

The Good Start Program

06/09/2022 revision

PARKINSON'S ASSOCIATION OF SAN DIEGO


WWW.PARKINSONSASSOCIATION.ORG



WELCOME TO THE GOOD START PROGRAM

Parkinson's Association of San Diego is pleased to offer our Good Start Program (GSP), designed for recently diagnosed patients and their care partners, but also for anyone who would like more information about Parkinson's. The program will provide participants with information on PD and on available resources in San Diego County.

This presentation represents the curriculum that is provided in the live program; the content will be discussed in more detail by qualified Parkinson's experts during live presentations



The program covers an overview of the complex nature of Parkinson's and treatment options. Topics of discussion include the importance of exercise, a review of medications, treatments and therapies, the importance of selection of the correct physician, and more to assist you on your journey and finding your best path to living your best life with Parkinson's. Each person with PD is different; you'll need to develop your own specific treatment plan in concert with your movement disorder specialist and/or neurologist.

HONORING KATHY BRUYERE

In September 2020, Kathy, a long-time PASD Board member, Good Start program champion and tremendous Parkinson's community advocate, passed away.

The PASD Board adopted a resolution honoring her and named its Annual Award for outstanding commitment to our Parkinson's Community in her memory.



ACKNOWLEDGEMENT OF DIAGNOSIS, ADJUSTMENT & MOVING THROUGH GRIEVING STAGES

After your diagnosis you may be feeling afraid, anxious and even depressed. Acknowledging these feelings is important.



MOVING FORWARD ON YOUR JOURNEY WITH HOPE TO LIVE YOUR BEST LIFE WITH PARKINSON'S DISEASE

Recognize that it's okay to have these feelings...
know that it's not the end of the road, it's just a different path.



MAINTAINING A POSITIVE ATTITUDE

There is nothing healthier than a **positive mindset**.

Positivity can lower rates of stress and depression.



MAINTAINING A POSITIVE ATTITUDE

Gratitude helps our brain scan for positivity; we can focus on the good things around us and go into the day with a feeling of happiness and gratefulness.



MAINTAINING A POSITIVE ATTITUDE

Remember that everyday
may not be great...

but acknowledging that
there is something good
in every day makes all the
difference.



Every morning
starts a new page
in your story.
Make it a great one today.

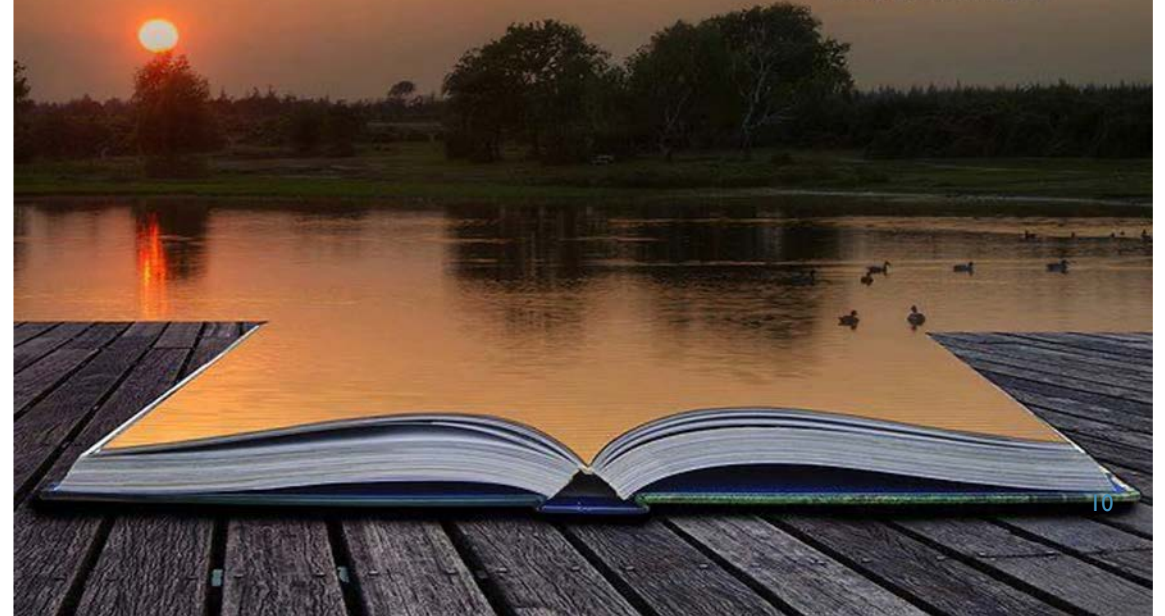
~ Doe Zantamata

MAINTAINING A POSITIVE ATTITUDE

Staying positive
gives you **control**
over your life!

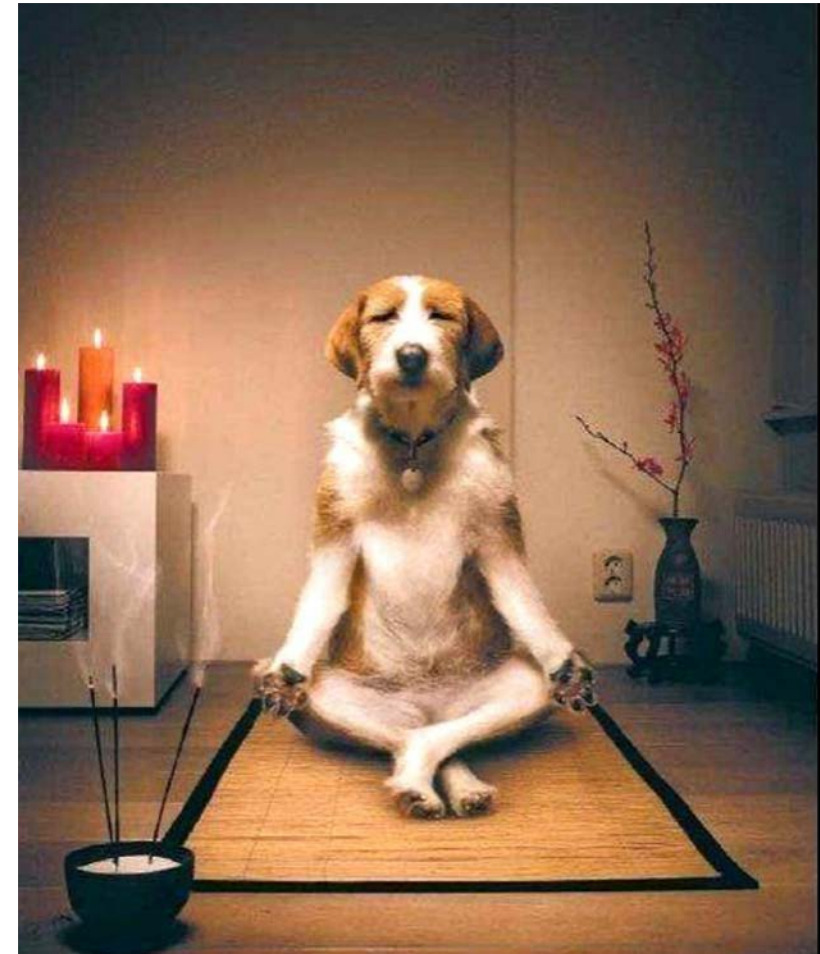
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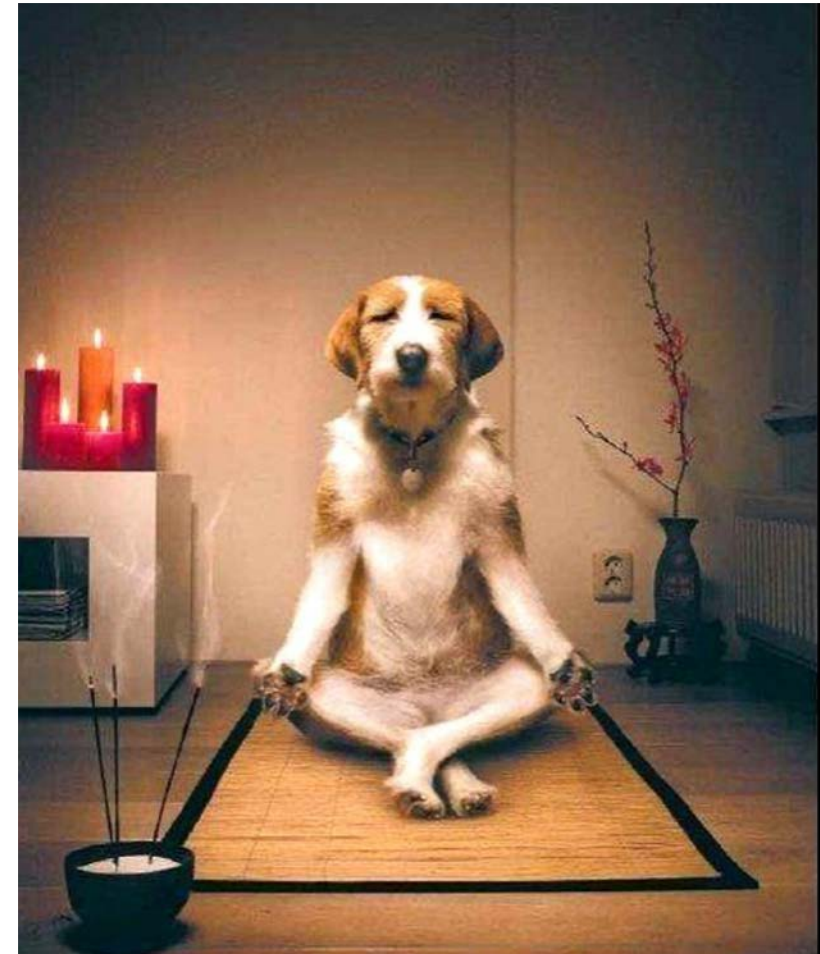
POSITIVE THINKING = POSITIVE OUTCOME

Meditation: You can change the pattern of your thinking by adding positive daily reflections and affirmations



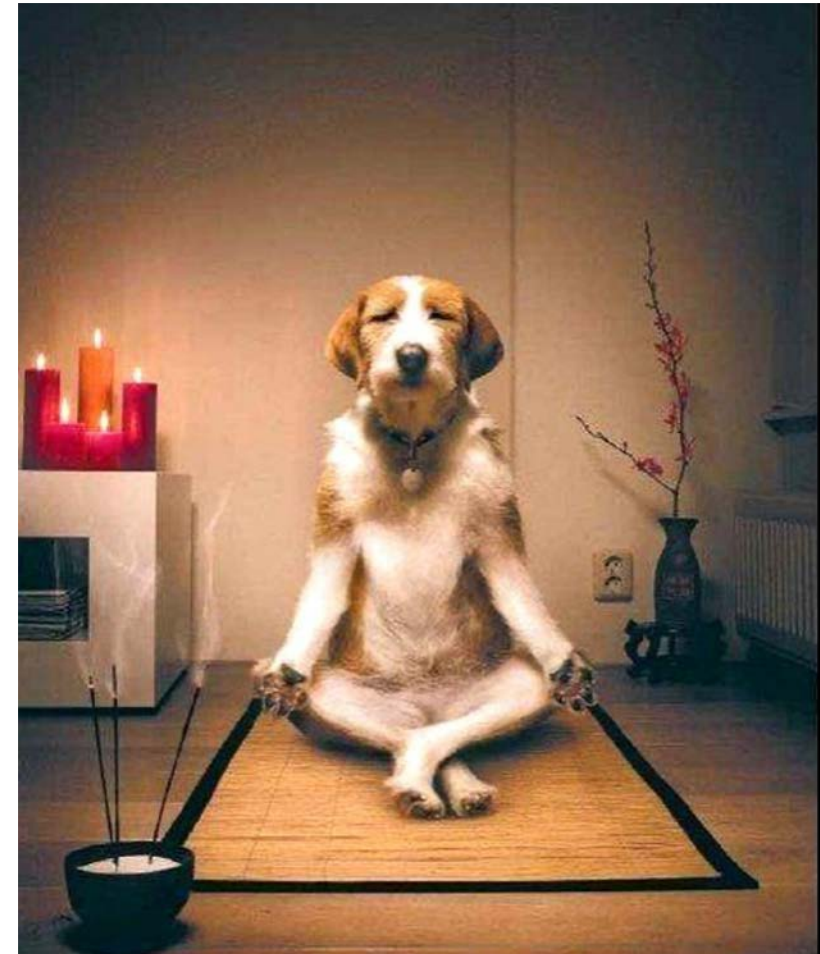
POSITIVE THINKING = POSITIVE OUTCOME

Deep Breathing: Change your brain waves by spending 10 minutes a day doing breathing exercises



POSITIVE THINKING = POSITIVE OUTCOME

Visualize Positive Situations: The brain doesn't know what reality is and what's imaginary



WHAT IS PARKINSON'S DISEASE?

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

(Michael J. Fox Foundation)

WHAT IS PARKINSON'S DISEASE?

- The substantia nigra cells produce dopamine, a chemical messenger responsible for transmitting signals within the brain that allow for coordination of movement.

(Michael J. Fox Foundation)

WHAT IS PARKINSON'S DISEASE?

- Loss of dopamine causes neurons to fire without normal control, leaving patients less able to direct or control their movement.

(Michael J. Fox Foundation)

FACTS OF PARKINSON'S DISEASE

Progressive Neurodegenerative Disease

Affects 1.2 million people in US. Incidence expected to double by 2030; approximately 10,000 in San Diego County

Age of onset typically between 50 and 65

10% of people diagnosed with PD are Young Onset; diagnosed between ages 20-50

FACTS OF PARKINSON'S DISEASE

Caused by loss of dopamine producing cells (80% loss before first symptom)

Loss of cells begins 20-30 years prior to first symptom

Genetics? Environmental causes? Combination of both?

No two people with PD have same disease, symptoms or progression of the disease.

THE PARKINSON'S JOURNEY IS DIFFERENT FOR EVERYONE

Progression differs from person to person

Symptoms vary; not everyone experiences the same symptoms.

While the following information is representative of PD symptoms, the presence of such symptoms varies from person to person

Work with your Movement Disorder Specialist to best manage your symptoms, progression and journey with PD

Parkinson's

what people see

tremors

what people don't see

anxiety
bladder issues
central pain
cognitive issues
constipation
depression
difficulty sleeping
fatigue
involuntary movement

loss of smell
muscle spasms
restlessness
sciatica
sexual dysfunction
skin cancer
slowed movement
speech changes
stiff muscles

my**parkinsons**team

PRODROMAL (PRE-DIAGNOSIS) SYMPTOMS

Symptoms can begin 10-20 years before diagnosis

Loss of Sense of Smell; Taste may be impacted

Constipation

REM Sleep Behavior Disorder

Tremor

Soft or Low Voice

Dystonia

Masked Face

Trouble Moving and Walking

Small Handwriting

Mood Disorders, including depression and anxiety

MOTOR SYMPTOMS & MANIFESTATIONS

Tremor

Rigidity (stiffness)

Bradykinesia (slowness of movement)

Postural Instability

Difficulty rising from a chair

Masking of face

Decreased blinking

Decreased or no arm swing

Small and/or illegible

handwriting

Generalized Pain

Shoulder or calf pain

NONMOTOR SYMPTOMS

Constipation and/or Irritable Bowel Syndrome

Urinary frequency/urgency

Dysphagia (difficulty swallowing)

Fatigue

Sleep Disorders

Neurogenic Orthostatic Hypotension

Dementia - ~30-50%

Cognitive changes

Executive function changes

Pain

Mood Disorders -depression, apathy, anxiety

NEUROLOGIST VS MOVEMENT DISORDER SPECIALIST

Neurologists are specialists who treat diseases of the brain and spinal cord, peripheral nerves and muscles. They complete a three year neurology residency

Movement Disorder Specialists are neurologists who complete an additional movement disorders fellowship.

This type of fellowship is generally 1-2 years long and focuses on Parkinson's Disease and related disorders

MOVEMENT DISORDER SPECIALIST

- Additional experience in prescribing PD-specific medications
- Extra proficiency at managing medication side effects
- Added skill at non-motor symptom management.
- Additional experience in botulinum toxin injections
- Training in deep brain stimulation (DBS) management
- Training in clinical trial methodology, as well as recruitment for and conducting of PD clinical trials

MEDICAL MANAGEMENT OF SYMPTOMS

Medications

- Levodopa/Carbidopa (Sinemet, Stalevo)
- Mono-Amine Oxidase Inhibitors (Azilect, Zelapar)
- Dopamine agonists (Mirapex, Requip)
- Anticholinergics (Artane, Cogentin)
- Amantadine (Symmetrel)
- Beta-blocking agents

MEDICAL MANAGEMENT OF SYMPTOMS

Medications

- COMT Inhibitors (Tasmar, Comtan)
- Rytary
- SSRIS
- Duopa
- Neuplazid

OTHER TREATMENTS/INTERVENTIONS FOR PD SYMPTOMS

Deep Brain Stimulation (DBS) - implantation of leads to targeted areas (usually STN or GPi in brainstem)

Duopa (continuous dopamine infusion through the intestine)

Subcutaneous Duopa delivery

Focused Ultrasound (minimally invasive targeted treatment to brain) has recently received approval for use in both tremor dominant PD and in advanced PD

ALTERNATIVE THERAPIES

Complementary and alternative therapies are broad and can include:

Chiropractic methods

Homeopathy

Music

Acupuncture

Naturopathy; nutritional and herbal supplements

YOUNG ONSET VERSUS OLDER ONSET: POSES DIFFERENT CHALLENGES

Financial Issues

Work

Raising Children

Dating

Disability



RESEARCH

Add www.clintrials.gov

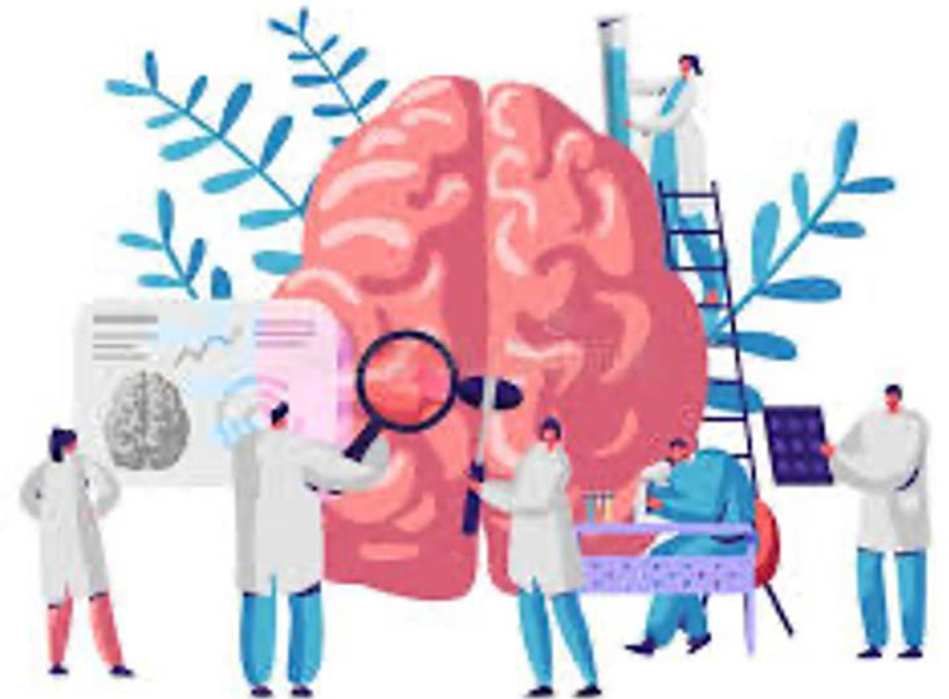
PPMI 2.0 through UCSD

Clinical trials through Neurology Center

FoxFinders.com

Clinical studies through San Diego VA hospital

Clinical trials through UCSD (on movement disorders clinic website)



Neuro Palliative Care Program(s)

Neuropalliative care is a **medical specialty that aims to improve the quality of life for patients and families facing serious, life-limiting neurological illnesses**. Our team uses a comprehensive, whole-person approach that addresses not only a person's medical issues, but also their emotional, spiritual and social needs. Neuropalliative care can begin at any time during your Parkinson's journey.

DEVELOP YOUR INDIVIDUAL CARE AND SUPPORT TEAM

YOU ARE AT THE CENTER OF YOUR CARE



Positive Attitude

Find Purpose

Mindfulness

Exercise

Socialize



- Your Care Partner
- Family
- Movement Disorder Specialist
- Nurse Practitioners
- Primary Care Physician
- Physical Therapist
- Occupational Therapist
- Speech & Language Pathologist
- Exercise Physiologist/Trainer
- Registered Dietitian
- Pharmacist
- Social worker, counselor, psychologist
- Psychiatrist
- Support Groups
- Mentors

ROLES OF YOUR TEAM

ROLE OF A CARE PARTNER

Establish a partnership — a mutual understanding of what kind of help with daily tasks and emotional support the person with Parkinson's wants and needs as the disease impacts your routines and lives.

Educate yourself on Parkinson's

Volunteer to help out with shopping, cooking, cleaning, etc.

Listen —be their shoulder to cry on

Look for worsening symptoms

Be patient with them as their symptoms worsen

TAKE CARE OF YOUR OWN HEALTH SO YOU CAN TAKE CARE OF YOUR LOVED ONE

Make **your** health a priority.

Eat healthy and get enough sleep.

Reserve enough time for your own interests.

Stay social and enjoy time with friends.

Recognize that emotions such as guilt and resentment are normal.

Be aware of signs of depression and get help.

Attend support groups to discuss problems – PASD can refer you to the available support groups in San Diego County.

Learn about the available resources that may help you and your loved-one.



Caregiver/CarePartner Resources

Helping You Care: Comprehensive Family Care Givers Resource

<http://www.helpingyoucare.com/3236/>

in-home-care-agency-what-to-ask Southern CA Caregiver Coalition

<https://www.caregivercoalitionsd.org/>

<https://tlcsenioradvisors.com/> Seniors Helping Seniors

<https://www.seniorhelpers.com/ca/san-diego/county>

Jon Schwartz – Partners in Aging <https://partnerinaging.com/about/>

Caregiver Resource and Magazine <https://www.caregiver.com>

Some Grapes Every Day with Intent



Gentleness

Be gentle with your self and with your expectations

Relaxation

Do something relaxing for yourself

Accomplishment

Tap into your gifts and your accomplishments. Do Something!

GRAPES, continued

Pleasure

Do something that brings you pleasure

Exercise

Do 30+ minutes of exercise – cardio – increases dopamine and endorphins

Social

Interact with people with positive attitudes

BENEFITS OF JOINING A SUPPORT GROUP

Being able to talk openly and honestly about your feelings is helpful.

Feeling less lonely, isolated or judged.

Reducing distress, depression, anxiety or fatigue.

Celebrating successes, big and small.

Improving skills to cope with the challenges of living with PD.

Staying motivated to manage PD symptoms and stick to treatment plans



FIND SUPPORT GROUPS ON PARKINSON'S ASSOCIATION WEBSITE





SUPPORT GROUPS – NORTH COUNTY



Location	Contact	Website	Mailing Address	Email	Phone
North County	Paul Dawson	https://ncpsg.org		paul@video-fire.com	760-497-1200
La Costa/Carlsbad	LaCosta/Carlsbad Chapter - NCSPG			scprphd@gmail.com	520-820-0339
Fallbrook	Fallbrook Chapter - NCPSPG		2724 Secret Lake Ln, Fallbrook, CA 92028	NCPSPGF@gmail.com	760-731-0171
Oceanside	Oceanside Chapter - NCPSPG		2001 South El Camino Real, Oceanside, CA 92054	Oceanside@NCPSPG.org	760-497-1200
Rancho Bernardo	Rancho Bernardo Chapter - NCPSPG			NCPSPGRB@gmail.com	



SUPPORT GROUPS - SAN DIEGO CENTRAL, EAST & RIVERSIDE COUNTY



Location	Name	Website	Mailing Address	Email	Phone
Central County	Nancy Floodberg	https://sdccpsg.org	3845 Leland St., San Diego, CA 92106	president@sdccpsg.org	619-857-6638
East County via zoom (virtual)	Lorenzo Higley	https://sdccpsg.org	5940 Kelton Ave., La Mesa, CA 91942	ECPSG@Cox.net	619-447-2855
Pacific Beach	YOPD, leader is Trace Hill			Hill.trace@gmail.com	



SUPPORT GROUPS – SPANISH GRUPOS DE APOYO



Location	Name	Website	Mailing Address	Email	Phone
Spanish Support Group	Lisbeth Garces	https://www.jcorg.org			619-971-3904
Virtual Spanish Parkinson's support group	Zoom Grupo De Apoyo Unidos Con El Parkinson's	https://us02web.zoom.us/j/84451212345			
Chula Vista	¡Juntos Unidos! Spanish Language Support Group	info@support4pd.org	270 F. Street, Chula Vista, CA 91910	acg008@ucsd.edu	858-822-0791



SUPPORT GROUPS – CARE PARTNERS



Location	Name	Website	Email	Phone
Southern Caregiver Resource Center	Virtual Caregiver Support Group	scrc@caregivercenter.org		800-827-1008
Well-Spouse	Virtual Spouse Care Partner Self Care Group: Contact Edna Culp		culpedna@gmail.com	858-922-3504



Support Groups - Atypical



Location	Name	Mailing Address	Email	Phone
Kearny Mesa	Care Partners for Lewy Body	6632 Convoy Court, San Diego, CA 92111		858-822-4800
La Jolla	Atypical Parkinson's, For PwP and Care Partners Contact: Darlene Gerow	9423 Health Sciences Drive, Medical Center Modular 1 Room 140, La Jolla, CA 92037	darlene.gerow@gmail.com	619-806-9649
La Jolla	Atypical Parkinson's, For Care Partners Only Contact: Darlene Gerow	9423 Health Sciences Drive, Medical Center Modular 1 Room 140, La Jolla, CA 92037	darlene.gerow@gmail.com	619-806-9649

WHY IS EXERCISE SO IMPORTANT

Exercise is important for people with Parkinson's disease because **it helps maintain balance, mobility, and the ability to perform daily routines.** Exercise and physical activity can improve many PD symptoms. It helps stimulate the release of dopamine in the brain. These benefits are supported by research.



FOUR CATEGORIES OF EXERCISE THAT ARE IMPORTANT FOR SOMEONE WITH PD

Aerobic training:

- Walking
- Swimming
- Running
- Cycling

Strength training

Postural muscles

Hip Extensors

Calves

Flexibility Training

Hamstring Stretch

Hip Flexor Stretches

Chest Stretches

Balance, Agility and Dual Task training

- PWR Moves!
- Balancing on varied surface
- Boxing
- Multi-directional stepping

OTHER TYPES OF EXERCISE:

Dance

Yoga

Pilates

Tai Chi

Playing Sports

Water Exercise

Take the Stairs



BENEFITS OF EXERCISE

Exercise creates brain change

Decreased stiffness

Better posture

Reduces pain

Improves bowel function

Improved motion of joints

Improves muscle tone

Enhanced quality of life



NO “EXERCISE PRESCRIPTION” IS CORRECT FOR EVERY PERSON WITH PARKINSON’S DISEASE BUT DOING NOTHING IS NOT THE ANSWER.



Rock Steady Boxing



Coach Me Strong



Dance for PD



NeuroLab 360

PHYSICAL THERAPY

Physical Therapy has been shown to help slow disease progression based on the UPDRS Motor Subscale.

The goal of physical therapy is to keep you active and independent.



PHYSICAL THERAPY

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.

Improves gait, balance, posture, flexibility, strength and endurance.

Reduces Pain

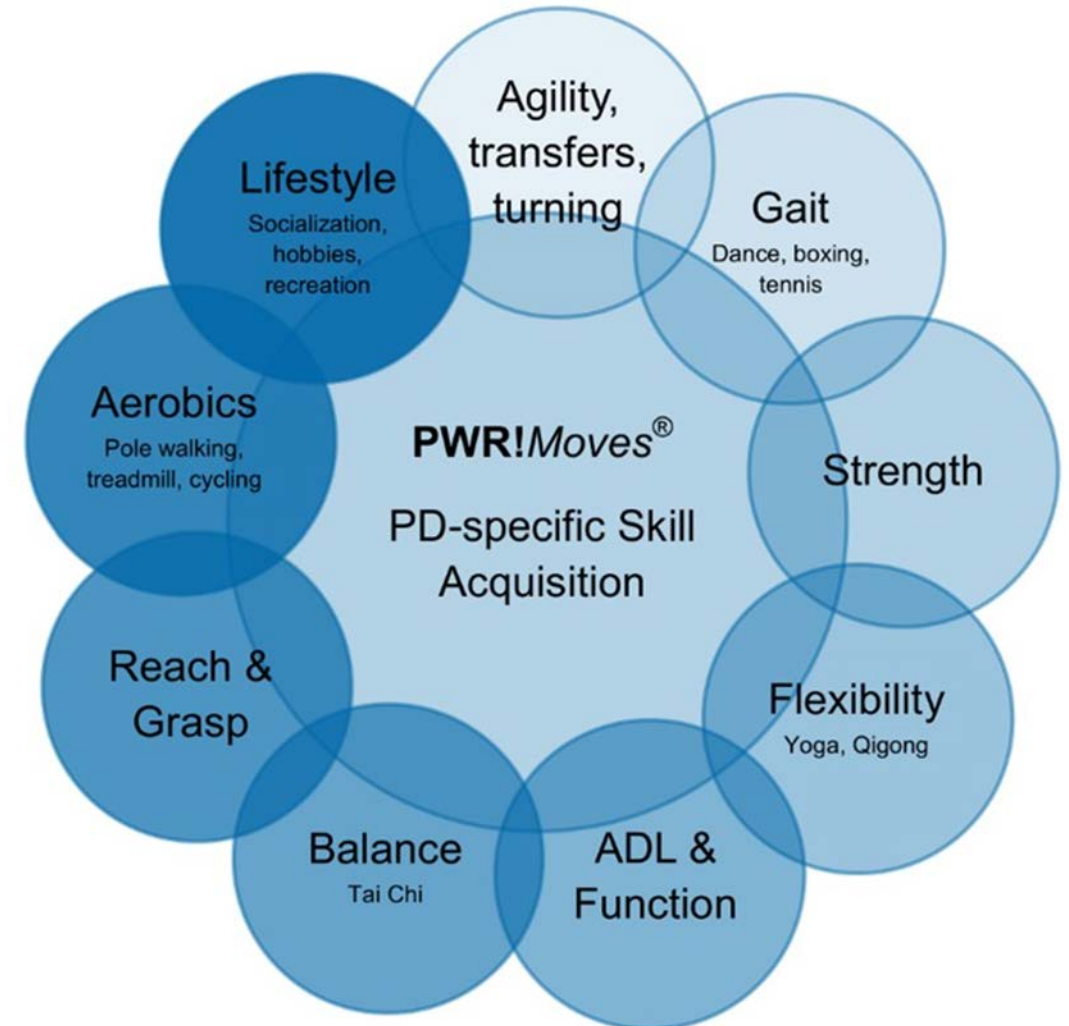


PWR! MOVES

Parkinson's-specific exercise program that works to improve neuroplasticity and slow the progression of Parkinson's Disease.

Focuses on large movements, PWR!

Moves targets **four** critical skills the disease attacks: antigravity extension, weight shifting, axial mobility, and transitional movements.



LSVT BIG

LSVT BIG, an intensive therapy program, helps patients with Parkinson's disease reduce their symptoms and slow the progression of the disease.

The specially designed program helps you improve your balance, move faster and make larger motions.

LSVT BIG® MAXIMAL DAILY EXERCISES



1. Floor to Ceiling



2. Side to Side



3. Forward Step and Reach



4. Sideways Step and Reach



5. Backward Step and Reach



6. Forward Rock and Reach



7. Sideways Rock and Reach

OCCUPATIONAL THERAPY

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

- Bathing and Dressing
- Eating and Drinking
- Toileting
- Hand Strength and Writing
- Meal Preparation
- Performing Housework
- Having the ability to continue to engage in hobbies like gardening, sewing, painting, etc.



SPEECH THERAPY

Speech disorders in individuals with Parkinson's Disease are known as **Hypokinetic Dysarthria**; speech that is slow, slurred or difficult to understand due to muscle weakness.

Almost 90% of individuals with PD will have a speech disorder.

Deteriorating Speech Clarity

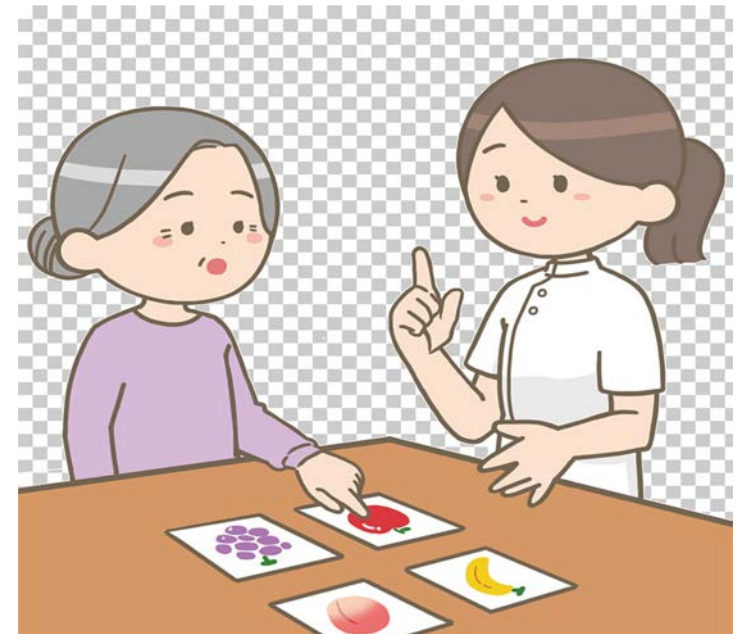
Decreased Voice Volume

Flat/Monotone Voice

Hoarse Voice

Reduced Breath

Lessened Facial Expression



EARLY INTERVENTION IS KEY FOR RETAINING SPEECH

LSVT (LOUD)

An effective treatment to improve vocal loudness in patients with PD.

Patients attend 16 sessions over the course of 1 month.

LSVT improves 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.

EARLY INTERVENTION IS KEY FOR RETAINING SPEECH

Parkinson's Voice Project (SPEAK OUT!)

Preserves the voices of individuals with Parkinson's through intensive speech therapy and follow-up support.

2-3 sessions per week for a total of 12 sessions

Emphasizes the use of intentional speech rather than automatic speech.

NUTRITION

Antioxidant and Mediterranean Diet

Berries

Cranberries

Pomegranate

Grapes

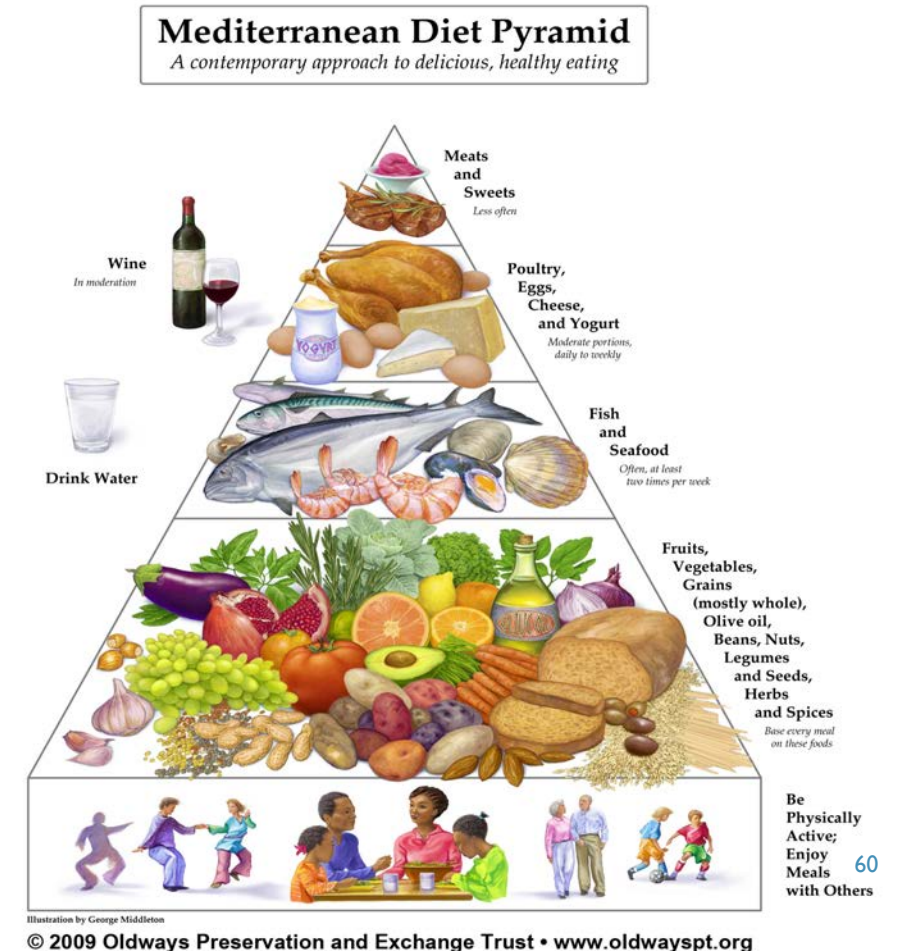
Yellow and dark green leafy vegetables

Red wine

Dark Chocolate

Green tea

Foods containing higher levels of omega-3 fatty acids like salmon, halibut, herring, mackerel, sardines, tuna and nuts.



PASD SERVICES

Empowerment Day

Good Start Program

Website resources, including information on necessary legal documents and for veterans

Support groups coordination

PASD SERVICES

Live phone contact

Educational events, podcasts, webinars

Locally produced educational short videos

PASD SERVICES

Hispanic Community Outreach

Transportation services available

Mobility and other devices available

Step by Step Walk/Golf Tournament

AWARE IN CARE KIT



Materials designed to help people with PD and Care Partners educate and advocate for better care in the hospital

- Online Download (Free)
- Aware in Care Packet (Free)
- Aware in Care Kit (\$8 Shipping charge)

To Download or Order Kit Materials, visit:

Parkinson.org/AwareinCare

One of the mentors listed below will follow up with each participant within one week of this meeting.



ART BRAUN



BOB FOLTYN



EDNA CULP



ELAINE
BROWNING



HANNA KLUNER



IRENE MILLER



JORGE SOTO



KRISTINE NEGRETE



LARRY ROSEN



LISA EVANS



LISA TATARYN



MICHAEL WALSH



PAT COUGHLIN



PAUL DAWSON



SAM COOPER



SANDRA MILLER



STEPHEN
LESTER



SUSAN RUBIO



TOM JOHNSON



WAYNE LABEL



BILL FARRINGTON



DIANE BELCHER



MARTY ACEVEDO

www.parkinsonsassocation.org



Thank you for attending the Good Start Program

Additional Resource Organizations for Parkinson's Disease

Davis Phinney Foundation for
Parkinson's

www.davisphinneyfoundation.org

Michael J Fox Foundation for
Parkinson's Research

www.michaeljfox.org

Parkinson's Foundation

www.parkinson.org

APDA www.APDA.Parkinson.org

PMDA (Parkinson's & Movement
Disorders Alliance)

www.pmdalliance.org

PD Avengers www.pdavengers.com

Parkinson's World Congress

www.worldpdcoalition.org

PASD is here to help throughout your journey!



www.parkinsonsassociation.org



Thank you for attending the Good Start Program