What is Parkinson’s Disease?

Muhammad Ali Parkinson Center
A National Parkinson Foundation Center of Excellence
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Muhammad Ali Parkinson Center

- National Parkinson Foundation Center of Excellence
- Expert Clinical Care and Center for Neuromodulation
- Educational Programs
- Recreational Programs
- Support Groups
- Newsletter
- Resource Center
- Ali Care
- Spanish Services
- Clinical Care
- Research
Who Gets PD?

- 1 in 100 over 60 years of age
- Average age of onset 60 years of age
- 15% diagnosed before 50 years of age
- Slightly more men than women
**Why Does This Happen?**

- **Environmental factors**
  - rural living, well water, herbicide use and exposure to pesticides
- **Genetic factors**
  - 15-20% have close relative with PD symptoms
- **Aging**
  - wearing away of dopamine accelerated
  - By 2050 18.7 million Americans will be 85 and older
- **Probably result of genetic predisposition coupled with a yet unknown environmental factor**
What is Parkinson’s Disease?

• Chronic progressive neurological disorder
• Certain brain cells or neurons in the substantia nigra (SN) die or are impaired
• Those neurons produce dopamine
• Responsible for coordinated movement and balance
• Loss of cells in other areas of the brain also contribute
Dopamine

- Helps transmit messages from the SN to the striatum
- Initiates movement
- Controls movement and balance
- Makes sure:
  - Muscles work smoothly
  - Under control and
  - Without extra or unwanted movements
Loss of Dopamine

• SN degenerate ⇒
  – decreased dopamine ⇒
  – lack of regulation of movement control centers in the brain ⇒
  – loss of control of movements ⇒

• Cardinal signs become apparent at 70-80% dopamine loss
  – Tremor, Rigidity, Bradykinesia, Postural Instability
Tremor

• Present in 70% of people
• Involuntary movement
  – Resting tremor
  – Lessens with intentional movement
• Commonly starts on one side of body
• May occur in hand, arm, foot, leg, chin, lips or tongue
• Increases with stress and anxiety
• Disappears with sleep
Bradykinesia

- Slowness of movement
- Incomplete movement, difficulty initiating movements and sudden stopping of ongoing movement.
- Loss of spontaneous or automatic movement
- Slowness may interfere with daily routines; getting dressed, shaving or showering may take much of the day.
- “Freezing”, small steps or shuffling gait
- Significant problem and the most disabling symptom
Freezing of Gait

- Occurs in about 30% of people with PD
- Usually several years after diagnosis
- Momentary inability to move feet during walking
- Feet feel “stuck to the floor”
- Last for a few seconds
- Once starts it usually persists and will happen frequently
- One of the main causes of falls
- Exercise may be helpful
- Worsens with stress or cognitive loading
Freezing of Gait

• Occurs
  – Crowded environment
  – Doorways
  – Escalators, elevators
  – Change in floor surfaces
  – Lineups
  – Tight spaces
  – Steps or curb
  – When try to turn
Freezing Tips

• Take deep breaths to relax and to decrease anxiety
• Make sure weight is placed equally on each foot
• Change direction – if unable to move forward, move sideways or backwards
• Exaggerate lifting feet
• Rock back and forth
• Count aloud 1,2,3 Go…
• Sing or hum and then start walking – marches work best
Freezing Tips

• Estimation walking
• Pick a target and walk towards it
• Look ahead – not down
• Step over imaginary object or line on the floor
• Laser cane or walker
Rigidity

- Stiffness or inflexibility of the limbs and/or trunk
- Muscle tone is always stiff and does not relax – leads to decreased range of motion
- Felt as “tightness” in limbs
- Can cause pain and cramping
Postural Instability

• Consists of alterations in postural control while standing, when responding to an unexpected destabilizing perturbation, or when performing voluntary movements

• May be present at diagnosis but becomes more prevalent and worsens with disease progression
Postural Instability

- Abnormal postural reflexes make balance and coordination difficult & dangerous
- Leads to falls
- Trouble keeping upright
  - Seen as a forward lean sometimes backward
  - Stooped posture
- Affects gait
Parkinson Gait

- Gait changes include:
  - Slowness in walking
  - Short shuffling steps and a flexed posture
  - May include festination and/or freezing of gait (FOG)

- Particularly impaired are:
  - Dual tasking
  - Turning
  - Walking backwards
Other Signs of PD

- Small handwriting
- Lack of arm swing in one arm
- **Decreased facial expression**
- Speech changes
- Excessive saliva
- Difficulty swallowing and drooling
- Pain
- Low blood pressure
- Fatigue/loss of energy
- Changes in mental function over time
Other Signs of PD

- Mood disorders, Depression/anxiety
- REM behavior / Sleep disturbances
- Constipation
- Loss of sense of smell
- Urinary frequency
- Sexual dysfunction
- Low blood pressure
- Fatigue/loss of energy
- Excessive saliva
- Weight loss / gain
- Changes in mental function over time
  - Memory difficulties, slowed thinking, confusion and in some cases dementia
Depression/Anxiety

- May be an initial symptom of PD
- May precede the onset of motor symptoms in up to 30%
- Reactive depression at the time of initial diagnosis is common
- May be greater in younger patients
- No clear correlation between degree of depression /anxiety and severity of PD
Psychoses

- Loss of contact with reality that often leads to behavioral and emotional changes
  - Hallucinations and Delusions
    - Hallucinations- usually visual created by the mind w/o a specific trigger
    - Delusions- usually persecutory or jealousy
- Typically side effect of PD medication
- Leading cause of nursing home placement
Treatment for Psychosis

- Require same attention as motor symptoms
- Adjust or reduce or d/c medications
- Balancing act between good PD motor control and psychosis
- Hallucinations- usually if the person moves closer to the object, the lighting is improved or the person blinks the image will disappear
- Delusions- Best to distract and change subject
Cognition

• Changes in cognition in Parkinson’s disease are difficult to measure
• Estimates that 1/4 to 1/3 will have mild cognitive impairment while another ¼ to 1/3 will have dementia
• MCI- does not interfere with functioning ability at work or home
• Dementia- decline in multiple mental abilities including memory and require help
Co-Existing Conditions Affecting Cognition

- Depression
  - Affects memory, attention and problem solving skills
- Anxiety
  - Can interfere with memory storage, disrupt attention and affect complex task performance
- Sleep Disturbance
  - Impacts attention, alertness, memory, judgment and ability to multi-task
- Fatigue
  - Can cause problems with thinking and memory
  - Best to divide tasks into shorter sections that are more manageable and maximize the person’s attention and energy resources
  - Best to do more complex tasks earlier in the day when the person feels fresh

Successful treatment of all of these with therapy and medication can improve cognition
How is PD Diagnosed?

- No standard diagnostic tests (blood test or x-ray)
- Medical history
- Neurological exam
- Rule out other conditions
- Should see a Movement Disorder Specialist
  - neurologist who specializes in PD
- Positive response to PD medication
Progression of PD

• Mild Parkinson’s
  – Movement symptoms may be inconvenient, but do not affect daily activities
  – Movement symptoms, often tremor, occur on one side of the body
  – Friends may notice changes in a person’s posture, walking ability or facial expression
  – Parkinson's medications suppress movement symptoms effectively
  – Regular exercise improves and maintains mobility, flexibility, range of motion and balance, and also reduces depression and constipation

*From the Parkinson Disease Foundation website*
Progression of PD

• **Moderate Parkinson’s**
  – Movement symptoms occur on both sides of the body
  – The body moves more slowly
  – Trouble with balance and coordination may develop
  – “Freezing” episodes — when the feet feel stuck to the ground — may occur
  – Parkinson's medications may “wear off” between doses
• Parkinson's medications may cause side effects, including dyskinesias (involuntary movements)
• Regular exercise, perhaps with physical therapy, continues to be important for good mobility and balance
• Occupational therapy may provide strategies for maintaining independence
Progression of PD

- **Advanced Parkinson’s**
  - Great difficulty walking; in wheelchair or bed most of the day
  - Not able to live alone
  - Assistance needed with all daily activities
  - Cognitive problems may be prominent, including hallucinations and delusions
  - Balancing the benefits of medications with their side effects becomes more challenging
Treatment Options

• Medication
• Surgery
• Non-pharmacological Treatments
  – Rehabilitative Therapies
  – Exercise
  – Complementary and Alternative Therapies
Medication

• **Goal**
  – provide relief from PD *motor* symptoms
  – alleviate muscle rigidity, improve speed and coordination of movement, and lessen tremor

• **Considerations**
  – does a decrease in function warrant meds
  – some symptoms respond better than others
  – potential long term side effects
  – treatment evolves as illness progresses
Common Medication Classes

• Carbidopa / Levadopa – Sinemet
• Dopamine Agonists
  – Apokyn, Mirapex, Requip, Neupro
• Anticholinergics
  – Artane, Cogentin
• MAOB inhibitors
  – Selegiline, Azilect
• COMT inhibitors
  – Comptan, Tasmar
Carbidopa - Levodopa

• Gold standard
  – Levodopa - precursor to dopamine
  – Carbidopa -
    • Inhibits the breakdown of levodopa allowing more to cross the blood/brain barrier
    • May reduce common side effects – nausea / vomiting

• Available in immediate and extended release as well as dissolvable tablets placed under the tongue
Carbidopa - Levodopa

• Recommendations:
  – Take on time every time
  – Best to take on an empty stomach ½ hour to a full hour before meals with a full glass of water
  – Can be taken with food but best to take with foods that do not contain protein
  – Ginger tea, soda and graham crackers can alleviate the nausea
  – Always have an extra dose with the person
What do the Medications Do?

• All related to dopamine
  – Replace/replenish dopamine
  – Prevent breakdown of dopamine
  – Stimulate release of dopamine
  – Mimic dopamine
  – Prevent breakdown of levadopa
  – Improve mobility and disability
What do the Medications Do?

- Treat motor symptoms – do not stop disease progression
- **TIMING IS IMPORTANT!!**
- Management is complex and dynamic
- Very individualized
- No one right strategy for what drugs to use at what disease stage
- Responses vary
Medication Side Effects

- Nausea / vomiting
- Loss of appetite
- Dry mouth
- Daytime sleepiness
- Vivid dreams
- Hallucinations
- Insomnia
- Lightheadedness
- Dopamine Agonists- increased obsessive compulsive behaviors
On-Off

• On Time
  – Good response to medicine
  – Able to take part in usual daily activities without too much trouble

• Off Time
  – Symptoms of PD return
  – Taking part in usual activities becomes difficult
Wearing Off

- Medicine not working as well as it should for as long as it should
  - Gradual decline in motor ability before time for next dose
  - Effect of a dose diminishes noticeably between doses
  - Unpredictable motor fluctuations
- Usually at the end of a dose and before the next dose is taken
- Not just motor symptoms – look for increased anxiety, fatigue or depression
Wearing Off

A Typical Day

- Symptoms adequately controlled ('on' time)
- Symptoms not adequately controlled ('off' time)
- Symptoms are alleviated
- Symptoms begin to return
- Wearing-Off Period
- Medication Starts to Work
- Time

PD Medication
Dyskinesia

- Presence of involuntary, uncontrolled extra movements or wiggling
- Able to move well
- Sitting still may be difficult
- Different from rhythmic trembling of tremor
- Jerking, twisting or turning movements of the arms, head or legs
- Often the result of too much medication
  - Carbidopa/Levodopa
Other Issues

• **Motor Symptoms**
  – Target of medication

• **Non-Motor Symptoms**
  – Big impact on Quality of Life
    • Depression, fatigue, sleep disorders, cognition, constipation
Hospitalization and PD

- People with PD are hospitalized 50% more than their peers without PD
- 3 out of 4 people with PD do not receive medications in time in the hospital
  - 61% of people who did not get their meds on time had serious complications from it
- Hospitals often are unaware of medications that are contraindicated for those with PD
Hospitalization and PD

- People with PD suffer avoidable complications at a higher rate than non-PD patients.
- This yields longer hospital stays than non-PD patients (2-14 days).
- This results in a 44% higher risk-adjusted mortality.
For more information about Aware in Care or to order a free kit, visit www.awareincare.org or call NPF’s Helpline 1-800-4PD-INFO (473-4636)
Deep Brain Stimulation

- Places an electrode in a specific area of the brain
- Attached to a battery/programming unit
- Degree of stimulation adjusted
- Does not destroy brain tissue
- Electrode can be removed with no damage to brain
Deep Brain Stimulation Surgery

- Not a cure
- Does not stop disease progression
- Considered when medication options do not work as well
- Most patients still require meds
Non-pharmacological Treatments

- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Exercise
- Complementary and Alternative therapies
Exercise & Brain Changes

• Contributes to neuroplasticity – maintain old connections, form new ones and restore lost ones

• Studies suggest that intensive exercise can improve brain performance
  – May be neuroprotective
  – Allows brain cells to use dopamine more efficiently

• Activity at any level will be beneficial

• Periods of inactivity can revert protection benefits
Exercise and Symptom Management

• Improvements in balance, tremor, flexibility, strength and coordination
• Improve mobility
• Decreased falls
• Increased sense of well-being
• Positive influence on non-motor symptoms such as mood and constipation
• Slows cognitive decline
• Valuable for social interaction
• Helps prevent bone loss
• Improves pulmonary and cardiovascular health
• Actively engaged in their own treatment
Changes in Voice and Speech

• 70-90% PLWP experience these changes
• Typical Speech Complaints
  – Soft or weak voice
  – Reduced pitch variability
  – Breathy, hoarse voice
  – Imprecise speech sounds
  – Excessive rate of speech (6-13%)
  – Reduced rate of speech
Changes in Voice and Speech

- Occurs over an extended period of time
- PD primarily affects coordination and movement of muscles used for breathing, voice production and clarity of speech
- Scaling problem
  - Inability of internal cueing
  - Inability of self-perception & self-regulation
PD Symptoms

• Rigidity/Stiffness
  – Vocal Chords
  – Facial Muscles – Flat Affect
  – Decreased Blinking
  – Decreased Hand and Arm Movement
  – Decreased Posture Changes
Non-Verbal Communication

- 70%-90% of communication is non-verbal
- It is not what is said, but how it is said
- PLWP have reduced non-verbal behaviors
- PLWP is unaware of giving fewer cues
- PD partners rate the communication skills less than the PLWP rates his/her communication skills
Research

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Non-verbal Communication Study

- Two groups of older couples
  - 83 couples
  - One group with PD, one group without PD
  - Age: M=69.6 (range 50-90 years)
  - Education level: M=16 years
  - PD duration: M=10.3 years (range 3-31 years)
  - PD meds: all but one on dopamine replacement
Non-verbal Communication Study

- Comprised of 9 messages
- Sat across the table from each other
- **PLWP** was the message sender and the partner the message receiver
Scenario

• You come into the room and find your partner going through your dresser drawer

• Message: “What are you doing in my drawer?”

Positive: You realize your partner is doing something to surprise you and you love surprises!

Neutral: You are just curious.

Negative: You are angry as you have told your partner never to do this.
Results

PD Couple Accuracy

- Positive  2.6
- Neutral   5.4
- Negative  4.9
- Possible of 9

Matched Well Couples

- Positive  4.1
- Neutral   6.4
- Negative  7.6
Perceptions of PD’s Effect on Communication

- 67% of PD couples felt that PD had little or no effect on their non-verbal communication.
What Might This Mean to PLWP and his/her Partner?

- PLWP are limited in their ability to send and receive NV cues
- PLWP are unaware of the effect PD has on their ability to send and receive NV cues
- PD has an affect on partner’s ability to interpret
- PD reduces positive communication received by the care partner
Why This Topic?

• The potential of PD to negatively impact or isolate people from those who care for them is real

• The ability to communicate non-verbally is critical to our personhood and our relationships

• We are all a part of the answer
Interventions

- Avoid Motor Tasks + Talking
  - Speech volume tends to decrease with increased language demands
  - Increase in long pauses
  - Speech rate decreases
  - Decreased speech intelligibility for some tasks
Interventions

• Make participation active-2 way street
• Postpone the conversation
• Allow extra time
• Be patient
• Wait….for a response
Interventions

• Reduce rate of information-present in smaller chunks and slower speech
• Consider complexity of words and sentences
• Give choices
Interventions

- Relationship focused
- Genuinely care about the other person
- Desire to understand before being understood
- We all act and respond on the basis of our understanding
- Encourage the other person to express himself by showing interest in what he is saying.
Intervention

- Lack of non-verbal cues may be distracting
- Consider sitting side-by-side
- Have a pleasant view
- Hold hands
- Listen carefully to the words
LSVT LOUD

- http://www.lsvtglobal.com
- Evidence of 20 years to support efficacy
- Exercise program improving voice loudness, articulation, facial expression and swallowing
- Systematic approach re-calibrating loudness/effort
- Need a doctor’s order
Lombard Effect

- Involuntary tendency to increase voice volume when speaking in a noisy environment
- Preserved in PLWP
Device/Utilizing Lombard Effect

- Device senses when you speak
- Uses background noise that automatically forces PLWP to adjust to loud noise.
- Do not have to force loudness
- Do not have to think about speaking loud
FM Systems

Voice Amplification
- Person Speaking wears the Transmitter
- Person listening wear the Receiver
- Can have multiple Receivers
- Wireless
Stephen Hawking

• “Communication is the essence that makes us human”