

# Parkinson's 101

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## What You and Your Family Should Know

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# Objectives

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- Learn what causes Parkinson's and who gets it
- Understand treatment options and the importance of a multi-disciplinary care team for Parkinson's management
- Learn about Parkinson's resources and support

# What is Parkinson's Disease?

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- Second most common neurodegenerative condition after Alzheimer's
- Accumulation of just several (out of countless possible) symptoms
- Because susceptible dopamine-secreting brain cells are damaged and lost
- Resultant declining dopamine level causes increasing malfunction of the brain's autopilot circuit which controls movements and coordination
  
- Symptoms and progression are different for everyone
- Incurable, yet very manageable and NOT fatal

**People with Parkinson's disease can live well for many years with expert care, support, and the right resources!**

# Early Signs of Parkinson's

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6 Constipation



3 Loss of Smell



2 Small Handwriting



10 Stooping or Hunching over



4 Trouble Sleeping



9 Dizziness or Fainting



7 A Soft or Low Voice



5 Trouble Moving or Walking



9 Mood Changes



8 Masked Face



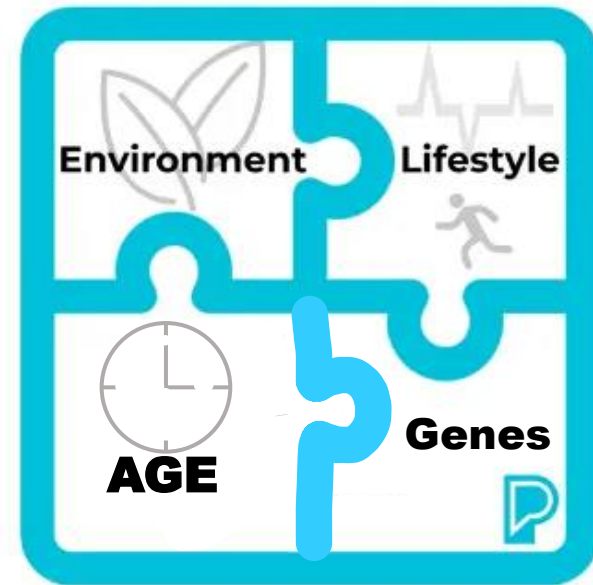
1 Tremor

# What Causes Parkinson's Disease?

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The cause of Parkinson's is not ONE trigger, but a combination of factors accumulated over a lifetime contributing to increased risk.

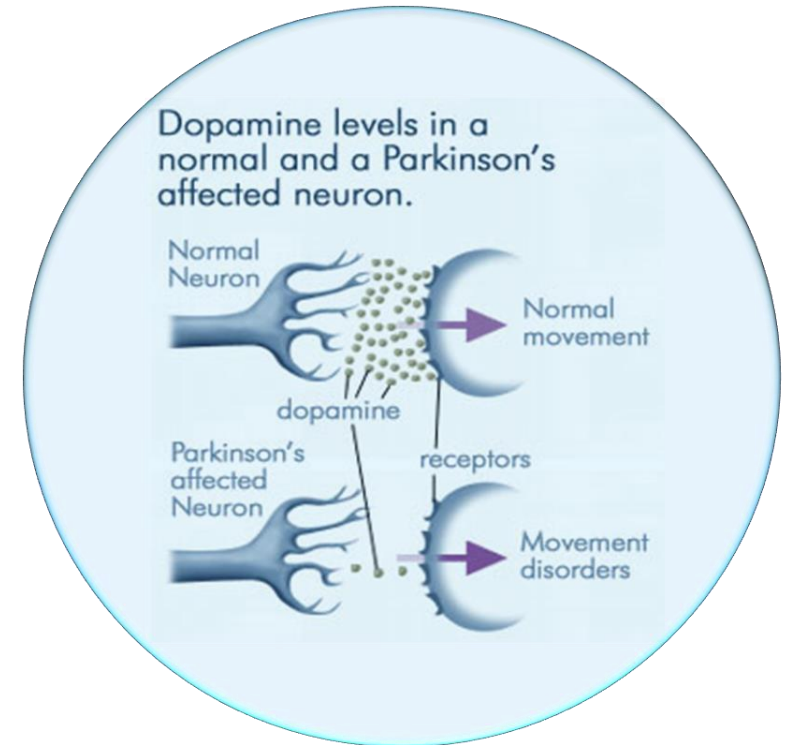
- Increasing AGE is the greatest *risk*
- Chemical exposure
- Inflammation
- Injury
- Genetics





# What's Happening in the Brain?

- From birth, dopamine-producing brain cells (neurons) accrue damage
  - Alpha synuclein protein misfolds → Lewy bodies
- Production of dopamine gradually decreases as neurons start to die off
  - Non-specific symptoms may start 20 years before diagnosis
- Once a threshold of neurons is lost, there is no longer enough dopamine to control movement
  - More obvious symptoms start, leading to diagnosis and initiation of medication
- Medication suppresses symptoms allowing maintained quality of life
  - Further loss → need for increasing doses over time



**Researchers are working on ways to stop or slow down the loss of dopamine-producing cells.**

# What You Should Know About Symptoms?

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- Insidious onset, slow progression
  - May lead to initial difficulty getting a diagnosis
  - Sudden worsening is NOT expected so look for other causes
- Everyone with PD has rigidity and slowness
  - Beyond that, your symptom set is UNIQUE
- Usually asymmetric, chance determines the worst side

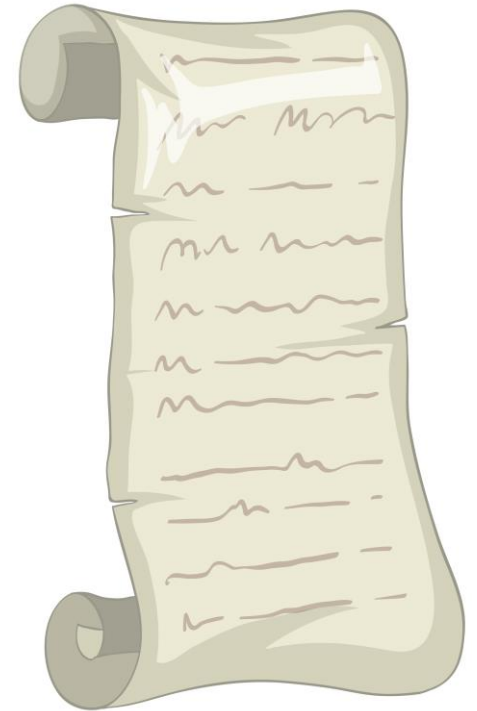


Image by brgfx on Freepix

# Motor (Movement) Symptoms

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- Primary (at least two needed for diagnosis)
  - Resting tremor only in 70%, sometimes “internal” tremor felt not seen
  - Bradykinesia = “slow movement”
  - Rigidity (vs. dystonia) = stiff inflexible muscles
  - Postural instability = “righting” reflexes lost
- Secondary
  - Freezing of gait (or speech)
  - Festination of gait (or speech)
  - Stooping posture
  - Shrinking handwriting
  - Mask-like facial expression
  - Excess saliva and drooling



# Non-motor (Non-movement) Symptoms

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- **Mood:** anxiety, depression, apathy
- **Cognitive:** slower, poor focus; difficulties with word-finding, decision-making, multi-tasking, visual-spatial
- **Psychosis:** hallucinations, delusions
- **Autonomic:** constipation; urinary urgency, frequency, incontinence; low blood pressure; sweating, temperature dysregulation
- **Sleep:** RBD, insomnia, hypersomnia, sleep-wake reversal
- **Vision:** dry eyes, blurry, double
- **Sexual:** erection, orgasm, libido
- **Fatigue, pain**



# How is Parkinson's Diagnosed?

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- Detailed medical history and physical exam
  - Requires presence of “primary” symptoms
  - Consult with Parkinson's specialist helpful
- DaTscan *optional* to rule in “parkinsonism”
- MRI *optional* to rule out other causes
- Levodopa trial *optional* to support Parkinson's diagnosis
- Skin biopsy *optional* to differentiate PD from MSA (parkinsonism)
- Absolute diagnosis can only be made at autopsy



# Building a Parkinson's Healthcare Team

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- Family and friends including a Healthcare Buddy
- Neurologist
- Primary care provider
- Therapists: physical, occupational, speech
- Mental health specialist
- Support groups
- Pharmacist
- Dietician
- Social worker or case manager
- Other: GI, cardiology, ophthalmology, urology; dermatology, dentist

**& YOU!**

# Participate: Support Groups

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**Support groups play a vital role in supporting PWP and families.**

- Emotional – others understand when you share experiences and feelings, reducing isolation, anxiety, depression
- Education – access to information, options, resources helps you make informed decisions about your care
- Practical assistance – provide transportation, meals, home care services to improve quality of life
- Advocacy – for policies and programs including funding, research, access to healthcare services, and for caregiver support

# Symptom Management: Finding the Right Doctor

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**For help finding experts  
in your area, call our toll-  
free Helpline at 1-800-  
4PD-INFO (473-4636)**

- Movement disorder neurologist is ideal
  - May need to travel to find one, or telemedicine
- Focus is on:
  - Reducing a person's symptoms now
  - Preventing complications in the future
  - Improving quality of life throughout
- Ideal doctor listens, provides advice and care, and responds during times of need
  - Knows rules, makes appropriate exceptions



# When To Start Treatment?

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**The decision of when to start treatment is made through discussion between the neurologist and the individual.**

- Start medications when symptoms severe enough to interfere with daily living
  - Personal philosophy important
  - Standard of care is to start at diagnosis
  - Levodopa trial may help in diagnosis
- Delaying treatment too long is unwise
  - May increase fall risk
  - Harder to reverse entrenched impairment
  - MYTHS: levodopa is a “last resort”, levodopa loses effectiveness over time



# Symptom Management: Medication Categories *in 1967*

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- **Dopamine**
  - Forms of carbidopa/levodopa (IR)
  
- **Other**
  - Amantadine IR

# Symptom Management: Medication Categories *Today*

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- **Dopamine**
  - Forms of carbidopa/levodopa (IR, CR, ER capsules, combo, enteral suspension)
- **Dopamine agonists**
  - Pramipexole IR/ER, ropinirole IR/ER, rotigotine patch
- **Dopamine extenders**
  - COMT: entacapone IR, opicapone ER
  - MAO-B: selegiline, rasagiline, safinamide
- **Other**
  - Amantadine IR/ER, istradefylline
- **Rescues**
  - Apomorphine injection, levodopa inhalation

# Symptom Management: Medication

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People with Parkinson's may take a variety of medications at different doses and times of the day in order to manage symptoms.

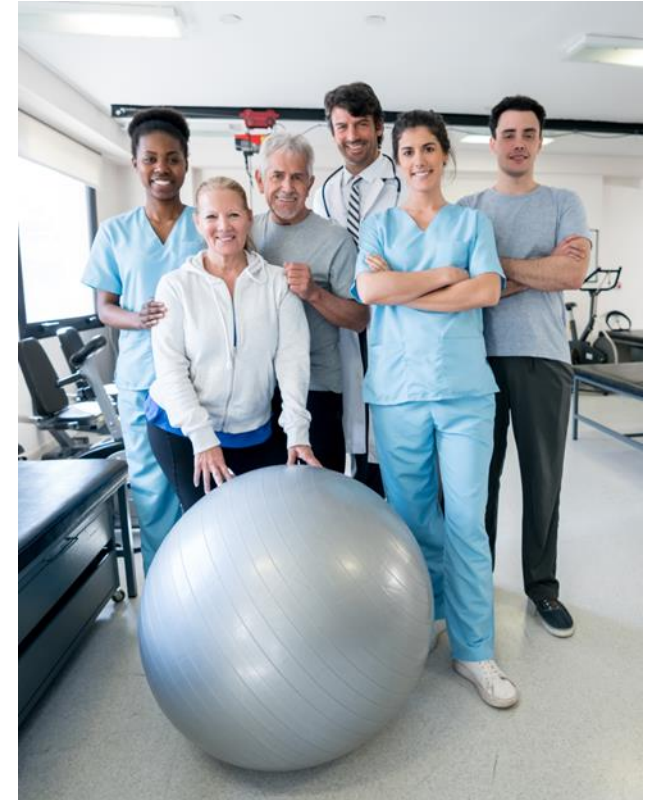
- Your regimen should be UNIQUE
- Variety of options for younger, fewer for older
- Choice depends on symptoms, tolerability, insurance
- Goal: reduce symptoms, allow you to function as normally with as few side effects as possible
- Maximal effectiveness comes with taking meds on an empty stomach on a regular schedule



# Symptom Management: Treatments

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- Physical therapy
- Occupational therapy
- Speech, language, swallowing therapy
  
- LSVT-BIG and LSVT-LOUD
- PWR! Gym, Knockout Boxing, Rock Steady Boxing
- Tai chi, dance, yoga, ...





# Symptom Management: Surgeries & Procedures

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**Surgery isn't right for everyone- talk to your doctor about whether this is an option for you.**

**Surgical options can be explored if symptoms aren't well-controlled with medication alone.**

- Deep Brain Stimulation
- Lesioning surgery
- MRI guided Focused Ultrasound
- Duopa Intestinal Gel Pump
- Not a cure, but manages fluctuations

# Symptom Management: Exercise

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- Exercise is as important as medication!!
- Maintains and improves
  - Mobility, strength, flexibility, balance
- Eases secondary symptoms
  - Constipation, mood, pain, cognition
- Decreases risk of falling
- SLOWS symptom progression
  - At least 2.5 hr/wk moderate to vigorous
  - Aerobic, strength, balance, stretching



**Do whatever you will stick to and enjoy!**

# Nutrition

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- Maintain balanced nutritious diet
- Fluids, fiber, fruits, veggies
- Protein
  - Stagger LD doses and meals
- Unintended weight loss
  - Get evaluated by PCP!
  - Small frequent meals
  - Calorie dense foods
  - Crackers or toast w/LD for nausea
  - Spices, colors, textures
  - Soft foods, thickeners
- Vitamin D3

# Living Well

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**“Trying to hide symptoms expends energy, causes embarrassment, and isolation. The sooner you accept your condition, the sooner you can begin coping with it and living your life.”**



- Talk about your fears – it makes them appear less overwhelming
- Stay as independent as possible
- Learn to accept help when you really need it
- Reprioritize, adjust expectations
- Manage stress, find solutions
- Focus on small victories
- Get organized
- Allow extra time for everything
- Make a plan, set goals
- Stay connected – socialize

# Participate: Research

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Research plays a vital role in helping us understand Parkinson's.

- Clinical studies
    - Drug trials
    - Surgical trials
  - Observational studies
  - Genetic studies
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- Receive closer attention, more frequent evaluations
  - Protected from harm by: FDA protocol, research ethics, Institutional Review Boards





# Summary

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- Anyone that lives long enough might get Parkinson's
- Everyone with Parkinson's has different symptoms and progression, and should have a unique medication regimen
- Parkinson's is very manageable
  - Most symptoms can be alleviated with the right combination of medications and therapies as obtained through multi-disciplinary teams

