





ROADMAP TO THE FUTURE

WEDNESDAY, OCTOBER 21, 2020



PARKINSON'S DISEASE

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WELCOME AND INTRODUCTIONS



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Vice President, Chief Scientific Officer

American Parkinson Disease Association



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FINANCIAL DISCLOSURES

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Honoraria: Jazz, Acorda, Midwestern University

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SOME ALARMING STATISTICS

- PD on increase
- PD results in loss employment
 - Retire 4-7 years earlier
- Less than ½ of PD patients treated by neurologist
- · PD mortality higher than once thought
 - About the same as having a heart attack
- Skilled nursing used by 44%



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PALLIATIVE CARE PRINCIPLES

- Focus on the person rather than disease
- Relief of suffering
- Quality of life not quantity
- Often involves care partner or caregiver
- Intensive management of complex symptoms
- Often uses a team approach

"Palliative care is about living as well as you can for as long as you can"

Dr. Steve Pantilat, Director of UCSF Palliative Care Program







TIME FOR PALLIATIVE CARE

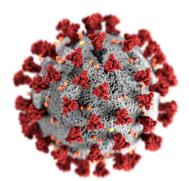
- · Time of diagnosis
- Change in level of function
 - · After fall, illness or with cognitive decline
- Assistance with ADLs
- Psychological issues
 - Depression, anxiety
- Care partner distress
- Hospice



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PARKINSON AND COVID

- PD and risk of infection
- PD and risk of adverse outcome
- Social impact on PD









TIME OF DIAGNOSIS

- Research
- Education
- · Consideration of work and hobbies
- · When to start PD medication



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RESEARCH

Parkinson's Disease Pipeline 2020 (McFarthing, 2020)

- 145 active phase 1-3 clinical trials
 - 37 (26%) Phase 1
 - 14 (10%) Phase 1/Phase 2
 - 61 (42%) Phase 2
 - 28 (19%) Phase 3
- 57/145 (39%) were disease modifying trials
- 88/145 (61%) were symptomatic treatment trials







RESEARCH

Disease Modifying Trials

- · Kinase Inhibitors
 - Inhibitors of LRRK2, c-Abl, Src/Bcr-Abl
 - ASO LRRK2
- Immunotherapy- MAB against alpha-syn
- Gene Therapy- dopamine and growth factors
- GLP-1 agonists (several used in DM)
- Glucocerebrosidase targeting
- Weird things fungal extracts, botanicals, microbiome

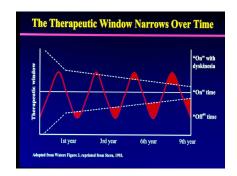


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EDUCATION

MOTOR Symptoms

- Tremor
- Rigidity
- Bradykinesia
 - Slow movement



Most remain stable for about 5 years and then progress







EDUCATION

NON-MOTOR Symptoms

- Mood
- Sleep
- Bowels
- Bladder
- Blood pressure
- Sense smell
- Cognition
- Hallucinations
- Compulsive behaviors
- Skin
- Fatigue





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ADDRESSING WORK AND HOBBIES

- · PD may cause symptoms that are visible
- PD may cause changes in voice
- PD may cause difficulty getting thoughts out
- PD may cause fatigue
- PD may cause balance problems
- PD may cause trouble with hand coordination

All these things may affect work and hobbies.

Advice: Do what you can now but have a plan B and C



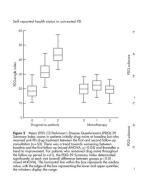




WHEN TO START OR ADJUST PD MEDICATION

Main goal is to reduce the symptoms (not signs) of PD with the least amount of side effects

- · Reduce disability
 - · Occupation, gait, chores, ADLs
- Socially disabling symptoms
 - Tremor
- · Reduce complications of PD
- Almost all medications approved to treat PD work on motor symptoms of PD



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TREATMENT PRINCIPLES

Early treatment

- MAO inhibition (rasagiline/selegiline)
- Agonist vs. levodopa
 - Agonist for young PD
 - Levodopa for older PD
 - · Most end up on both
 - No difference after about 7-10 years follow-up

Advanced disease

- Add-on therapy
 - · Motor fluctuations and dyskinesia
- · Lots of research





NEW PD MEDICATIONS

- Safinamide (Xadago): a new MAOI FDA approved March 2017
- Opicapone: COMT inhibitor FDA approved July 2019
- Inbrija inhaler FDA Approved December 2018
- Apomorphine FDA approved in 2004, 2020
- Istradefylline (Nourianz) FDA Approved August 2019

Medication for Off time and levodopa-induced dyskinesia:

- Gocovri (Amantadine ER) FDA Approved August 2017
- Osmolex FDA approved 2018

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EXERCISE

- Resistance training in PD
 - · Improves muscle strength
 - Reduces instability
 - · Decreases falls
 - Improves QOL
- Aerobic exercise in PD
 - Treadmill, cycling, walking
- Stretching in PD
- Combination of resistance training and aerobic is likely best
- Helps fatigue!!









ADDRESS MOOD

- Depression and anxiety in 40-50%
- Peaks in early PD and more advanced
- Independent predictor of quality of life
- Treatable!
- Lots of options
 - SSRI, SNRI, TCA





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ADDRESS SLEEP

Most people with PD don't sleep well

- Many causes
 - Motor, bladder, pain, mood, OSAS, RLS, RBD, primary
- Good sleep hygiene first line defense







GOOD SLEEP HYGIENE

- · Get rid of false beliefs
- Avoid caffeine and nicotine close to bed
- · Don't use alcohol as sleep aid
- · Avoid evening fluids
- Avoid evening diuretics
- No long naps
- Exercise early in the day

- · Sleep and wake at the same time
- Keep room cool and dark
- White noise
- Avoid the late evening news/scary movies
- Once up, let light in
- No OTC meds unless you talk with your doctor



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DON'T FALL

Really, I mean it: DON'T FALL!

- 55% of PD patients fell in the last year across all stages
- 33% of falls result in fracture (Parashos, 2002)
- · Leading cause of nursing home placement
- Most are preventable:
 - Exercise, PT, OT, assess cognition, assistive devices, addressing bone health, addressing BP







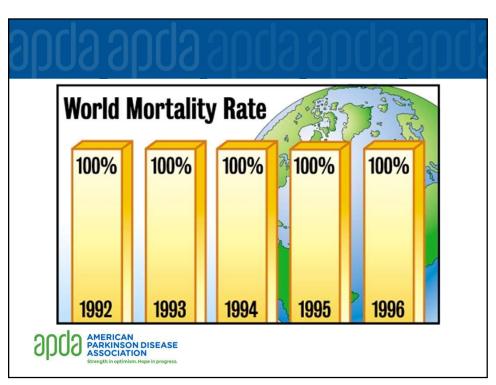
WHEN TO CONSIDER ADDITIONAL CAREGIVING

- Frequent falls
- Significant hands on care
- Needing help at night
- Cognitive issues
- Needing assistance with medications
- Can't leave patient alone

Options: In-home care, assisted living, group homes, traditional nursing homes, state programs, VA



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ADVANCED DIRECTIVES

- Only 9% of PD patient die in home (vs 17% elderly)
- 55% die in hospital
- Less than 1% receive hospice services

Why does this have to be?

- Talk with your families:
 - Not only about CPR and life support but also....
 - · Where do you want your care?
 - · Who do you want doing your care?
 - Hospitalization and end of life care



(Snell, 2009)

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SPIRITUALITY

"Are you at peace?" If not, why not?

- Spirituality is not just religion:
 - · Purpose and meaning in life
 - Connection to self and others
 - · Connection to nature
 - · Connection to higher purpose
- 85% PD patient embarrassed, 26% have shame



(Fleury, 2020)





ADDRESSING SPIRITUALITY

- · Be kind to yourself
- If you are a care partner, find joy in it
- If a patient who needs care, allow yourself to be cared for
- Meditate
- Breathe
- Practice mindfulness
- Acknowledge strong emotions
- Get support





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