

Parkinson's Disease Information Session

How to Live with Parkinson's Disease



Twin Tiers Parkinson Disease Support Group
Southern Tier Parkinson Disease Support Group
Di's Personal Fitness, featuring Rock Steady Boxing



Sunday October 27, 2019 2-4pm
Elmira Riverview Holiday Inn. Elmira, NY

Parkinson's Disease Information Session

How to Live with Parkinson's Disease

TODAY'S PRESENTORS:

Nancy Nealon	Parkinson's Foundation	585-234-5355
Robyn Ballard	Southern Tier Parkinson Group	607-351-6959 robynblld@yahoo.com
Robert Tomkins	Twin Tiers Parkinson Group	robertwtompkins@gmail.com
Gloria Friedman	Aware in Care Ambassador	607-731-4967 Gloria@gsfriedman.com

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Goals for today's talk

Technical definitions of Parkinson's

Symptoms and Treatments

Life Changes

Long term planning

Questions

I am not a medical professional, I am presenting this material from a non-medical point of view.

Stranger danger

Quality of site

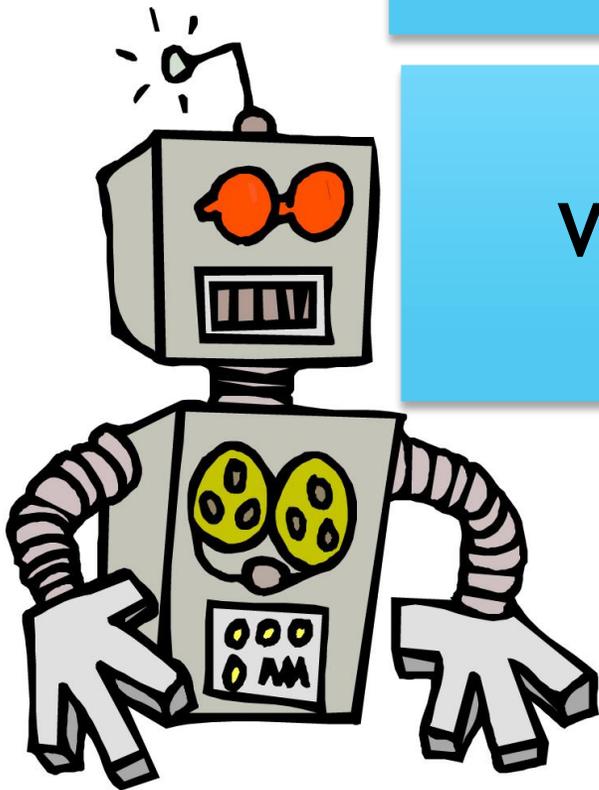
Quality of information

Viruses

Opinion versus Fact

What works for someone else might not work for you

Do not download any software or open any email that doesn't look "right".
Say NO to toolbars.
Look for lock symbol.



The doctor says Parkinson's Disease, now what?

You don't die from Parkinson's

**When you've met
one person with Parkinson's,
you've met
one person with Parkinson's**

**Unlike Alzheimer's you don't forget things, it
just takes longer to remember them.**

What is Parkinson's Disease

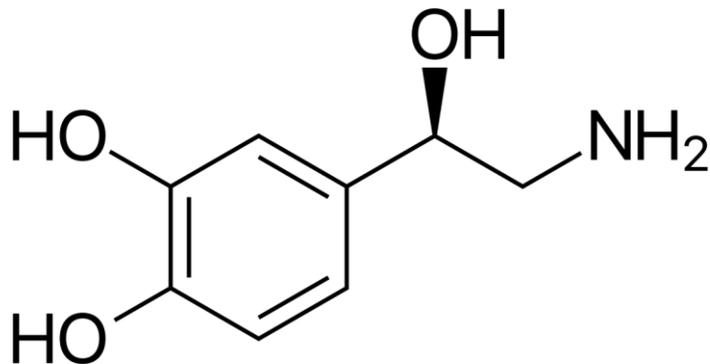
Parkinson's disease (PD) occurs when **brain cells that make dopamine, a chemical that coordinates movement, stop working or die.** Because PD can cause tremor, slowness, stiffness, and walking and balance problems, it is called a “movement disorder.” But constipation, depression, memory problems and other non-movement symptoms also can be part of Parkinson's. PD is a lifelong and progressive disease, which means that symptoms slowly worsen over time.

More History

In 1817 an English doctor, [James Parkinson](#), published his essay reporting six cases of paralysis agitans. *An Essay on the Shaking Palsy* described the characteristic resting tremor, abnormal posture and gait, paralysis and diminished muscle strength, and the way that the disease progresses over time.

What is Parkinson's Disease - the Technical Stuff

Parkinson's is a lack of Dopamine

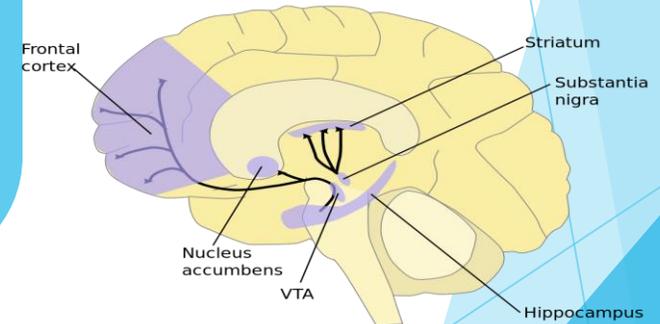


- Dopamine is a naturally occurring chemical in the body. It controls many areas of the brain but particularly movement
- By the time most are diagnosed the dopamine is 20% of normal

What is Parkinson's Disease - the Technical Stuff

Parkinson's is a degenerative disorder of the central nervous system

- The motor symptoms of Parkinson's result from the death of cells in the substantia nigra, a region of the mid-brain.



What is Parkinson's Disease - the Technical Stuff

Parkinson's is degenerative

- Over time, cells will continue to die and medications might become less effective
 - (this is not a reason to avoid medication)
- In general progression is linear, if it starts out slow, it will probably remain slow.
- There are drugs that are believed to slow progression (Azilect, Rasalgaline)

What is Parkinson's Disease - the Technical Stuff

Researching for a cure

- Basic science (years before clinical trials) are being done to rebuild, replace natural dopamine
- Other studies focus on stem cells
- Increasingly, there are theories that Parkinson's is an autoimmune disease, starting in the stomach

Terms you need to know - Abbreviations

**PD - Parkinson's
Disease**

**PWP - Person
with Parkinson's
Disease**

CG - Caregiver

**MDS - Movement
Disorder
Specialist**

Terms you need to know

Idiopathic - no known cause

Resting tremor - a rhythical movement when arm is relaxed, disappears when being used

Rigidity/Cogwheel Rigidity - muscle stiffness a trained doctor can detect

Bradykinesia - Slowness of movement

Dyskinesia - uncontrollable movement, can be from too much or too little medication

How is Parkinson's Diagnosed

In general, Parkinson's is diagnosed by observations of the examining doctor.

- Resting tremor is a major sign

If symptoms improve when taking Sinemet (Carbidopa-Levodopa) then the diagnosis is made.

DAT /PET scans can be used but expensive - they track how the dopamine moves through the body

There are some genetic markers that can be checked.

Common First Symptoms

Tremor or shaking.

Loss of sense of smell.

Gait (walking) problems.

Small handwriting.

Trouble sleeping.

Constipation.

Soft or low voice.

Dizziness or fainting.

Masked Face.

Stooped posture.

Quick Break - Summary of Information

**Parkinson's is a
slowing of the
entire body**

**It is
progressive**

**Requires active
participation
on your part**

After being diagnosed what do I do?

Learn as much as you can about Parkinson's Disease

Keep moving - make Exercise a priority

See a Movement Disorder Specialist

Reality - you have the diagnosis, now what

If newly diagnosed and not on medication, consider volunteering for a clinical trial.

- Clinical trials often want people not taking medication but others are open to a wider range of patients.

Determine the best way to tell family and friends. A Movement Disorder Specialist's office might have a Social Worker who can assist with ideas.

There will be a "new normal" but don't give things up until you have limitations.

Every case is different, but don't isolate yourself. Travel, stay active, join a support group. Don't be afraid to use a walking or balance aid (rolling walkers)

After diagnosis you probably won't be able to get Long Term Care Insurance so it's critical to get your long term finances in order.

You need a team. Start with your spouse if applicable. Remember to take care if the caregiver.

Reality - you have the diagnosis, now what - Clinical Trials?

National Institutes of Health

Michael J Fox Trial Finder

Types

- Invasive
- Non invasive
 - With equipment
 - Observational or documentation only

Talking to friends and family

Depends on the person's age and prior knowledge.

Find literature at their level and leave it with them.

Repeat the mantras from the beginning of this presentation.

Make sure they understand you haven't changed, you are just dealing with a medical issue.

New Normal

Ideally you will find a medicine combination that works and you figure out your bodies ups and downs

Work with your spouse/caregiver on what you can give up or change. Also work on signals for social situations

This “new normal” might change over time but it should be something that you can “Live Well” with.

Adjusting to that New Normal

Use mechanical aides

Change schedule

Consider retirement

Travel

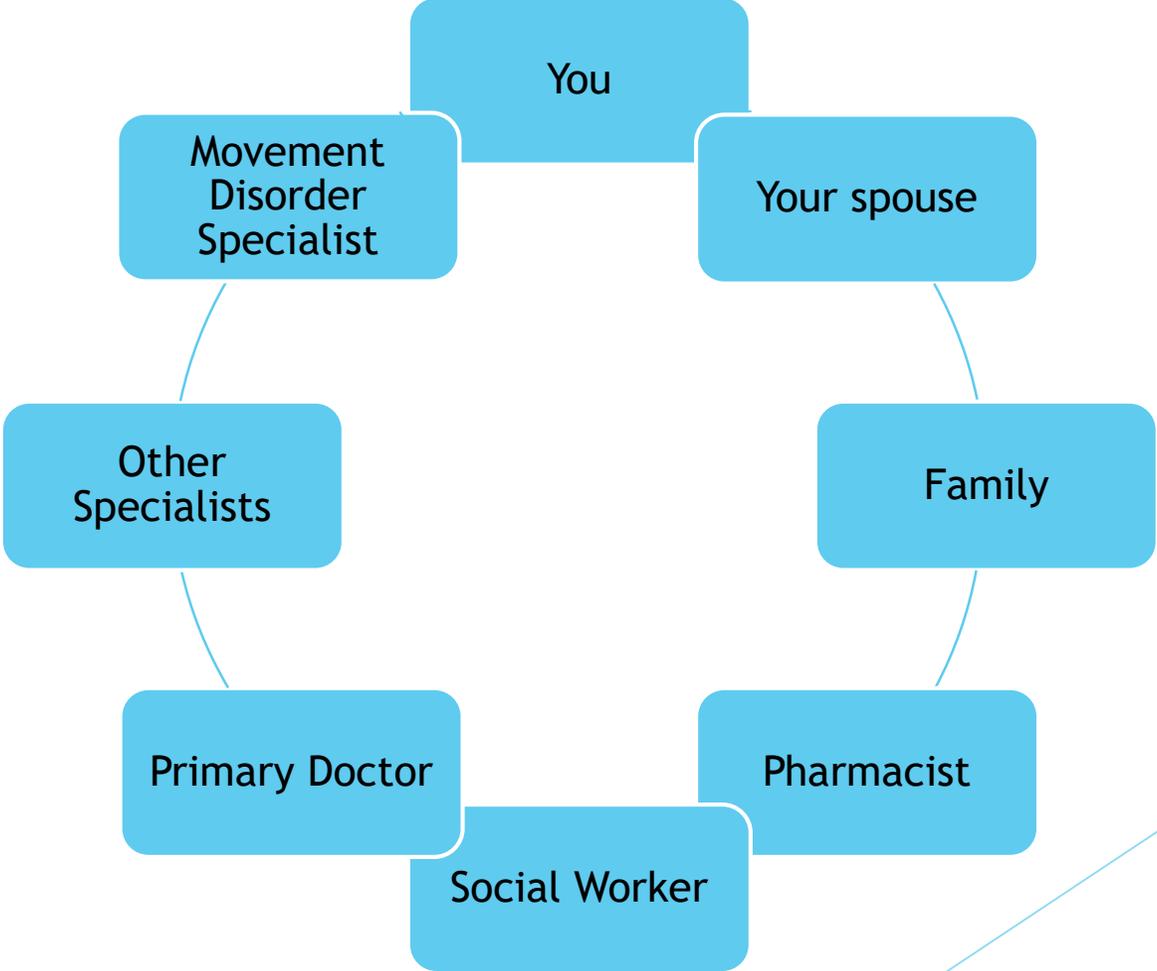
Get involved

Long Term Planning

After diagnosis you probably won't be able to get Long Term Care Insurance

Health care proxy. Make sure your family knows your wishes

Your Team



Common Medications

Carbidopa-Levodopa (Sinemet, Rytary) -
Carbidopa is artificial dopamine, levodopa helps it get through the blood/brain barrier

- Small yellow pill, can be cut in half
- regular or extended release 10/100 or 25/100nded release
- Variations with generics

Common Medications

Rasalgaleone (Azilect)

- Purpose is to help body use whatever dopamine is there more effectively
- It is designed for this drug will slow progression so often give as a first medication for Young Onset.
- Available in generic but still expensive

Ropinirole (Requip, Mirapax)

- At lower dosage used for restless leg syndrome
- Can cause erratic behavior
- This drug helps the body make more of its own dopamine

Surgical Procedures

DBS - Deep Brain Stimulation

Duplo - a stomach pump to deliver carbidopa

Cautions

Must take medications on time everytime.

Be your own advocate

Make sure your medical professionals are knowledgeable about PD

Don't put off taking medication if it will make your life easier.

Evaluate every pain or twitch to see if symptom changes with medicine cycles

- **If a doctor can't find a problem, it's probably related to Parkinson's**

Take Aways

Parkinson's is not fatal, complicating, but not fatal

Must take medications on time every time.

Be your own advocate

Educate yourself, attend symposiums, support groups, conferences

Take medication if it will make your life easier.

Keep moving, join Rock Steady or other exercise program

Make sure your team are all knowledgeable about Parkinson's Disease

LIVE WELL

References for these slides

Parkinson 360, Michael J Fox Foundation, <https://www.michaeljfox.org/parkinsons-101>

Guide for the Newly Diagnosed, Carey Christensen, et al,
https://files.michaeljfox.org/Guide_for_the_Newly_Diagnosed.pdf

10 Early Warning Signs of Parkinson's Disease, National Parkinson Foundation, pamphlet

www.parkinson.org - Parkinson Foundation

Wikipedia - Parkinson's Disease

"Using Technology in Your Battle With Parkinson's", GS Friedman, October 2015 presentation

www.webmd.com WebMD - Various Articles on Parkinson's Disease

Other References

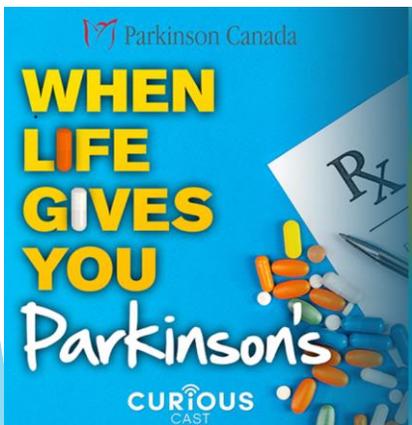
When Life Gives You Parkinson's

<https://curiouscast.ca/podcast/160/when-life-gives-you-parkinsons/>

- Larry Gifford has developed an excellent podcast about Living with Parkinson's. His descriptions run true of people with young onset Parkinson's. He is in his 40's and his wife and 9 year old son participate as well. A full episode is released bi weekly with shorter episodes on many of the "off" weeks.
- <https://curiouscast.ca/podcast/160/when-life-gives-you-parkinsons/>

Perseverance by Tim Hague

- This book, written by a person with Parkinson's who won The Amazing Race Canada is a good motivational book.
- www.michaeljfox.org/understanding-parkinsons/resources



Other references: Support Groups

Southern Tier Parkinson's Group	Robyn Ballard	www.pdsupportgroup.com
Twin Tier Parkinson's Group	Robert Tompkins	robertwtompkins@gmail.com
Rock Steady Boxing - DI's Personal Fitness	Diane Carozza	Facebook Group - Dispersonalfitness
Corning YMCA	See their website	Recently announced a spinning for Parkinson's class
Patients Like Me	Online support group	www.patientslikeme.com



Other references: Organizations



Parkinson Foundation

- www.Parkinson.org
- See separate slides

Michael J Fox Foundation

- www.michaeljfox.org
- Parkinson IQ & You
- Educational programs
- Trial Finder
- More...



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

www.Parkinson.org

SOCIAL / SHARING

Ask the Doctor

Ask the Pharmacist

Ask the Surgical Team

Ask About Nutrition

Talk to a Speech Clinician

Open Forum

Caregivers

DBS Forum

Young Onset Forum

The screenshot displays the Parkinson's Foundation website interface. At the top, there is a navigation bar with the logo, a helpline number (1-800-4PD-INFO), and a 'DONATE' button. Below this is a secondary navigation bar with 'Forums' and 'Members' tabs, and a 'View New Content' button. The main content area is titled 'Ask The Surgical Team' and includes a description of the forum's purpose, a 'Frequently Asked Questions' link, and a 'Subforums' section. The 'Subforums' section lists 'Archive - 2011 Posts of the Week' with 16 topics and 17 replies. Below this is a pagination bar showing 'Page 1 of 17' and a 'Please log in to post a topic' button. The main forum list shows three pinned posts, each with a title, start date, number of replies, and views.

PARKINSON[®] NATIONAL FOUNDATION
Call Our HELPLINE 1-800-4PD-INFO
DONATE

Forums Members View New Content

Medical Questions Ask The Surgical Team

Sign Up For Our E-NEWSLETTER Like us on FACEBOOK

Ask The Surgical Team

Kelly D. Foote, M.D. and Michael Okun, M.D. answer questions about surgical matters and Parkinson's disease. All posts in this forum are anonymous. Without seeing you and examining you the doctor cannot make specific diagnoses and recommendations. The suggestions given in this forum are for general information only.

Frequently Asked Questions - Step by step guides Posted by Forum Admin

Subforums

Archive - 2011 Posts of the Week 16 topics 17 replies Post of the Week: Why do pe... By Dr. Okun 12 Dec 2011

Page 1 of 17 1 2 3 NEXT » Please log in to post a topic

Recently Updated

Start Date	Most Replies	Most Viewed	Custom
PINNED Post of the Week: New Study on Constant Current DBS Started by Dr. Okun , 14 Jan 2012	6 replies 2,445 views	Dr. Okun 18 Jul 2015	
PINNED Post of the Week: GPI DBS is Making a Comeback for Parkinson's Disease Started by Dr. Okun , 24 Jun 2012	8 replies 2,435 views	Dr. Okun 04 May 2015	
PINNED Post of the Week: STN DBS Worsens Language Function Started by Dr. Okun , 12 Aug 2012	11 replies 2,389 views	Dr. Okun 27 Feb 2015	

Other references: Organizations

American Parkinson Disease Association

- www.adaparkinson.org
- How to live better

PMD Alliance

- www.pmdalliance.org
- Networking

World Parkinson Coalition

- World conference every three years for “everyone”
- www.worldpdcoalition.org www.wpc2022.org

World Parkinsons Congress 2023 Barcelona Spain



Ron and Gloria Friedman

Other references: Exercise



Rock Steady Boxing

- <https://rocksteadyboxing.org/>

Dance for PD

- <https://danceforparkinsons.org/>

Cycling for PD

- Do a web search. Try this link from ABC News
- Try this link from ABC News
<https://abcnews.go.com/GMA/OnCall/parkinsons-treatment-wheels/story?id=8109965>

LVST Big/LVST Loud

- These programs are offer by many physical therapists. A prescription is needed, just like for Physical Therapy

QUESTIONS / DISCUSSION

