

PARKINSON'S ASSOCIATION OF SAN DIEGO

WWW.PARKINSONSASSOCIATION.ORG

THE GOOD START PROGRAM

February/March, 2020



How are you feeling about your diagnosis? You're not alone in this journey

You may feel:

Afraid

Angry

Sad or depressed

Confused and anxious or nervous

Stressed

Embarrassed or ashamed

Helpless or powerless

Numb

Overwhelmed

Hopelessness

After today's session, we hope you'll feel:

Compassion and empathy

Safety

Understanding

Trust and Support

Friendship and connection

Hope and encouragement

Informed

BACKGROUND ON PARKINSON'S DISEASE:

DR. JAMES PARKINSON (11 APRIL 1755 – 21 DECEMBER 1824) WAS AN ENGLISH SURGEON, APOTHECARY, GEOLOGIST, PALEONTOLOGIST AND POLITICAL ACTIVIST WHO IS BEST KNOWN FOR HIS 1817 WORK ON AN ESSAY CALLED THE SHAKING PALSY IN WHICH HE WAS THE FIRST TO DESCRIBE "PARALYSIS AGITANS." A CONDITION THAT WOULD LATER BE RENAMED PARKINSON'S DISEASE.

- ESTIMATED 10 MILLION WORLDWIDE
- ESTIMATED 1 MILLION NATIONALLY
- 60,000 PEOPLE ARE DIAGNOSED EACH YEAR IN THE U.S.
- AT LEAST 117,000 PEOPLE WITH PD IN CALIFORNIA
- PARKINSON'S OCCURS IN MEN (BY 50% GREATER) THAN WOMEN
- THE AVERAGE AGE OF ONSET IS 60

UNDERSTANDING PARKINSON'S DISEASE

Parkinson's disease is a disorder of the central nervous system that results from the loss of dopamine producing cells in various parts of the brain, including a region called the substantia nigra.

Dopamine is a chemical messenger that transmits signals within the brain that allow for coordination of movement. Loss of dopamine causes neurons to fire without normal control, leaving patients less able to direct or control their movement.

Choosing your Doctor

A Movement Disorder Specialist is a neurologist who has completed an additional two years of training in a fellowship and specializes in the diagnosis and management of patients with Parkinson's Disease, Essential Tremor, Dystonia, and other movement disorders. Your movement disorder specialist (MDS) will work with you to determine the best course of therapy for you during your journey with Parkinson's disease.

Motor Symptoms of Parkinson's Disease

- Tremor - may start only on one side and later appear on both sides
- Slowness of movement - “bradykinesia”
- Rigidity or stiffness
- May have postural instability or poor balance

Non Motor Symptoms related to Parkinson's Disease

Mood disorders

Increased sweating

Loss of sense of smell

Fatigue

Constipation

Sleep disorders, including REM

sleep behavior disorder

Dystonia

Bladder issues - urgency,
frequency

Neurogenic orthostatic
hypotension

Sexual dysfunction

Hallucinations or delusions

Cognitive Changes

Visual changes

MEDICATIONS UTILIZED FOR MANAGEMENT OF PD SYMPTOMS

Levodopa, Carbidopa-Levodopa

MAO – B Inhibitors

Dopamine Agonists

Anticholinergics

Amantadine (Symmetrel)

COMT Inhibitors

Others, including symptom management for non-motor symptoms

*Each person with PD has different symptoms with different responses to therapy. Work with your movement disorder specialist to determine the correct regimen for best management of YOUR PD.

STAGES & PROGRESSION OF PARKINSON'S DISEASE

Please note that each person's Parkinson's disease is different and progresses at different rates and to different degrees. The following table should **NOT** be interpreted as an automatic or expected progression for every person with Parkinson's disease. Communication with your Movement Disorder Specialist is most helpful for management of your disease and its progression.

	Early PD		Mid-stage PD	Advanced PD	
Stage of Parkinson's Disease	1	2	3	4	5
Severity of Symptoms	<p>MILD</p> <p>Symptoms of PD are mild and only seen on one side of the body (unilateral involvement)</p> <p>SYMPTOMS</p> <p>Tremor of one hand</p> <p>Rigidity</p> <p>Clumsy Leg</p> <p>One side of the face may be affected, impacting the expression</p>	<p>MILD</p> <p>Symptoms of PD on both sides of the body (bilateral involvement) or at the midline</p> <p>SYMPTOMS</p> <p>Loss of facial expression on both sides</p> <p>Decreased blinking</p> <p>Speech abnormalities</p> <p>Rigidity of the muscles in the trunk</p>	<p>MODERATE</p> <p>Symptoms of PD are characterized by loss of balance and slowness of movement</p> <p>SYMPTOMS</p> <p>Balance is compromised</p> <p>Inability to make the rapid, automatic and involuntary adjustments</p> <p>All other symptoms of PD are present</p>	<p>SEVERE</p> <p>Symptoms of PD are severely disabling</p> <p>SYMPTOMS</p> <p>Patients may be able to walk and stand unassisted, but they are noticeably incapacitated</p> <p>Patient is unable to live an independent life and needs assistance</p>	<p>SEVERE</p> <p>Symptoms of PD are severe and are characterized by an inability to rise</p> <p>SYMPTOMS</p> <p>Patients fall when standing or turning</p> <p>May freeze or stumble when walking</p> <p>Hallucinations or delusions.</p>

OTHER THERAPIES AND CURRENT RESEARCH

Deep Brain Stimulation
Focused Ultrasound therapy
Stem Cell Research
Causal factors for PD;
Gene therapy
Alpha synuclein, the gut and PD
Use of current FDA approved meds
(for other diseases, such as diabetes
and leukemia) for PD
Effect of exercise on PD symptoms
Many more

Consider Joining a Clinical Trial or Study

Michael J Fox Foundation
<https://www.michaeljfox.org/page.html?Participate-in-Parkinsons-Research>

Fox Trial Finders
www.foxtrialfinder.michaeljfox.org

www.clinicaltrials.gov

UCSD www.clinicaltrials.ucsd.edu









VA San Diego

Scripps Research www.scripps.edu

Sandford Burnham Institute

Others

STRETCH BREAK

<p>1 BACK EXTENSION</p>  <p>Repeat 3 times, 5 seconds each</p>	<p>2 NECK FORWARD</p>  <p>Do once for 15 seconds</p>	<p>3 NECK LEFT & RIGHT</p>  <p>Repeat 3 times, 5 seconds each</p>	<p>4 ELBOW PULLOVER</p>  <p>Repeat 3 times 5 seconds each, both sides</p>
<p>5 SHOULDER OVER</p>  <p>Do once for 15 seconds on each side</p>	<p>6 SHOULDER ACROSS</p>  <p>Do once for 15 Seconds with each arm</p>	<p>7 SHOULDER BACK</p>  <p>Do once for 15 seconds each arm</p>	<p>8 BRIDGE STRETCH</p>  <p>Do once for a second</p>

NUTRITION: FOOD FOR THE BRAIN

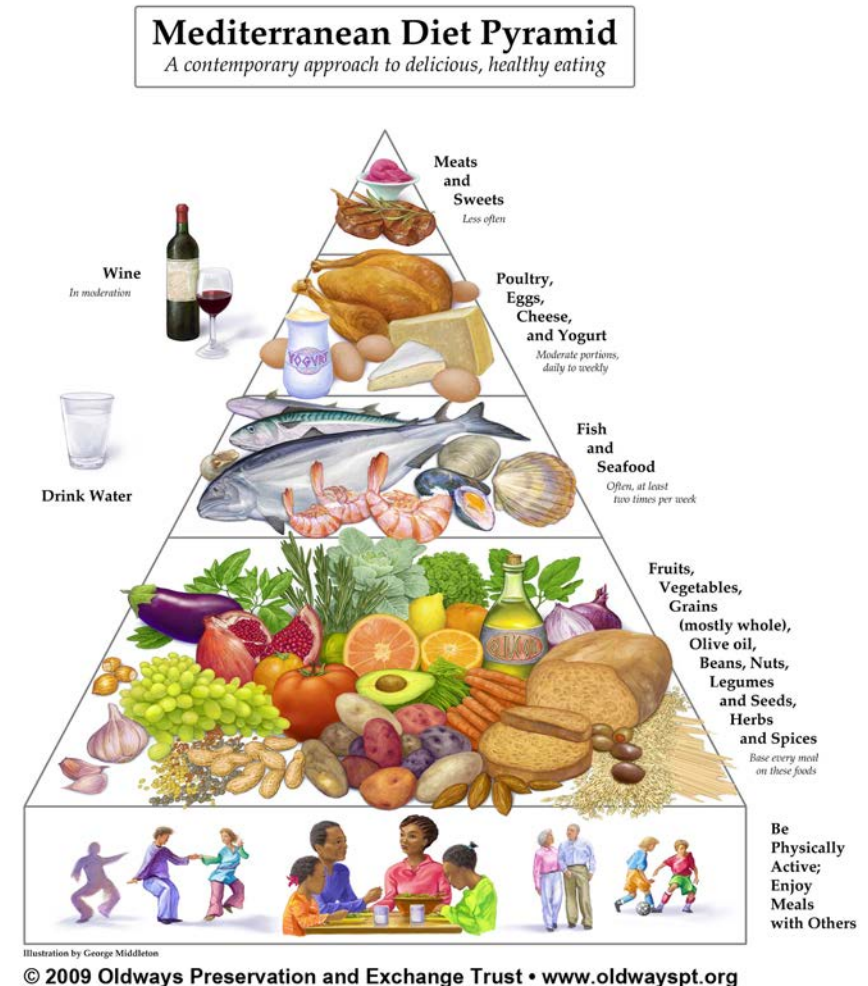
No singular diet can treat Parkinson's disease or its symptoms, but a healthy and balanced diet can improve general well-being. Most clinicians recommend a Mediterranean lifestyle.

Fresh fruits and vegetables provide key vitamins and minerals, antioxidants, beta carotene, and fiber.

Stay hydrated!

Certain medications (Carbidopa/Levodopa) compete with protein for absorption in the intestine (protein sources include meat, eggs, and cheese). Sometimes, this can alter the effectiveness of levodopa in the brain. Talk to your MDS to determine the correct regimen for dosage and timing of meds and meals.

Vitamin D and B complex vitamins



EXERCISE: ENGAGING IN PHYSICAL ACTIVITY & MOVEMENT

Exercise should be part of your daily management of your symptoms and may slow progression of your disease

Enhanced quality of life

Easier mobility with day-to-day tasks

Increased flexibility of the muscles

Improved motion of the joints

Decreased stiffness

Better posture

Faster movements

Heightens body awareness that may enhance posture and motor control during walking

Improves bowel function

Decreases feelings of isolation & depression

Creates an overall sense of well-being

Reduces pain

Improves muscle tone

Exercise your brain as well – learn something new every day. Do the crossword puzzle, Soduko, work on a jigsaw puzzle. Interact with others(those you know and new people to meet). Socialize!

EXERCISE HELPS AND SHOULD BE PART OF YOUR DAILY TREATMENT PLAN TO MANAGE YOUR SYMPTOMS



Rock Steady Boxing

Yoga

Medical Integration –
Neuro/Parkinsons
Tri City Wellness
and Fitness Center

Resistance Training

Walking

Swimming/Aqua
classes

Tai Chi

Pilates

Stretching

Cycling

Dance



PHYSICAL AND OCCUPATIONAL THERAPY: INCREASE STRENGTH, ENDURANCE, GAIT, BALANCE, AND HELP RELIEVE PAIN

Physical

Focuses on the physical rehabilitation of people with the goal of restoring mobility.

Physical Therapists educate people on managing their condition to maintain long-term benefits.

Physical Therapists focus primarily on anatomy and the person's strength, functional capacity and motor development.

Improve gait, balance and strengthening muscles using visual and auditory cues.

Occupational

Focuses on enabling people to engage in daily activities as seamlessly as possible.

Occupational Therapists suggest adaptations and modifications to the person's environment to prevent the risk of falling.

Occupational Therapists combine physical aspects with mental health and design exercises that teach people coping and management skills within their limits.

Note: As Parkinson's disease progresses and people experience worsening motor skills (like difficulties with posture, balance, and walking), a loss of independence, inactivity, fear of falling, and increased social isolation can ensue.

EXERCISE!

Speech Therapy, including Speech, Language, Swallow and Cognition

(SLP) Speech Language Practitioner can:

- evaluate the patient's speech difficulties and help the patient improve vocal communication.
- evaluate issues with swallowing, participate with diagnostic testing, and offer solutions for improvement in swallow function
- assist with strategies to improve communication
- evaluate cognition and changes in cognition; offer strategies to help

Requires referral from MD

Voice Therapy

LSVT (LOUD) is an effective treatment to improve vocal loudness, vocal clarity and breathing. Patients are trained to focus on voice volume and clarity, as well as, the physical requirements of improving their speech.

Parkinson's Voice Project (SPEAK OUT!) preserves the voices of individuals with Parkinson's through intensive speech therapy and follow-up support.
(<https://www.parkinsonvoiceproject.org/providers.aspx>)

Tremble Clefs is a fun way to incorporate voice therapy while singing with other PwP.

Audability



Aware
in Care

Parkinson's Foundation¹⁹

IMPORTANT LEGAL DOCUMENTS:

- 1. Medical Directive:** A legal document in which a person specifies when or what medical actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity. It also allows one to designate a person to make similar decisions under those circumstances.
- 2. HIPAA Authorization:** Enables one to authorize the release of medical information to certain designated individuals only, due to privacy restrictions imposed by law which otherwise prevent such release of information.
- 1. Power of Attorney:** Allows you to designate one or more persons to conduct your business affairs while you are alive but unable to communicate.
- 2. Revocable (Family) Trust:** Allows you to direct who gets your property upon your death or incapacity and avoids the costs or problems of probate court administration.
- 3. Will:** Allows you to direct who gets your property upon your death and avoids the financial and legal problems associated with dying intestate.

VA BENEFITS: [HTTP://WWW.VABENEFITS.VBA.VA.GOV](http://www.vabenefits.vba.va.gov) OR PHONE 1-800-827-1000

VETERANS ADMINISTRATION (VA) SERVICE CONNECTED DISABILITY (SCD) FOR PARKINSON'S

- Honorably discharged veterans who are diagnosed with Parkinson's disease are presumptively qualified for service connected disability pension and related health benefits administered by the VA for exposure to "Agent Orange" herbicide. Qualifying service is considered to be service in Vietnam between 1962 and 1975, the Korean DMZ between 1968 and 1971, Thailand between 1961 and 1975, or service as crewmember or worker on C-123 aircraft between 1972 and 1982. Otherwise, an honorably discharged veteran diagnosed with PD who can establish a causal connection between the disease and related service during either the Gulf War, service as a former prisoner of war (POW), or service involving exposure to herbicide storage outside Vietnam may also be entitled to SCD.

NON-SERVICE CONNECTED DISABILITY (NSCD) PAYMENTS or AID AND ASSISTANCE PAYMENTS ADMINISTERED BY THE VA.

- An honorably discharged veteran who served at least 90 days on active duty, with at least one day having been served during wartime, and who is certified by a medical doctor to be in need of Personal Assistance and/or a Protective Environment may qualify for non-service connected disability payments and Aid and Assistance payments when certain financial constraints are met. Generally, entitlement occurs when that veteran's out of pocket medical expenses exceed or closely approximate \$127,610 (2019).
- Similarly, a surviving spouse who was married to a qualified veteran for at least one year and had been residing with the veteran at the time of death may also qualify for Aid and Assistance payments and benefits from the VA when specified financial conditions continue to be met. Once established, Aid and Assistance benefits also entitle the recipient to free medication, medical equipment, glasses²¹ and hearing aids, and incontinence supplies.

SEVEN TENETS FOR LIFE WITH PARKINSON'S DISEASE

MICHAEL J. FOX FOUNDATION

There is no “one size fits all” description of Parkinson’s disease.

Your symptoms and progression are not like anyone else’s. Monitor your Parkinson’s, educate yourself on the disease and become the top expert on you.

Isolation can worsen symptoms.

You don’t have to manage your disease on your own. A team-based approach (including a movement disorder specialist and allied care professionals) can help you stay physically and emotionally strong. Keep open lines of communication with loved ones and consider joining a support group.

Don’t settle.

Parkinson’s disease varies, and so do treatment options. Designing a regimen that feels comfortable and effective for you will take time and, likely, more than one try. Keep working with your doctor and care team until you get there. Make changes to address progression of your disease as needed.

Hone your news instinct.

The latest research is the latest hope, but in our 24/7 media environment, there’s a learning curve to interpreting science news. Find experts you trust, seek out credible updates and commentary and let go of the rest. Being news-savvy can help you maintain peace of mind.

SEVEN TENETS, CONTINUED

Get engaged.

There are as many ways to contribute to better outcomes for yourself and others as there are people with Parkinson's. Participating in research studies or advocacy, raising funds, starting a blog or support group – however you choose to get involved – can give you a sense of control and help bring us to a world without Parkinson's.

Parkinson's is a non-linear disease.

You can have good days, weeks, and months even during trying times. Exercising, eating well and staying involved with your social circle, community and activities you enjoy can have a major influence on your Parkinson's path.

Be prepared.

Parkinson's diagnosis or not, we all face certain issues in our later years. Make sure your family understands wishes for end-of-life-care, and put your will and estate in order. Having challenging conversations at the beginning of your journey with Parkinson's can help lighten the burden as the disease advances.

MINDFULNESS AND A POSITIVE ATTITUDE

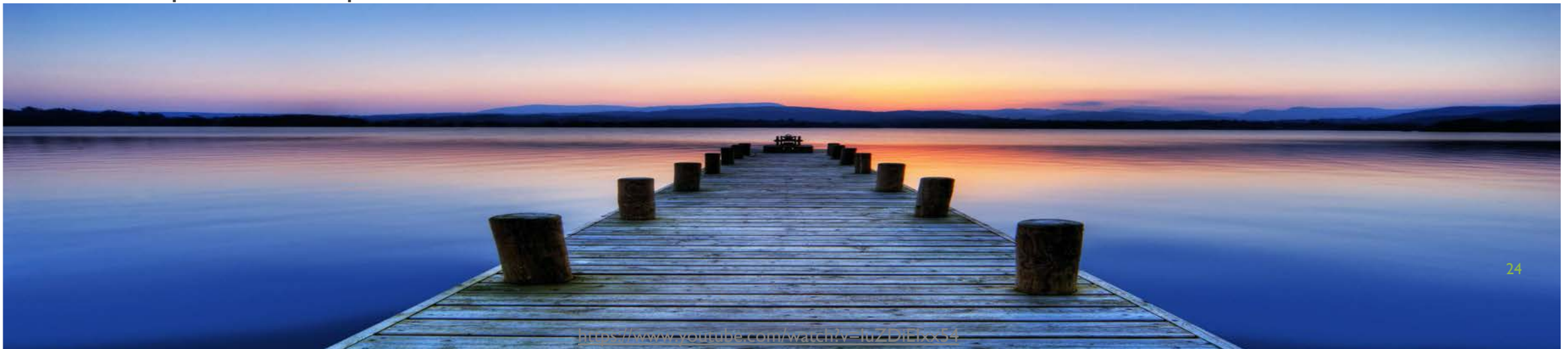
You are not alone. A great quality of life is achievable. Staying positive gives you control over your life.

A mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations, used as a therapeutic technique.

Mindfulness can lead to structural changes in brain areas affected by PD.

Mindfulness training can improve quality of life, combat depression and reduce fatigue.

Mindfulness can help with movement, postural stability and reduce stress.



Keep yourself emotionally and physically healthy.

Socialization is vitally important.

Reserve enough time for your own interests.

Self-care is important for you and your loved one.

Recognize that emotions such as guilt and resentment are normal.

Be aware of signs of depression and get help.

Attend support groups to learn from experts as well as others in the PD community – PASD can refer you to available support groups in San Diego County.



CARE PARTNER

Take care of your own health so you can take care of your loved one.

RESOURCES AND SUPPORT GROUPS EXERCISE AND OTHER THERAPIES



<http://parkinsonsassociation.org/support-groups-resources-2019/>

LOCAL PARKINSON'S SUPPORT GROUPS

North County Parkinson's Support Group:
1200

www.NCPSG.org

Paul Dawson 760-497-

Fallbrook, Oceanside, Carlsbad, Encinitas, Rancho Bernardo

SD Central County Parkinson's Support Group www.SDCCPSG.org Nancy Floodberg 619-857-6638

Veterans La Jolla, Pacific Beach, Point Loma Flying SOLO

UCSD Parkinson's Support Group Network www.support4PD.org David Higgins 619-565-0411

Otay Torrey Pines, Vi-La Jolla, Mission Valley, Flying SOLO, Young Onset, Duopa SG, Chula Vista,
Ranch, Espanol

East County Parkinson's Support Group www.EastCountyPSG@cox.net Lorenzo Higley 619-447-2855

La Mesa



Questions & Answers