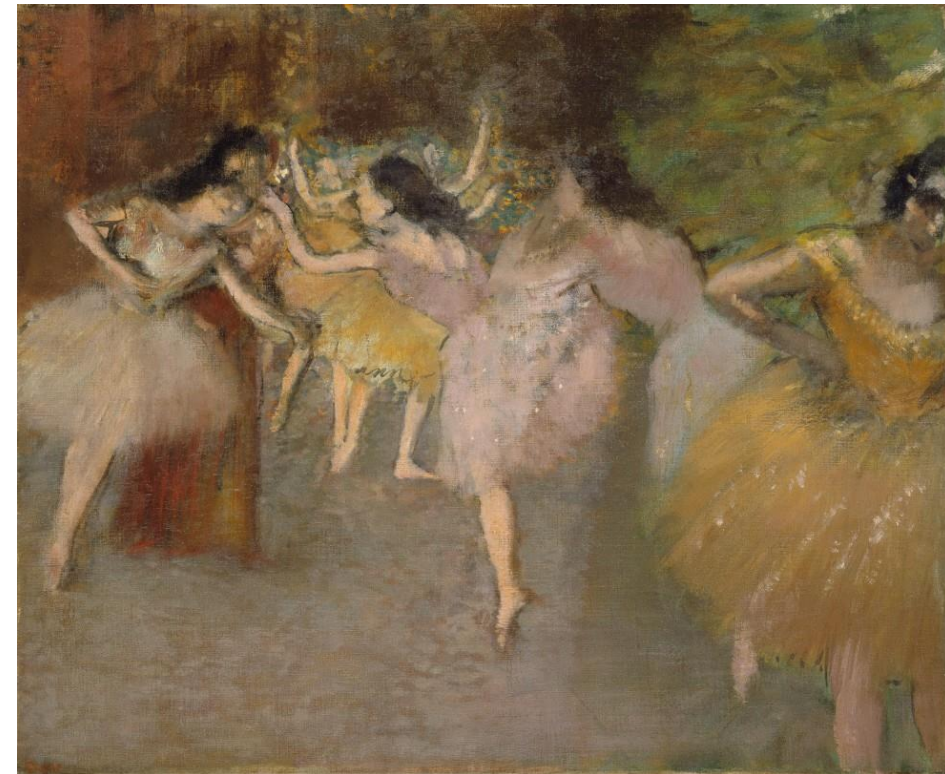
Exercise promotes endogenous opioid release and activates descending inhibitory pain pathways, raising the pain threshold.

Reduced Rigidity & Stiffness

Targeted stretching and mobility work directly reduces musculoskeletal pain driven by rigidity and postural changes in PD.

Mood and Sleep Benefits

Exercise improves both depression and sleep quality, two powerful modulators of pain perception and tolerance in chronic disease.



Rehearsal Before the Ballet, Edgar Degas

Sleep, Pain, and Parkinson's: A Vicious Cycle



Asking the Right Questions: Pain History in PD

1

Location & Radiation

Where is the pain? Does it radiate? Focal dystonic pain differs markedly from diffuse nociplastic discomfort or referred radicular pain.

2

Quality & Character

Is it burning, cramping, aching, stabbing, or electric? Character often reveals mechanism

3

Timing & Fluctuation

Does pain track with medication cycles? Pain that worsens in the "off" state and improves with the "on" state strongly implicates dopaminergic fluctuation as the driver.

4

Aggravating & Relieving Factors

What makes it better or worse? Positional changes, activity, heat, rest, and medication timing all provide diagnostic clues.

Shoulder Pain in Early Parkinson's: A Diagnostic Pitfall



Shoulder pain is one of the most common presentations that precedes a Parkinson's disease diagnosis, sometimes by several years.

It is frequently misattributed to rotator cuff pathology, frozen shoulder (adhesive capsulitis), or degenerative joint disease, leading to unnecessary orthopedic interventions.

The underlying mechanism in PD is axial and limb rigidity reducing shoulder mobility, combined with abnormal posture and reduced arm swing.

When to suspect PD could be the cause of shoulder pain:

- Unilateral predominance corresponding to the more affected PD side
- Absence of significant rotator cuff pathology on imaging despite severe symptoms
- Concurrent subtle motor changes: reduced arm swing, mild bradykinesia, or postural change
- Improvement with dopaminergic therapy

Central Sensitization in Parkinson's Disease

What Is Central Sensitization?

An amplification of neural signaling within the central nervous system, causing hypersensitivity to stimuli, including stimuli that would not normally be painful (allodynia) or that cause disproportionate pain (hyperalgesia).

Why It Occurs in PD

Dopamine plays a crucial modulatory role in descending pain inhibitory pathways. Dopaminergic neurodegeneration in PD may impair these pathways, reducing the brain's capacity to suppress pain signals contributing to nociplastic pain patterns.

Clinical Implications

Patients with central sensitization may respond poorly to peripheral analgesics alone. Centrally acting agents including SNRIs, gabapentinoids, and optimized dopaminergic therapy, are more likely to provide meaningful relief.

Patient & Caregiver Education: What You Need to Know

Pain Is Expected and Treatable

Pain is a recognized and common feature of Parkinson's disease. It is not a sign of disease progression or failure. Most types of PD-related pain can be significantly improved with the right approach.

Track Pain Relative to Medications

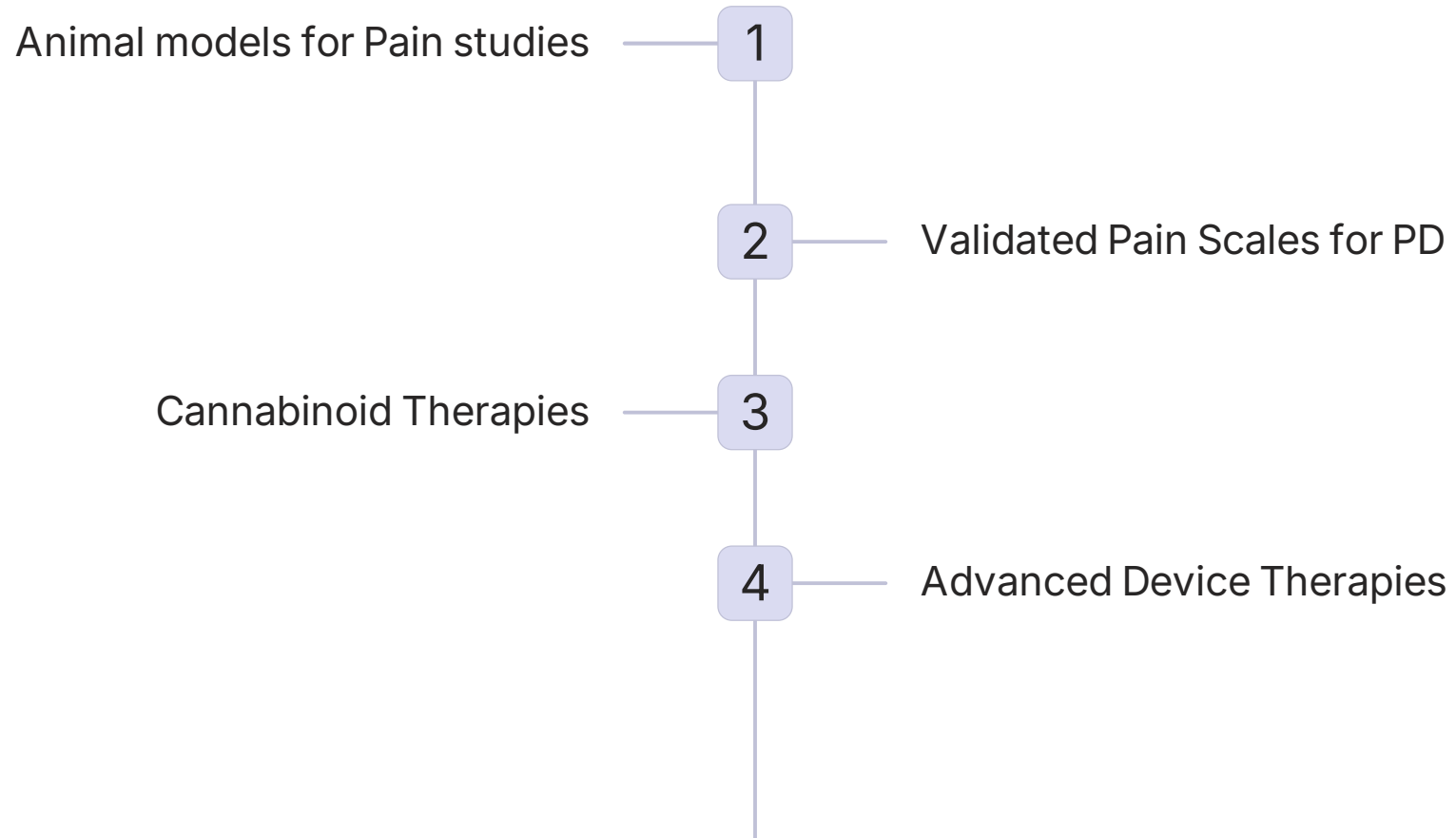
Keeping a simple diary of pain timing in relation to medication doses can reveal critical patterns that dramatically change the treatment approach.

Speak Up - Pain Is Underreported

Many people with PD normalize or minimize their pain. Caregivers can play a vital role in advocating for pain assessment at clinical visits and reporting changes in pain patterns between appointments.



Emerging and Future Directions in PD Pain Research



Summary:

Pain in Parkinson's Disease

Pain is one of the most prevalent, impactful, and undertreated dimensions of the Parkinson's disease experience.

It demands the same clinical rigor we apply to motor symptoms.

Recognize
Classify
Treat PD first
Escalate thoughtfully

- ❏ Pain in PD is real, it is common, and it is treatable.



David Teniers the Younger, *A Surgical Operation*, 1631-1640,