

COPING WITH THE EMOTIONAL ASPECTS OF PARKINSON'S

Ode to Parkinson's Disease

Coping with Parkinson's

I am Strong But I am Tired

Moving with Mood Changes in Aging and
Parkinson's

PD Community Blog

Ode to Parkinson's- Poem from Member Wednesday April 25, 2012

Ode to Parkinson's

Posted with Permission by Author John Tripp, Diagnosed with PD 2006

(April 8, 2012 Version 2)

They told me I have Parkinson's,
and all they know for sure...
it will get worse every year,
'til someone finds a cure.
I felt so alone and frighten,
I'll become some sort of freak,
bent over and shaky,
unsteady on my feet.
So I began preparing
to hide myself away
but then thought of Muhammad -
(once known as Cassius Clay).
A proud and mighty fighter,
knocked down by this disease,
then stood and lite that Olympic flame
so all the world could see.
Then I thought of Michael Fox,
(he does not hides away)

but leads the charge to find a cure
for Parkinson's today.
So I make this promise,
I will never hide,
but live life to the fullest
(and set my fears aside).
And though I may be shuffling,
as you pass me by,
I'll hold my head high as I can
And greet you eye to eye.
And, if my struggles make you skittish,
look closer and you will see,
I'm the same person I've always been,
just packaged differently.
So when someone is struggling,
be kind as you can be.
It's not some freak you're seeing
it's just Muhammad... Michael... and Me.



Monique L. Giroux, MD

Guest Blogger, Former Medical Director of NWPF

Recent Posts

[Stronger Together: Parents with Parkinson's \(/stay-informed/blog/stronger-together-parents-with-parkinsons/\)](/stay-informed/blog/stronger-together-parents-with-parkinsons/)

[Surprising Ways Yoga and Meditation Can Heal \(/stay-informed/blog/surprising-ways-yoga-and-meditation-can-heal-seniors-and-caregivers/\)](/stay-informed/blog/surprising-ways-yoga-and-meditation-can-heal-seniors-and-caregivers/)

Coping with Parkinson's Disease

Overview

Parkinson's Disease (PD) is a degenerative, progressive neurologic disorder that affects the way you move. Treatment focuses on reducing the symptoms to enable a normal, active lifestyle. While medication is necessary, you can do your part to maintain a healthy lifestyle by eating a balanced diet and staying physically active in order to contribute to your overall health and well-being.

Caregivers

Coping with a chronic (ongoing) medical condition is challenging for all persons: patient, spouse, children, extended family, and friends. Everyone involved has their own emotions, finances, stresses, worries, and frustrations.

Support groups and respite care centers offer the primary caregiver a resource for help and a shared support network with others dealing with similar life challenges. The caregiver's health is just as important as the person with Parkinson's.

Medications

The goals of treatment are to manage symptoms, delay disease progression, and minimize the beginning of new symptoms. There is growing evidence that early treatment is beneficial in the long term, whether the symptoms interfere or not with daily activities. Medication for PD restores the concentration of dopamine in the brain to near-normal levels. Sinemet® (carbidopa-levodopa) is the "gold standard" of therapy. Brain cells use levodopa to produce more dopamine, which is the neurotransmitter lacking in PD. More dopamine helps relieve the symptoms of PD such as stiffness (rigidity), shaking (tremor), slow movements (bradykinesia), difficulty walking, smaller handwriting (micrographia), and a lack of facial expression.

Maximize medication treatment

- Because protein interferes with the absorption of carbidopa-levodopa, take the medication either 30 minutes before or one to two hours after a meal. If nausea is a problem, eat a low-protein snack, such as soda crackers or juice with your medication. If the nausea does not resolve, call your doctor. You may need supplemental carbidopa to help resolve this side

effect. Carbidopa minimizes some of the side effects (nausea, loss of appetite, vomiting, low blood pressure) of levodopa.

- Take all medication with a full glass of water. This allows the drug to fully dissolve and move through the digestive tract.
- Immediate-release carbidopa-levodopa tablets may be split, broken, or crushed and mixed in food, such as applesauce. However, the controlled-release (CR, SR, ER) or extended-release pills (blue, gray or speckled in color, depending on the dosage) should not be split, broken, or chewed as it can cause the medication to be absorbed in an ineffective manner.
- Dopamine agonists such as pramipexole (Mirapex) or ropinirole (Requip) may be prescribed. These medications require a low dosage at the beginning and a slow titration up to help avoid or minimize side effects. They should also be stopped slowly to avoid a sudden worsening of PD symptoms.
- If entacapone (Comtan) is prescribed, it should be taken with each dose of carbidopa-levodopa. This drug allows more levodopa to reach the brain by blocking enzymes that breakdown levodopa in the body before it reaches the brain.

Exercise

Research studies have shown that exercise and dance (e.g., Tango) are beneficial for symptom management and may slow down the progression of the disease.

- Regular exercise increases the power of neurotransmitters in the brain to enhance mood and positive thinking.
- Regular exercise can help relieve the muscle tension that builds up in the body.
- Regular exercise can improve self-image and thus help deal with life's daily stresses.
- Regular exercise helps patients with PD experience a milder and less-progressive disease process. It also helps keep bones strong, maintain balance and prevent falls.
- Stretching exercises enhance flexibility.
- Strengthening programs can improve the muscles for maintaining balance and good posture.
- The American Parkinson Disease Association (APDA) has free exercise booklets. Call 1-800-223-2732 or online at www.apdaparkinson.org.

- The Parkinson's Foundation has two programs available in video or DVD format. Call 1-800-473-4636 or online at www.parkinson.org.

Diet and nutrition

According to the National Institute of Aging, the element most absent from the diets of Americans is *nutrition*, foods that provide the proteins, carbohydrates, vitamins, minerals, hydration, fiber, and fats that allow the body to operate at its best. PD medications and symptoms can sometimes reduce the pleasure of eating, so it is important to make the best food and nutrition choices to maintain optimal health as the disease progresses.

- See a nutritionist or dietician to help adapt your needs to your lifestyle. They can build a food plan that fits your likes and dislikes.
- Review the dietary guidelines recommended by the U.S. Department of Agriculture at www.myplate.gov.
- Water is the most important fluid to drink, flavor it with lemon or fruit juice if you don't like it straight. Drink six to eight glasses a day.
- Fiber (whole grain breads, brown rice, green leafy vegetables, nuts) is critical to help with prevention of constipation problems and provide natural sources of vitamin E, which may have a protective effect against PD.
- Calcium, magnesium, and vitamins D and K are bone-strengthening nutrients found in dairy products.

Activities of daily living

There are many things a person does every day without even thinking about it such as bathing, brushing teeth, walking, turning in bed, signing checks, cutting food. When a person is diagnosed with Parkinson's, it can eventually make all of these things more difficult. The following tips are meant to be helpful and raise awareness of adjusting to some of the difficulties with PD.

Falling

- Remove throw rugs and low-lying obstacles from pathways inside and outside your home.
- Use a cane when necessary.
- Avoid using stepladders or stools to reach high objects.
- Stop walking or sit down if you feel dizzy.
- Install handrails, especially along stairways.
- Slow down when you feel yourself in a hurry.
- Before rising from your bed or bath, pause for a moment in a sitting position.

Sensory complaints

- Stretch every day, especially before exercising.
- Exercise daily to build stamina.
- Warm baths and regular massage will help relax tired muscles.
- When your hands or feet get cold, wear gloves or warm socks.
- Don't overdo physical activities; know your limits and stay within them.

Turning in bed

- Install nightlights.
- Install light switches where you can reach them easily while in bed.
- When turning to one side, first turn your head, then push off with the opposite foot and rotate your hips. As soon as your hips start to move, reach with your uppermost arm in the same direction.
- When you want to sit up, lie on your side facing out, near the edge of the bed. Place both hands flat on the bed in front of your chest. Push down with your hands, and swing your legs over the edge.
- To get out of bed, first sit up on the edge of the bed, put both feet on the floor, place your hands next to your hips, and push off slowly.
- Satin bed sheets or satin pajamas reduce friction and make movement easier.

Sleep problems

- Depression can cause insomnia. Tell your doctor about sleep problems and feelings of sadness.
- Watch for breathing difficulty during sleep. Sleep apnea can be associated with PD.
- Restless leg syndrome is a common off symptom in PD that can cause sleep problems.
- Excessive daytime sleepiness can be caused by dopamine agonists or other PD medications. Avoid alcohol, caffeine and fluid intake at night. Avoid daytime naps and try to re-establish a normal sleep-wake cycle.
- Tell your doctor about motor activity during dreams (striking out, yelling). This can be seen in PD, can disrupt sleep, and can be easily treated.

Dressing

- Replace clothes that have complicated fasteners with ones you can slip on easily, such as sweatpants, sweatshirts, or pants with elastic waistbands.
- Avoid clothes that fasten in the back.
- Look for clothes and shoes with Velcro fasteners, or have the buttons and zippers on your clothes replaced with Velcro.
- Consult your medical supply store or a catalog for dressing aids, such as dressing sticks and long-handled shoehorns.
- Make your dressing area "user friendly." Install clothes rods and drawers that make your clothing easy to reach.
- Dress sitting down on a bed or a chair. Place the clothes you plan to wear next to you on the bed or on a table within easy reach.
- Always wear shoes or slippers.
- Put clothes on and take clothes off from your stiffer side first.

Hygiene

- "Accident-proof" your bathroom. Replace glass partitions and slippery bath mats, and use paper cups.
- Tile flooring in the bathroom can become slippery and dangerous when wet. Consider replacing it with wall-to-wall carpeting.
- Install sturdy grab bars next to the bath, toilet, and wherever else you need balance and support. Never use towel racks for support.
- Avoid standing up in the bathtub. If you like to take showers, consider sitting down in the shower or place rubber mats on the floor of the tub.
- Instead of drying with a towel after you bathe, put on a terry-cloth robe.
- Use an electric toothbrush. Ask your dentist for recommendations.

Walking

- If you notice yourself shuffling, slow down or stop walking and check your posture.
- Keep your feet a comfortable distance apart, eight to ten inches.
- Stand up straight with your head over your hips.
- Buy a good pair of walking shoes with a low heel and good arch support. Avoid running shoes or shoes with crepe soles.
- Exaggerate lifting your feet and swinging your arms. With each step, pretend you are stepping over a log.
- Practice taking long steps.
- When you need to turn around, don't pivot on one foot. Instead, walk around in a circle until you're facing the direction you want to go.

Swallowing

- Take extra-small bites of food, chew thoroughly, and swallow carefully.
- Chop up your food in a food processor, so that it's easier to chew and swallow.
- Always swallow your food completely before taking more food into your mouth.
- Use an electric warming tray to keep your food hot so that you won't feel the need to rush.
- Family members and caregivers should consider receiving training in the Heimlich maneuver.
- Swallow excess saliva before you put food into your mouth.
- Keep a beverage at hand during meals and take frequent sips.

Freezing

- When you freeze, stop trying to walk; instead, press your heels to the floor.
- Look straight ahead, not down.
- Pick a target and walk toward it, especially when walking through doorways.
- If you're walking with someone, have the person hold your arm or elbow.
- Develop a regular stretching and exercise program. Regular movement can help you maintain your sense of balance and posture.

- Stand up straight, with your head over your hips, but don't lean backwards.

Tremor

- Perform difficult tasks when you feel well and when your medication is working effectively.
- Relax. Sit down from time to time, relax your arms and shoulders, and take deep breaths.
- Get a regular massage.
- Ask your physical therapist or doctor to recommend a stretching and exercise program.
- Avoid caffeine and alcohol.
- Get plenty of rest.

Salivation

- To control saliva accumulation, you must swallow. Swallowing may no longer be an automatic reflex. You may have to force yourself to remember to swallow.
- Chew gum or suck on a piece of hard candy.
- Try sleeping on your side, so that you won't wake up choking during the night.
- Swallow excess saliva before you put food into your mouth.
- Keep a beverage near you during the day. Get in the habit of frequently taking small sips.

Cutting food

- Use "non-skid" or rubber place mats that will help you keep your plates and serving dishes from sliding.
- Eat foods that do not require cutting with a knife.
- Use a food processor to chop or shred your food after it is cooked.
- Ask someone to cut your food for you.
- Use large-handled utensils that are easy to grip.
- If you own specially adapted utensils, carry them with you whenever you plan to eat out.
- Use flexible straws to prevent spills.

Speech

- Take a breath before you start to speak, and pause between every few words or even between each word.
- Exaggerate your pronunciation. Pretend that your listener is hard of hearing and needs to read your lips.
- Face your listener directly when speaking.
- Finish saying the final consonant of a word before starting to say the next word.
- Express your ideas in short, concise phrases or sentences.
- Exaggerate facial motions as you practice reciting the alphabet, counting numbers, or reading a magazine or newspaper out loud.
- Encourage your family and friends to ask you to speak louder or repeat yourself if they can't understand what you're saying.
- Speak for yourself, and speak often. Don't get in the habit of letting others speak for you.

Handwriting

- Try using a large-body pen or pencil or one with a build-up handle.
- Experiment with different types of pens. Felt-tip pens, for example, have a "slippery" feel that offers less resistance.
- Lift your arm up from time to time, straighten your elbow, and move your fingers.
- Instead of writing by hand, use a typewriter or computer. If you don't have keyboard skills, practice a little every day. The exercise will help improve your dexterity.
- If someone is available to type for you, use a Dictaphone or smartphone.
- Consider corresponding by recording your messages on a computer or a smartphone.

Taking care of business

The Parkinson's Foundation has developed a thorough guide to getting your household and personal documents organized at www.parkinson.org

- Organize your medical histories
- Keep a journal of medications and dosages
- Organize your personal financial documents
- Insurance and long-term care plans
- Livings wills, durable power of attorney, advanced medical directives

Sources & links

If you have any questions, please call Mayfield Brain & Spine at 800-325-7787.

Support

A support group provides an opportunity for patients and their families to share experiences, receive support, and learn about advances in treatments, and medications. Please contact one of the associations below for resources in your area.

Links

Parkinson Support and Wellness
parkinsoncincinnati.org

Parkinson's Foundation
www.parkinson.org

American Parkinson Disease Association
www.apdaparkinson.com

Family Caregiver Alliance
www.caregiver.org



updated > 7.2018

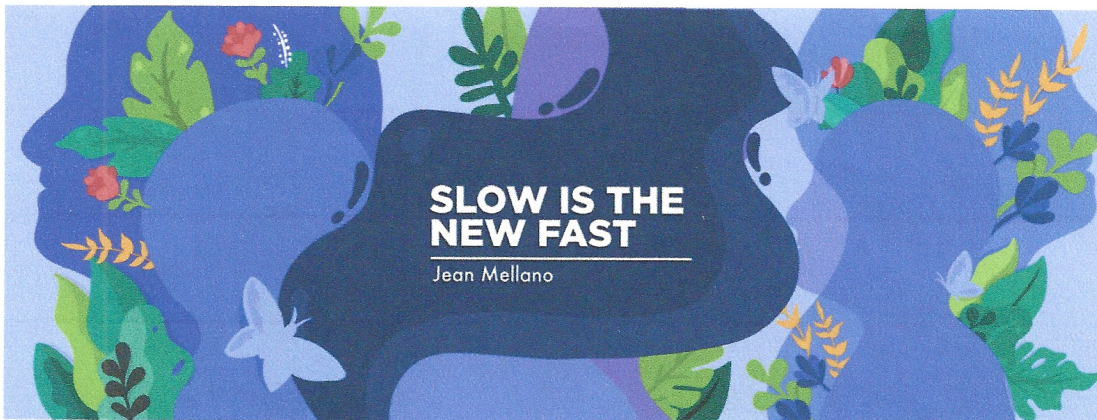
reviewed by > Maureen Gartner, RN, M.Ed., George Mandybur, MD, Mayfield Clinic, Cincinnati, Ohio

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I Am Strong, but I Am Tired

parkinsonsnewstoday.com/2021/08/10/i-am-strong-but-i-am-tired/

August 10, 2021



"I think for me, any great art is art which communicates human emotion."
– Greg Lake

Good art evokes emotion. This sculpture, by Simone Wojciechowski, titled "Tired Soul," represents exactly how I feel:



“Tired Soul” by Simone Wojciechowski. (Courtesy of Simone Wojciechowski Sculptures)

Why am I tired?

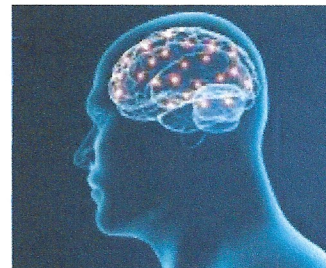
Lately, I seem to be grasping at straws. I am trying to find a reason besides my incurable and progressive Parkinson’s disease to explain why I feel so horrible. I am always uncomfortable in my own body.

Almost six years after my diagnosis, I still cannot accept that my symptoms are due to Parkinson’s. I keep searching for another reason to explain them, evidenced by my research on hyperparathyroidism.

After all the lab and imaging tests and doctors’ appointments, my hyperparathyroidism diagnosis has been deemed a borderline case. Hence, I need to accept that my extreme fatigue, brain fog, and mood issues are most likely due to Parkinson’s. The disease is progressing, and I seem to have no power to slow it down.

Recommended Reading

August 5, 2021 News by Forest Ray PhD



New Algorithm Groups Parkinson’s Symptoms to Predict Progression

I was strong

When I was diagnosed in 2015, I thought I was invincible and could control and slow down my disease progression with exercise. However, my worsening nonmotor symptoms of fatigue, apathy, and depression leave me between a rock and a hard place. These symptoms prevent me from doing the very things I need to do to improve my quality of life and possibly slow down this disease. What a vicious cycle!

I am still tired

My daily life seems to revolve around Parkinson's. Planning my day must incorporate when and where I can take my medications (every three hours). Add doctors' appointments and Parkinson's-related therapies, and my day seems to be all about the disease. This is wearing me down.

It doesn't help when people tell me I look fine. Thanks to years of dance training, I have developed a strong sense of body awareness. This means I have a good understanding of my own body. I feel and see changes in myself that others cannot.

More often than not, I fake feeling good. This requires a great deal of energy and effort, both mental and physical.

When well-meaning people comment that there are so many others with Parkinson's whose symptoms are much worse than mine, I feel awful. When driving their point home by saying others with Parkinson's would probably love to change places with me, the guilt settles in. However, I cannot compare myself with others; we all have different life experiences, and the disease impacts everyone differently. Only I can feel my symptoms, and I alone must handle the cards I am dealt.

How can I help myself?

I realize I must get out of my own way and dig deeper than I ever have before. Digging deep never came easily to me, but when faced with adversity in the past, I wouldn't give up. As a dancer, I was able to push myself to do the choreography one more time at an exhausting rehearsal, even though I had been dancing for several hours after a full day at my corporate job.

While biking in the mountains of Mallorca, Spain, during a horrific storm, I was able to return the 10 miles to the hotel on my own, hydroplaning downhill on the steep mountain switchbacks in a pelting downpour with gale-force winds. I dug deep and made it to safety in one piece without crashing.



“Pity Party Hats.” (Photo by Jean Mellano)

It is time for me to take off the hats. Firstly, I need to stop feeling sorry for myself. Secondly, can antidepressants improve my mood?

I have been resistant to taking them due to the struggles my late life partner had with them. Lately, loved ones and healthcare professionals have encouraged me to pursue this option. Also, an acquaintance of mine with Parkinson’s told me her life has turned around since she started taking an antidepressant.

Since my late husband passed in 2015, I have been a mental health advocate. I need to practice what I preach. There is no shame in taking antidepressants, and I plan to pursue this path to improve my quality of life.

I will be strong again.

This column has a very different ending than I had originally envisioned. When I started writing, I was so full of despair (and had been for weeks). I had lost all hope.

The feelings of despair and hopelessness that can result from living with this disease are to be expected. Parkinson’s is a formidable adversary and it is understandable to lose hope at times. We are only human.

“No matter how much falls on us, we keep plowing ahead. That’s the only way to keep the roads clear.” – Greg Kincaid

Note: Parkinson’s News Today is strictly a news and information website about the disease. It does not provide medical advice, diagnosis or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or another qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website. The opinions expressed in this column are not those of Parkinson’s News Today or its parent company, BioNews, and are intended to spark discussion about issues pertaining to Parkinson’s disease.



**MOVING WITH
MOOD CHANGES
IN AGING AND PARKINSON'S**

A LOOK AT DEPRESSION AND ANXIETY



**MJFF Third Thursdays Webinar
(Replay of June 2020 Webinar)**

WHAT WE'LL TALK ABOUT

- » Why Mood Changes Happen in Aging and Parkinson's
- » How Mood Symptoms Impact Life and Care
- » What Depression and Anxiety Look Like
- » How to Talk about Mood Changes
- » What Treatment Options are Available
- » Where Research is Leading



The Michael J. Fox Foundation for Parkinson's Research

SSRI Depression

Paxel

SNRI

Zoloft

ANXIETY

Cognitive Behavior Therapy

Exercise

Social

Related

Meditation

TODAY'S SPEAKERS



Moderator:
Karen Jaffe, MD
MJFF Patient Council
member
Founder, InMotion
*Diagnosed with
Parkinson's in 2007*



Irene Richard, MD
Professor of Neurology
and Psychiatry at
University of Rochester
School of Medicine
and Dentistry



Roseanne Dobkin, PhD
Professor of Psychiatry
at Rutgers University



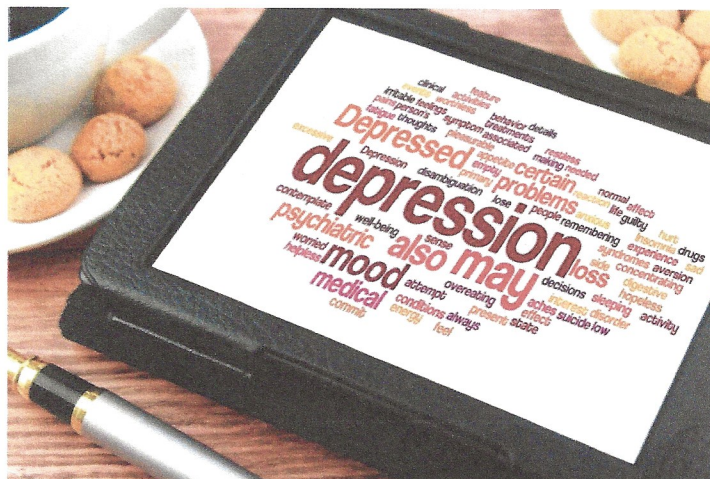
Sebastian Krys
Grammy and Latin
Grammy Winner
CEO, Rebeleon
Entertainment Inc.
*Diagnosed with
Parkinson's in 2019*



MANY PEOPLE WITH PARKINSON'S EXPERIENCE MOOD CHANGES

Depression and anxiety can:

- Arise in response to life with Parkinson's
- Be symptoms of the disease itself
- Happen throughout the Parkinson's journey
- Impact movement symptoms, treatment effect and quality of life
- Occur together or separately



Quick Tip:

Mood changes can feel isolating, but you are not alone. There are many supports, resources and treatments to help.



MOOD CHANGES LOOK DIFFERENT FOR DIFFERENT PEOPLE



Depression Symptoms

- Low mood
- Decreased interest in activities
- Sleeping too much or too little
- Thinking changes
- Weight or appetite change
- Fatigue
- Feelings of guilt, worthlessness or suicidality



Anxiety Symptoms

- Worry that is difficult to control
- Restlessness or feeling on edge
- Sleep problems
- Difficulty concentrating
- Irritability
- Less energy
- Sudden-onset panic or anxiety attacks



Quick Tip:

Some mood symptoms, such as sleeping or thinking changes, can be part of Parkinson's on their own.



TALK WITH YOUR LOVED ONES AND DOCTOR ABOUT MOOD CHANGES

If you experience changes:

- Reach out to people you trust to share your feelings
- Discuss with your doctor, even if they don't ask
- Get support in an online group or 1:1 chat

If you notice changes in a loved one:

- Gently broach the subject with open-ended questions such as "How are you feeling?"
- Listen
- Ask how you can support



Quick Tip:

Depression and anxiety are medical conditions, just like diabetes or heart disease. Treat them as you would any other serious health concern.



THERE ARE MANY OPTIONS FOR EASING MOOD CHANGES

Options to consider with your doctor may include:

- Prescription medication
- Talk therapy
- Support groups or other social connections
- Physical exercise
- Meditation and other mindfulness practices



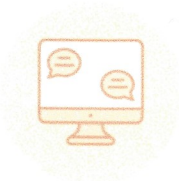
Quick Tip:

Your doctor can help you find the treatment regimen and resources that best meet your symptoms and needs.



RESEARCH IS LEADING TO BETTER TREATMENTS FOR MOOD CHANGES

- Testing available drugs in Parkinson's
- Developing therapies specific to Parkinson's mood changes
- Using technology to deliver care more broadly
- Creating tools to fully measure mood changes



Quick Tip:

You can match to ongoing studies in Fox Trial Finder.

Visit www.foxtrialfinder.org.





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Conversation
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Educational
Resources
[michaeljfox.org/
guides](https://michaeljfox.org/guides)

Mood Changes and Parkinson's

Read this guide to learn more about mood changes and how to manage them. It also includes information on when to seek help and how to talk to your doctor.



When do mood changes happen?

Mood changes can happen at any time, but they are most common in the first few years after diagnosis. They can be caused by the disease itself, or by the stress of living with Parkinson's.

What can I expect?

Some people feel sad or angry, while others feel happy or excited. These feelings can change over time, and they can be caused by the disease itself, or by the stress of living with Parkinson's.



How are mood changes treated?

Mood changes can be treated with medication, therapy, or a combination of the two. It's important to talk to your doctor about your symptoms and how to manage them.

michaeljfox.org

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Participate in
Online
Research
ppmionline.org

Find a
Clinical Trial
Near You
[michaeljfox.org/
trial-finder](https://michaeljfox.org/trial-finder)

QUESTIONS?

Submit your questions
for our panelists
and moderator
in the Q&A box.



The Michael J. Fox Foundation for Parkinson's Research