



PARKINSON'S 101

Presented by the Colorado Parkinson Foundation and the
Colorado Springs Parkinson's Support Group

Introduction

- Jill Reid, MS
 - Acting Chairman, Colorado Parkinson Foundation
 - Program Director, Vice President, and Acting President, Colorado Springs Parkinson's Support Group
- Caregiving credentials



Goals



- Train you on the do's and don'ts of caregiving for people with Parkinson's disease
- Retrain you annually to update your knowledge as the disorder progresses
- Give you information that you can share with others
- Give you specific things you can do that will improve the quality of life for people with Parkinson's Disease

New Things in PD

- DAT scan: diagnoses PD; available now
- Duopa: also called Duo-dopa. New PD medication delivery system, has infection problems fixable by having gastro change out tubing every six months
- Sleep Deep Brain Stimulus surgery—more on next slide
- Light therapy: learn more at https://www.youtube.com/watch?v=rubtUI_FDt4
- Free “Aware in Care” hospital kits available from the National Parkinson Foundation
 - 1-800-4PD-INFO
 - www.parkinson.org

Deep Brain Stimulus (DBS) Surgery

- Improves quality of life, leading to better health and longer life
- Treats a variety of PD symptoms:
 - Slowness, facial expression, rigidity, tremors, fine and coarse motor skills, flexed elbows and wrists, and stooped posture
 - Freezing to some extent
- Does not treat balance and PD dementia
- Usually not recommended until 4 years after onset of first symptoms, with exceptions



Other Technologies

- Voice recognition software
- Tremor-compensating eating utensils
- iPhone—movement-compensating cameras
- Duopa medication delivery system
- Lane Assist cars
- Bicycles built for two, especially with 3 wheels
- Theracycle forced exercise:
 - Forced, Not Voluntary, Exercise Improves Motor Function in Parkinson's Disease Patients, July 2009, Cleveland Clinic

Great and Inexpensive Tools!

- Plate rings to help with eating
- Nosey Cups to reduce choking
- Squatty Potty to help with constipation

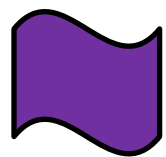
Today's Program

- Introduction to Parkinson's
 - *Dr. Melissa Nirenberg's presentation*
- Caregiving Tips
- *Helpful Hints*
 - Useful Activities
- *Q & A*
- Humor and PD (time permitting)
- **When we're done, you'll know more than....**



Introduction to Parkinson's

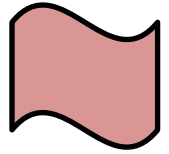
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Introduction to Parkinson's

- Neurological disorder
- Progressive, but very slowly
- Loss of neurotransmitter called dopamine
 - Dopamine allows smooth, coordinated function of muscles and movement
 - Adversely impacts movement and other roles of muscles in the body
- Effects every system in the body except the endocrine system (hormones)

Introduction to Parkinson's



- Dr. Brian Grabert (best PD neurologist in CO) likens treating PD to treating diabetes (including self-medicating)
- Pill management is **KEY** to managing PD well and maximizing a patient's quality of life and longevity
- Unique disorder
 - Effects each person differently, with different symptoms and different speed of progression
 - Each person with Parkinson's has to figure out how much meds to take and how often to take them
 - Can vary dosage as needed

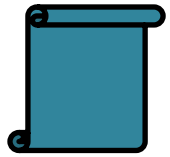


Dr. Nirenberg's Presentation



Caregiving Tips

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SOME PRELIMINARY PD FACTS

- Primary Parkinson's med = carbidopa-levodopa = carblevo = Sinemet (until a few years ago)
- People with PD (PWP) need to be treated by a neurologist, PA, or NP who specializes in Parkinson's
 - There are several in Colorado, including 4 in Colorado Springs (PA Beth Harmon, Dr. Bradley Priebe, Dr. Apura Komatineni, NP Michelle McClendon). At UC Anschutz, Dr Michael Korsmo
 - Another local neurologist with good reviews: Dr. Andrea Manhart of UCHealth
 - Neurologists, NPs, and PAs who don't specialize in PD don't have enough in-depth knowledge and experience, especially in medication management
 - In reality, the PWP is his own best "neurologist"
- Scheduled pill times VS intervals
- B6 deficiencies common but often untreated

THE FIVE STAGES OF PD AND PILL MANAGEMENT

- You may need to be able to distinguish Stage 1 from other stages
- Pill management becomes critical starting in Stage 2
- ***The later stages of PD can be avoided!!!***

Stage 1

- Most newly diagnosed PWWs are in Stage 1
- They may or may not be prescribed carblevo
- Adhering to hard and fast carblevo schedule is not as important as it is later
 - Don't experience swings between "on" and "off"
 - Best to keep as close as possible to schedule that works for them, though (ADLs easier)

Stage 1 Symptoms

- On only **one side of body**
- You'll see some or possibly all of the following
 - Greatly reduced eye blinks (8-12 per minute)
 - Tired arm or leg muscle
 - One arm that doesn't swing
 - Stiffness
 - Difficulty getting out of a chair
 - Slight stooping

Stage 1 (cont)

- Tremors
- Reduced fine motor skills (ex, handwriting)
- Slightly dragging a foot
- Orthostatic hypotension (caused by PD and/or PD medication)
- Turn and pivot well, normal stride, no or very rare falls

Stage 2

- Symptoms from Stage 1
 - On **both sides of body**
 - Worse
- Possible additional symptoms
 - Shorter gait
 - Balance problems with occasional falls
 - Choking
 - Difficulty pivoting
 - Reduced motor skills
 - Cognitive issues

Stage 2 (cont)

- Good medication management is **CRITICAL** now
 - Goal of good medication management:
 - One big “on” period that lasts all day
 - No “off” periods
 - To achieve this goal, take next dose of carblevo before last one wears off
 - Time between pills is more important than scheduled times
 - If PD symptoms appear regularly between doses, schedule needs adjusting
 - Keep log (dose times, when symptoms reappear)
 - Keep log for about a week

Stage 2 (cont)

- PWP himself can adjust schedule and inform provider later for a new prescription OR can take log to provider and have him make new schedule

Stage 3

- *Can be avoided!!!*
- Symptoms from Stage 2 worse
- Likely new ones
 - Shuffling
 - Festination
 - Slower and stiffer
 - Less stable, with more frequent falls
 - May be difficult to pivot without help or coaching
 - May need a walker

Stage 3 (cont)

— Freezing

- Feet won't start from standstill
- Feet stop in narrow areas (ex, doorways) but body keeps going forward
- Meds don't help
- Psychological phenomena, not physical
- Overcome by cognitive overrides: change the mindset!
 - Tell him to
 - » Pick up knees, not feet
 - » Step up like climbing stairs
 - » Step over a log
 - Point a light beam one stride ahead

Stage 3 (cont)

- Overcome by cognitive overrides/changing mindset (cont)
 - Marching music
 - Strips of colored tape
 - » In narrow areas
 - » Perpendicular to direction of movement
 - » Something to aim for!
 - Have him step over a cane handle **J**
 - Special exercises (more on that later)
- Freezing can also result from fear
 - Going up stairs is easy
 - Going down stairs is very hard
- Never pull or push a PWP who is freezing—support and coach to change his mindset to get him moving!
- Try to keep the walker close to the body

Stage 4

- *Can be avoided!!!*
- Stage 3 symptoms worse
 - Can't walk without a walker
 - Pivoting extremely difficult if not impossible
 - Freezing a lot
 - Probably can't get out of chairs without help
 - Lots of falls
 - Lots of choking

Stage 5

- *Can be avoided!!!*
- Wheel-chair bound
- Bed-ridden
- Feeding tube for food, fluids, and meds

Pill Management and PD Progression

- Good medication management gets more critical as Parkinson's Disease progresses because the brain produces less and less dopamine
- Most critical in Stage 5, even though use of limbs is practically non-existent
 - **Other muscles are critical to survival**
 - Diaphragm and chest wall for breathing and coughing
 - Throat muscles for swallowing saliva safely
 - Intestines
 - Bladder

Pill Management and PD Progression (cont)

- Most PWPs die from aspiration pneumonia and bowel blockages resulting from poor pill management
- If you think current dose and schedule aren't working or could work better
 - Adjust yourselves OR
 - Log pill times and “on”/”off” periods for provider
- Pill schedule dependent on observation by others for a PWP in Stage 5!

Parkinson's and Self-Medicating

- Some days, normal carblevo dose isn't sufficient
 - Change in metabolism?
 - Bad night's sleep?
 - No one knows why
- It's OK for PWDs to take extra carblevo when needed (say, ½ or 1 pill)
- Like diabetics with insulin, they can take what they need when they need it
- If your provider says otherwise, run away!!

★ *Protein VS Carblevo* ★

- Compete for absorption and uptake into brain
- Protein wins out every time and reduces carblevo efficacy by some 30%
- Solution?
 - Avoid eating protein within one hour of carblevo
 - OR if can't avoid protein within one hour, take extra carblevo—1/2 pill should do
 - OR avoid all proteins until dinner time
 - The need to be “on” and mobile is less critical at night
 - Generally don't need carblevo during sleep
- Beware! Protein is in a lot of foods and drinks

✚ *Protein VS Carblevo (cont)* ✚

- Protein can be a useful tool for those times when a PWP has too much levodopa in his system
 - Causes excessive, unwanted movements or talking—known as dyskinesia
 - Few bites of cheese or some meat, milk, or ice cream will “kill off” excess levodopa and get dyskinesia under control
- ASIDE: If he has dyskinesia regularly
 - Probably needs to cut back on carblevo or extend time between pills
 - But some people need to be dyskinetic in order to be “on”

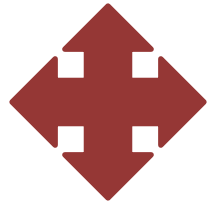
Carblevo and Nausea

- Fairly common
- Carbidopa portion is an anti-nausea drug
- Amount of carbidopa in carblevo is not enough for some people
- Carbidopa can be prescribed separately
- If separate carbidopa not available, eating saltines or other non-protein foods before taking carblevo helps

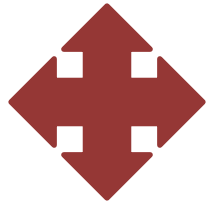


Parkinson's and Constipation

- Universal in Parkinson's, per Dr. Nirenberg
- Not trivial—second leading cause of death is bowel blockage
- Tips
 - Suggest your PWP eat high-fiber food
 - Good hydration essential
 - Miralax works well, with no addictive side effects
 - At least 30 minutes moderate intensity aerobic exercise 5 days a week, especially after meals
 - Metamucil wafers work very well for some people
 - Colonic massage 10 minutes after meals or first thing and last thing at night—see Danielle Mulligan's February 2021 lecture on CPF website
 - Squatty Potty—effects on blood pressure



Parkinson's and Constipation



- Helpful recipe for constipation
 - 1 cup applesauce
 - 1 cup oat bran or unprocessed wheat bran
 - 1 cup prune juice
- Mix ingredients. Start with 1 to 2 tablespoons each evening, followed by 6-8 ounces water or juice
- If no change occurs within 2 weeks, slowly increase to 3-4 tablespoons

Parkinson's and Choking

- Effects all PWPs sooner or later
- Throat muscles react too slowly to direct food or liquid into esophagus; ends up going down the windpipe and into the lungs
- Can lead to aspiration pneumonia, the leading cause of death
- Swallowing and voice therapies such as LSVT Loud and PT/OT are of tremendous help

Parkinson's and Choking (cont)

- Solutions
 - Have PWP swallow hard and forcefully
 - If PWP can't swallow forcefully, tuck chin when swallowing
 - Add thickening to fluids, especially water (but just enough!)
 - Suck on ice cubes to get water down safely
 - If choking on pills, take pills with sparkling water
 - If taking pills with sparkling water doesn't work, grind up pills and put in apple sauce, apple butter, honey, or jam
 - Note: Don't grind up ER or CR carblevo

Parkinson's and Cramping

- Hands and feet
- Feet turning inwards
- Dystonia
- Treatments
 - Botox injections
 - Prescription cream compounded by Professional Pharmacy LLC in Colorado Springs (BAC/DIC/GAB/LIDO/PRILO)

Effects of PD on Vision

- Imbalance amongst 6 eye muscles
- Abnormal contrast sensitivity and dull color vision (don't drive after dusk or before dawn!)
- Convergence insufficiency
- Dry eyes
- Blurred vision
- Reduced eye movement
- Double vision—very common
- Fatigue and difficulty reading
- Hallucinations and visual disturbances
- Higher incidence of cataracts and glaucoma

Help for Vision Problems

- Neuro-ophthalmologists and optometrists such as the ones at UC Health Eye Center Anschutz in Aurora and Dr. Heather Van Law in Colorado Springs
- Dr. Stander, neurologist in Colorado Springs, treats visual changes in PD as well
- Proper diagnosis of precise vision problems can lead to the restoration of normal vision
- <https://www.apdaparkinson.org/what-is-Parkinson's/symptoms/eye-vision-issues>

A decorative graphic on the left side of the slide, consisting of white lines and circles on a blue gradient background, resembling a circuit board or a stylized tree structure.

HELPFUL HINTS

Walkers

- U-Step II



- Upright walkers




Helpful Hints:

Hospitals

- Hospitals are hazardous places for PWPs (see our website for safe hospitals in the area)
- PWPs ***MUST*** have strong advocates
- Best to give Medical Durable Power of Attorney to someone you trust so they can protect you
- 2nd hospital visit for unresolved issues
 - If you're released from the hospital but come back for a 2nd visit for same (unresolved) issue, the hospital will get penalized
 - To avoid penalties, staff will try to get you to sign a form consenting to observation only—DON'T SIGN IT or you'll get billed for the 2nd visit
 - They may even leave you in waiting room, even if you're in severe pain, to avoid the penalties of a 2nd visit

Helpful Hints:

Attitude and Activities

- Role of humor and attitude 
- Patients in all stages benefit from activities
 - Exercise
 - Socialization
 - Participation in life-long interests

Helpful Hints:



Parkinson's and Exercise



- Exercise that involves movement is VITAL
- Only thing proven to slow progression of disease
- Can reverse symptoms (ex, Barbara Willis)
- Increases longevity in Parkinson's
- Improves cognitive scores in PWP's
- Increases brain volume
- 150 minutes per week of increased heart rate

Helpful Hints:

Parkinson's and Exercise

- If you exercise with moderate intensity 3-5 days a week, you can avoid Stages 3 through 5
- Why do you need to overcome apathy to exercise like this?
 - For your sake, well-being, and quality of life
 - If not for you, then for your family caregivers
 - If caregiving for you leads to burn-out of your family caregivers, who will be around to help you when you need it?

Helpful Hints:

Movement Exercise

- Walking at 2 ½ miles per hour
- Hiking
- Stationary biking
- Water aerobics
- Neuro pong (ping pong on steroids)
- Moving to music (call it dance?)
- Rowing machines
- Movement exercises in a chair for safety
- Boxing
- PWR! Moves

Helpful Hints:

Other Exercises

- Resistance exercises to improve fine motor skills
- Wii Sports—exercise that's fun!
 - Bowling
 - Baseball
 - Balance exercises/games
 - Slalom skiing
 - Tilt board
 - Any balance board games
- Stretching
- Tai chi

Helpful Hints:

Exercise that Reduces Freezing

- Bicycling
 - Stationary bike
 - Floor-mounted pedals
- Daily, if possible
- Cycling motion KEY; resistance not needed

Helpful Hints:

Exercise that Reduces Freezing

- Stand on right leg
- Lift left foot and raise right arm
- Lower both
- Do 5-10 times
- Repeat with other leg
- Alternate legs 5-10 times



Helpful Hints:

Another Exercise that Reduces Freezing

- Stand on left leg
- Put right leg back
- Swing right leg forward
- Touch ground
- Swing right leg back
- Repeat with other leg
- Alternate legs 5-10 times



Helpful Hints:

Touch Therapy

- Anecdotal evidence about touch therapy (for example, deep tissue massage)
 - Doesn't raise dopamine levels but can relieve some of PD symptoms
 - Improves blood circulation, flexibility, and range of motion
 - Reduces tremors and eases cramping of fingers and toes
 - Helps PWWs to walk better, farther, and more often

Helpful Hints:

Additional Therapies to Consider

- Treating PD takes a team, so consider adding alternate therapies to your arsenal in addition to medication, PT, OT, LSVT Big and Loud, and exercise
- John Hopkins University researchers asked 201 PWPs about their use of complementary therapies
 - Massage, vitamins, acupuncture, chiropractic, Alexander technique
 - 26% used 2, 33% used more than 2, and 12% used 5 or more

Helpful Hints:

Socialization

- Encourage PWPs to socialize
 - PWPs tend to isolate themselves
 - Uncomfortable in public and embarrassed by disabilities
 - Can avoid this discomfort by being properly-medicated and well-exercised
 - Studies show that shrinking social network has same negative impact on longevity as taking up smoking

Helpful Hints:

Socialization (cont)

- Involve patients with Parkinson's in as many activities as possible; for example,
 - Cooking meals (use Blue Apron or Hello Fresh)
 - Playing card games (brain and dexterity)
 - Family outings
- Parties and other get-togethers
 - Minimize thin liquids and difficult foods
 - Offer finger foods
- Sing-alongs with friends
- Senior Center activities
- Afternoons usually best

Helpful Hints:

Safety and Low Blood Pressure

- In-home safety is key
 - Try to remove trip hazards like throw rugs
 - Widen narrow openings between pieces of furniture, if possible
- Low blood pressure and/or orthostatic hypotension (can be deadly if untreated)
 - Salt pills, if medically OK
 - Eat something salty, like potato chips
 - Blood pressure-boosting medication (midodrine, floriene)
 - Fluids
- Insist that providers test for orthostatic hypotension at every appointment

Helpful Hints:

Find Creative Solutions

- Observe what things cause problems and find creative solutions:
 - Stuff money into pockets rather than wallet after purchases
 - Serve mashed potatoes with peas or corn
 - Drink soup through a straw
- Effective solutions to problems take stress out of the situations, decrease embarrassment, and keep PD medications working

Helpful Hints:

Don't Coddle

- Don't coddle PWP
 - Let him do for himself
 - Many have apathy and will let you do everything if you offer to step in—you will accelerate his inability to do for himself
 - It's tempting to step in because it's faster—RESIST RESIST RESIST!
 - Have him start getting ready for appointments and outings two or three hours early

Helpful Hints:

Rushing

- Help your PWP avoid rushing at all costs!
 - Rushing makes him stressed
 - Medications “stop” working, symptoms get worse, and frustration mounts
 - Rushing actually slows him down!

Helpful Hints:

Apathy and Timing

- Apathy
 - No medical treatment available
 - Inspiration/persuasion
 - Brow beating
- Medication timing
 - Exercising and participating when meds are working
 - Varies from person to person and day to day

Helpful Hints:

Getting out of Chairs

- Why?
- Solution
 - Scoot to edge of chair
 - Put both feet as far underneath as chair allows
 - Lean forward to “heart-over-toes” position
 - Place both hands on chair seat
 - Push with hands and stand up

Helpful Hints:

Go to Support Group Meetings

- Encourage your PWP to attend our support group meetings
 - Will be with other PWPs who understand
 - Can learn from them how to solve PD problems
 - Can be inspired and encouraged to see others who are living well with PD, even decades after diagnosis.
- Encourage family members and caregivers to come—the more they know, the better for everyone!

Colorado Springs Parkinson's Support Group

- All-volunteer organization striving to help improve quality of life of our members through
 - Socializing
 - Sharing knowledge and information
 - Giving each other emotional support
 - Training professional caregivers
- Provides reimbursement for transportation if needed

Colorado Springs Parkinson's Support Group (cont)

- Central United Methodist Church Fellowship Hall
- First Saturday of each month
- 10 am to around noon
- Meetings include guest speakers and great potluck lunches
- August picnic and December party in lieu of regular meeting
- Extremely informative free monthly newsletter

Good Websites and YouTube Videos

- Websites that contain reliable information on PD research
 - davisphinneyfoundation.org
 - michaeljfox.org
 - pubmed
- Good overview of PD with Michael J. Fox (except there is no mention of DAT diagnostic tool)
 - “Parkinson’s Disease: A Guide for Patients and Families”
 - Available on YouTube at www.youtube.com/watch?v=fGlmOa5jko&feature=youtu.be
- All have links on our website, www.co-parkinson.org

Good Websites and YouTube Videos

- Complete version of Dr. Nirenberg's talk was at <https://www.youtube.com/watch?v=qzO2yTIpNwM>



One Last Thought

**Positive Attitudes and Humor Help
Everyone!**

Questions

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