



## Appendix







## We Are Family!

### Appendix Topics

- Common Myths and Misconceptions of Parkinson's Disease
- Drugs Treating Parkinson's Disease
- > Tips for when the unexpected happens
- > Tips for Virtual Training
- > Hope to Share with Your Clients and Class Participants
- Parkinson's Resources
- > References
- Colleen Bridges contact information

### Common Myths and Misconceptions of Parkinson's Disease

#### MYTH - Only elderly people get Parkinson's Disease.

Average age of diagnosis is 60 years of age. Approximately 15% of newly diagnosed patients are under the age of 50 and 10% are age of 40 or less.

#### > MYTH - Parkinson's Disease is only a movement-related condition.

While people with Parkinson's Disease suffer from tremors, rigidity, poor balance, bradykinesia and other motor symptoms, it is **only** partly a movement disorder. Parkinson's Disease has many non-movement symptoms such as depression, sleep disorder (REM), daytime fatigue, dysphagia, changes in speech, urinary incontinence, constipation, increased sweating, increased salivation, difficulty focusing, difficulty with visual-spatial relationship, hallucinations, delusions

### Common Myths and Misconceptions of Parkinson's Disease (cont'd)

#### MYTH - All people with Parkinson's have a tremor.

- Most have a tremor, but roughly 25% do not and will not develop one through life cycle of the of the disease.
- MYTH Parkinson's Disease only affects one part of the brain, the substantia nigra

#### pars compacta.

People with Parkinson's Disease do have damage to the neurons in the substantia nigra pars compacta, BUT also other areas of the brain impair cognitive, motor, and autonomic and sensory problems

### Common Myths and Misconceptions of Parkinson's Disease (cont'd)

### MYTH - Levadopa is the most common form of treatment for Parkinson's Disease, but stops working after five years.

Levadopa can help manage the symptoms of Parkinson's Disease for decades.

#### MYTH - <u>Parkinson's Disease is fatal.</u>

Most Parkinson's folks die *WITH* Parkinson's not *FROM* it. The most common cause of death is pneumonia and aspiration / pneumonia.

# Levodopa (Sinemet)

- Levodopa is an amino acid
- Transported to brain and converted to dopamine
- Maximum benefit experienced 60-90 minutes after dose
- Over time, benefits may reduce resulting in "on" and "off" times
- Common side-effects:
  - Low Blood Pressure
  - Nausea
  - Dizziness
  - Dry Mouth
  - Hallucinations
  - Dystonia
  - Dyskinesia
- Extend life span

# Dopamine Agonists

Examples are:

- Pramipexole (Mirapex)
- Ropinirole (Requip)
- Rotigotine (Neupro)

- Stimulate parts of the brain that are influenced by dopamine
- "Trick" the brain into thinking it is receiving dopamine
- Not as effective as Levodopa but smooths out "on" "off" effects
- Once desired benefit occurs, Carbidopa/Levadopa intervals increase to make effects last longer
- Common side-effects:
  - Hallucinations
  - Delusions
  - Sleepiness
  - Orthostatic hypotension
  - Compulsions including hypersexuality, gambling, over-eating

# Apomorphine "Rescue Therapy"

- "Rescue Therapy" means the use of a medication for a quick anti-parkinsonism response
- Apomorphine binds to dopamine receptors to produce desired response
- Typically injected under skin
- Common side-effects:
  - Nausea
  - Dyskinesia
  - Hallucinations
- Avoid taking if pre-existing hypotension or sulfite sensitivity exists
- Anti-nausea medication should be taken with Apomorphine

# COMT Inhibitors (Entacapone)

- Stops an enzyme that degrades the effectiveness of Levodopa
- Does not enter the brain, rather it protects levodopa from being broken down in circulation
- Taken alone, it has no effect on Parkinson's Disease
- Common side-effects:
  - Dyskinesia
  - Nausea
  - Loose stool
  - Orange urine
- Can be started and stopped abruptly

### Monamine Oxidase B-(MAO-B) Inhibitors

### Examples are:

- Selegiline (Eldeprye & Zelapan)
- Rasagiline (Azilect)

- MAO-B is an enzyme that degrades dopamine
- Doctors should be aware of mental illness before prescribing
- Common side-effects of Rasagiline:
  - Hallucinations
  - Delusions
  - Nausea
  - Insomnia
  - Dizziness
  - Orthostatic hypotension
- Selegiline is metabolized to an amphetamine and should be used with caution with people with anxiety, insomnia, cognitive decline or hallucinations.

## Amantadine

- Reduces Levodopa induced dyskinesia
- Dose- 1 pill/100mg
  - ➤ Take with or without food
  - ➤ Early in the day
  - ➤ No more than 5 pills daily
- Common side effects of Amantadine
  - ➤ Low doses rarely see side-effects
  - Fishnet pattern on legs and arms
  - ➤ Hallucinations
  - ≻ Paranoia
  - Confusion (this is a signal to taper off drug)
  - ➤ Dry mouth
  - ➤ Constipation
  - ➤ Tissue swelling

### Tips for when the Unexpected Happens

### (Continued)

#### ➤ Falls-

- Assess the individual's situation and determine origin of fall (dizziness, tripped over something, low sugar)
- Assess musculoskeletal injuries, if any
  - (Cover any sharp edges / corners)
  - \* Know how to correctly pick up someone off the floor
  - \* Know when it is best to have individual remain on the floor and call 9-1-1
  - \* Have assistant coaches continue with class while head coach works with fallen individual.

# OVERALL RULE - CALL 9-1-1 IF THERE IS ANY QUESTIONS OF CLIENT'S / PARTICIPANT'S WELLBEING

# Tips for when the Unexpected Happens (Continued)

#### > When a client or class participant attends class but is dealing with a musculoskeletal issue

- Ask them to describe the pain and location
- Review past day's events to determine the root of the problem
- Modify exercises for them
- Focus on specific PT for them
- Refer to physician or physical therapist.

#### Incontinence accidents

- **Discreetly** assist client/class participant to rest room
- Seek care partner if necessary
- Store extra clothes, adult depends, towels and hand cloths.

# Tips for when the Unexpected Happens (Continued)

#### Client/class participant brings guest to your workout

- Under 18 not admitted
- Only allow guest if room can accommodate the additional number based coach/student ratio
- Have guest sign liability waiver and review health history before admitting.

#### > Low blood sugar

• Keep nutritional snacks on hand to alleviate any blood sugar issues.

## Tips for when the Unexpected Happens - Behavior

#### Fitness Professionals are expected to dress appropriately, particularly the female

coaches as some medications cause lack of inhibitions, sex being one.

- Be aware of body position during certain exercises and stretches
- No frontal hugs
- Be friendly but no outside contact except for emergencies or group social events
- Report any inappropriate behavior on the part of a participant to the head coach so he/she can document any incidents

### Tips for Virtual Training

- ➤ Be prepared demonstrate all modifications where applicable
- Remind folks they are exercising at their own risk
- Provide liability waiver that includes online options
- > Have at least one assistant coach to maintain close eye on class
- > Review each individual exercise space to suggest any safety precaution
- > Cue lengthy exercise is small chunks and review slowly then put it all together
- > When composing routine, safety should be top priority

### Tips for Virtual Training (continued)

- > Lighting should be in front of Fitness Professional rather than behind for clearest visibility
- > Keep music low as it can come across as distracting to participants
- Promote conversation among participants to promote a strong community
- Ensure the participates can see most of your body (sometimes it a bit of a challenge to include feet)
- Mirror the class direction (when you tell them to throw a right, you throw a left, but they will see it as a right)
- Don't be afraid to challenge folks (some of my hardest classes have been during Covid-19 lockdown

### Hope to Share with Your Clients and Classes

" First of all, exercise has given me the desire and urge to exercise regularly. It has also introduced me to friends who share the same problem as myself. We are encouraged by one another and we are all fighters and we don't plan to allow this thing to beat us! Thank you to all the coaches who teach and work with us !"

#### Jervis- "fighter"

" As a care-partner, our exercise group, has become a "family" who will listen and share the ups and downs of the trip we are on. My feelings of being alone, helpless and hopeless are gone and i have the joy of connecting with fighters, their care-partners and the incredible coaches who remind us that "fighting back has NOT been cancelled!"

### Hope to share with your clients and



"Your program has saved my life and helped slow my PD progression. I am devoted to your classes! Thank you !"

#### Michael-"fighter"

"The benefits I derive from Rock Steady include great workouts that push me bePyond the effort I would give on my own, the fellowship of really good team mates who share the firsthand knowledge of the craziness of PD, inspiring leadership of dedicated coaches and volunteers, the discipline of regular classes, the laughter of people brave enough to laugh in the face of adversity, and genuine progress in overcoming that adversity. Plus, it is fun!"

### Hope to Share with Your Clients and Classes

"Tuesdays and Thursdays were always days that Clifford (aka-Stinger) looked forward to. They were days not only for him to get exercise that would help him but it was a time to be with the other guys. The fighters were like kids playing in a playground just having fun as best as they could. Clifford always greeted the other fighters with "Hi Guys". "

"The fighters were all his friends and they all cheered each other on. All the coaches and volunteers were very caring and supportive. The classes always made him feel better. The "guys" will always be family and I hope they continue to fight hard against PD."

**Eunice-** Carepartner

### Parkinson's Resources

Parkinson's Foundation helps patients actively enjoy life through expert care and treatment research.

<u>American Parkinson's Disease Association</u> provides support, education, and research to help you live a fuller life.

Michael J. Fox Foundation is helping to raise money for much-needed research to help find a cure. From ways you can get involved to a great blog chock-full of Parkinson's-related information, there is so much information here.

<u>Parkinson's Disease Foundation</u> provides information including news about the disease, information about upcoming events, insight into the latest research, and education about what to expect.

European Parkinson's Disease Association advocates for the rights and needs of patients and their families.

### Parkinson's Resources

<u>The Davis Phinney Foundation</u> is committed to supporting programs as well as research that help to deliver inspiration, information and provide tools that will enable people living with Parkinson's to have more control in managing their disease.

The Parkinson Alliance is the umbrella organization for the Parkinson's Unity Walk that takes place every spring in New York City. They also sponsor Team Parkinson, a fundraising racing event. You can find current news and information on research projects on their site.

Partners in Parkinson's has a program where you can be connected to an advocate who will listen, offer advice and support to patients and caregivers at no cost. This is just one of the services you can find through Partners in Parkinson's.

### Parkinson's Resources

<u>Caring.com</u> has a support group for caregivers, family and friends of those with Parkinson's disease. No subject is off-limits in this forum.

<u>The National Parkinson Foundation</u> has a site specifically geared to caregivers. They help carers navigate the emotional, financial, and physical challenges they may face caring for someone with Parkinson's.

COLLEEN BRIDGES - EFFECTIVE PROGRAM DESIGN PART 2							
MOVEMENT PATTERN	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	STRENGTH	BOXING
CARRY Gait, Cardio, ROM, Spatial Awareness, Vertical Core, Posture		March / Swing Arms	March / Rainbow Arms	March / Birddog Hold	Stand on One Leg / I's, T's, Y's	Levels 1 - 3 Farmer's Walk with Both Hands Farmer's Walk Single Arm Sit/Stand / Curl and Walk	Right Foot Step / Right Arm Punch (forward lunge)
HINGE Glutes, Back, Hamstrings	Supported Deadlift	Deadlift / Stand / Reach Arms Overhead		Single - Leg Deadlift	Cross - Over Deadlift	Seated Clamshells Seated Back Extension with Tubes Supported Deadlift Deadlift with Light Weights Deadlift with Curl / Press Grounded Deadlift with Weights Single Leg Deadlift Cross-Over Deadlift/Curl	Double High / High / Low Low Punch
PUSH (WITH LATERAL LUNGE) Gait, Shifting Weight, Deceleration, Rotation, Coordination	Wall Plank Isometric / Partner Push (seated/standing)	Push / Pivot with Twist	1/2 Warrior / Push with Both Arms	Cross-Body Single Arm Push / Half Warrior Step		Chest Press with Tubes Supine Chest Press with Bridge	Mitt Push from Side (side to bag) Step Foot onto Pad then Torso Punch and Step Back Down
PULL / SQUAT Posture, Legs, Coordination, Balance	Seated Knee Extension Shoulder Blade Pinch *do separately	>	Squat / Blade Pinch	Squat / Row	Squat / Row / Single Leg- ABduction	Squat / Row with tube (both arms) Squat / Row with Tube (single arm) Add Bosu / Pad / Half Foam Roller Lunge / Row and etc.	Step Right / Left then 3 Punch Combo
LUNGE (WITH POSTURE DRILL) Legis, Ankles, Deceleration, Posture, Coordination, Focus, Vertical Core	Seated Heel Raises /"T* Arms	Tap One Foot Back /"T* Arms	Reverse Lunge/ "T" Arms	Reverse Lunge /"T"/ Forward Lunge with SOFT Step		Tap One Foot Behind/ "T" Arms with Tubes Reverse Lunge / "T" Arms with Tubes Reverse Lunge/ "T" Single Arms	Reverse Lunge to Front Leg Kick Option- add boxing combo
ROTATION Legs, ROM Spatial Awareness, Vertical Core, Coordination, Cognitive	No Squat Circles	Squat / Circles	Haytoss	Haytoss but Alternate Sides		Haytoss with Ball Haytoss with Ball and Bosu / Pad Haytoss with Ball and use Single Leg	Torso Punch with High Jab & High Cross
BALANCE	Seated	Standing on Unstable Surface	Standing	Standing with One Foot on Unstable Surface	Standing with Both Feet on Unstable Surface	Walk a Tandem Line	Walk a Tandem Line with Eyes Looking to the Right / Left
Website	: power4parkinso	ons.com		Contact Ema	il: musiccity@rs	baffiliate.com	

### Hoehn and Yahr Scale

#### Modified Hoehn and Yahr scale

- 1.0: Unilateral involvement only
- 1.5: Unilateral and axial involvement
- 2.0: Bilateral involvement without impairment of balance
- 2.5: Mild bilateral disease with recovery on pull test
- 3.0: Mild to moderate bilateral disease; some postural instability; physically independent
- 4.0: Severe disability; still able to walk or stand unassisted
- 5.0: Wheelchair bound or bedridden unless aided

# Thank you !

Dear Fitness Specialist,

When <u>www.Medfited.org</u> asked me to create the Parkinson's Disease Fitness Specialist Certification, I was beyond ecstatic and immediately said "YES!!".

Over the following months I soon realized that in order to create the best possible program for you, I would need a team. And what better place to look for a team than my very own coaching staff! Wow! I am so incredibly blessed to work with some amazing and talented coaches. They not only love working with people living with Parkinson's Disease but they also love educating coaches so YOU can bring the highest quality of training to your clientele.

Together, we have spent hundreds of hours fact checking, planning, interviewing, creating powerpoints, videoing the modules, editing THEN...starting all over again because we weren't satisfied with the product.

My team (Betsy, Michelle, Abbey and Doris) is definitely a very special team and has pushed me to "better my best." I love them dearly and can't say thank you enough! But I will say...Team, rest up because we are not finished yet!"

To my "fighters", thank you so much for participating in this project and for being patient with me! You are making a huge impact in the Parkinson's community and I am so proud of you! WE ARE FAMILY!!

To Dr. Irv Rubenstein, thank you for believing in me. I hope you don't mind if I keep asking you questions! I love your brain!

# Thank you!

Dr. Bob Daggett, you are a genius! Wow! I could listen to you teach all day! Thank you for challenging me to think outside the box but know when to put the "lid" back on the box! ha!

To Medfit, thank you so much for this fantastic opportunity! I am excited to see a new generation of Fitness Specialists enter the "ring" to fight back against PD. I believe in the vision and mission of Medfit and I am proud to work alongside you! Keep up the great work!

Finally, my precious husband, Shane and my two boys Jackson and Jacob. You deserve a gold medal! Thank you for understanding my dream and supporting me through this journey. I am so blessed and I love you to the moon and back!

To close, I hope you, the Fitness Specialist, will have the opportunity to experience the same joy I do every day working with people living with Parkinson's Disease. This is truly a life-changing "job" and one I wouldn't trade for the world. Please feel free to reach out to me! Just because we have come to the end of the course doesn't mean I can't visit, encourage and support you. And just remember....

"Your client may have Parkinson's Disease BUT Parkinson's Disease doesn't have them"

Sincerely,

Coach Colleen

## Credits

Project Team- Abbey Boutwell- (videographer) <u>www.createwellllc.com</u> Michelle Bouve- (Coach) powerpoint, editing, fact checking Betsy Lerner- (Coach) powerpoint, editing, fact checking Doris Smith- (Coach) powerpoint, editing, marketing Seb Zwedie- (Coach) boxing video

Peter Frampton-voice over for Dr. James Parkinson (THANK YOU! You are the best!)

Charles Mickles-Young Onset PD Interview. Book "Mines Parkinson's, What's Yours?" available on Amazon website: <u>www.minesparkinson.com</u>

Christine Conti- "Let's FACE it together" <u>www.contifit.com</u>

Christy D- Speech Pathologist (Dysphagia video) Thank you!!

Renee Rouleau- Research Coordinator for Vanderbilt University. Thank you!

Tate Bradley and Steve Cronin-Fighters (DBS and Duopa Pump interviews) Thank you!

## Colleen Bridges

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Instagram: @Rock Steady Boxing Music City

Website: <u>www.Power4Parkinsons.com</u>



Thank you so much for joining me in the fight against Parkinson's Disease!