



CELEBRATING CAREGIVERS, SHOWING APPRECIATION, PROVIDING SUPPORT!

Family members with a relative with dementia often experience what has been called “the unexpected career of caregiver” and face multi-faceted, complex and stressful life situations that can have important consequences. While many caregivers say that they derive significant emotional and spiritual rewards from their caregiving role, many also experience physical and emotional problems directly related to the stress and demands of daily care. Each year, more than 16 million Americans provide countless hours of unpaid care for family and friends with Alzheimer’s and related dementias. Approximately two-thirds of dementia caregivers are women, about one in three caregivers (34%) is age 65 or older, and approximately one-quarter of dementia caregivers are “sandwich generation” caregivers, meaning that they care not only for an aging parent, but also for children under age 18.

Caregivers of people with dementia provide assistance for a longer duration than caregivers of people with other diseases. Well over half (57%) of family caregivers of people with Alzheimer’s and related dementias provide care for four years or more. More than six in ten (63%) Alzheimer’s caregivers expect to continue having care responsibilities for the next 5 years compared with less than half of caregivers of people without dementia (49%).

The caregivers we see almost every day have given us some powerful words that we can share:

“You have been a lifeline for me and my family.”

“I don’t know what I would do without your support groups and classes.”

“Our family appreciates the calls and the videos; just knowing there is someone calling and caring means the world to me.”

“My mom is so happy when she knows she is coming to the Alzheimer & Parkinson Association. It’s her world and she loves it.”

Alzheimer’s takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.

The numbers can be overwhelming, and as Alzheimer’s and other dementias progress, behaviors change – as does the role of the caregiver. While these changes can be challenging, here at the Alzheimer & Parkinson Association, we have resources to help you through each stage of the disease.

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A MESSAGE FROM THE

Executive Director



A caregiver and I were discussing how to find new perspective and we agreed that when things felt bleak it was time to be a detective: look for those moments of joy in all of the small places they hide. That “in the now” smile or laugh from a spouse who may not be able to identify you but is feeling loved and delighted ...now there is a hidden joy. You have done your job....you are the successful guardian of their happiness.

It's customary that with a new year comes the opportunity to look at life through a new lens. Often new options are discovered. Finding happiness can be a deliberate decision, so discovering how to find it can be equally deliberate.

Our wish for each of you is that finding joy in all of the places it hides becomes your pattern. Our mission, for those managing dementia care or those managing life with a movement disorder, is to help you find that pattern of discovering joy. Through support, education and connecting with others, there is joy to be found.

Happy New Year!

Peggy Cunningham

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2021-22

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Our Mission

We improve the quality of life for individuals and families in Indian River County who are affected by memory and movement disorders, through support, education, and connection.

Cover photos, left to right: Louise and Jack Porter, Tony Martini and Rosemarie Sangiorgi, Jeanette Lawson and Jeremiah Coonen

Judith Lemoncelli, Editor
Tania Ortega-Cowan, Design



The Washington Corner

WITH BRUCE McEVOY, CHAIR EMERITUS

By raising our voices together, we can influence public policy.

As people living with Parkinson’s disease and their loved ones know, you are — and often must be — your own best advocate. No one knows Parkinson’s better than those who live with it every day. When you share your story and experiences with lawmakers, you help them understand how their policy actions impact patients, families and care partners.

Anyone can become an effective advocate. It can be as simple as picking up the phone or sending an email to your Congress member to let them know how their vote will directly affect you. Or, you can visit your representative at his/her office or a town hall meeting. Social media is also a good way to connect with your legislators. And, you can write about Parkinson’s-related policy issues and submit an article or letter to your local news outlet.

Contact The Michael J. Fox Foundation at <https://www.michaeljfox.org/advocacy-resources> for information on advocacy. Request their toolkit for tips on sharing your story, printable documents to take to face-to-face meetings with members of Congress, and sample telephone scripts, email messages and social media posts.

Thank you for doing what you can to influence public policy!

Bruce

How To Improve Gait In Parkinson’s Disease

Michael S. Okun, MD, endowed Chair of Neurology at the University of Florida in Gainesville, and National Medical Advisor for the Parkinson’s Foundation, says there are many ways to improve gait. His research shows that syncing your rhythm to music is an effective way to improve stride and increase arm swing. And the type of music matters. For example, Dr. Okun found that using an up-tempo, beat-propelled song like the Bee Gees’ 1977 disco hit “Staying Alive” was highly effective in improving walking performance. “The

Bee Gees were better than a metronome,” he says. “But what works for one patient might not work for others,” he adds.

Dr. Fay Horak, PhD, PT, professor of neurology at Oregon Health & Science University, agrees. “Because some of these cues work for a while and then stop, you should have more than one handy,” she says. “Let’s say you’ve been walking using your laser pointer and you freeze. You might want to turn on the metronome feature on your phone.”

Normally, Dr. Horak explains, the legs, head, eyes, and torso work in a coordinated fashion in ambulation. In people with Parkinson’s, movement slows down and is less stable. People also make smaller rotations of the head, trunk, and pelvis. “This makes it especially difficult to turn safely,” Dr. Horak says. “We’ve done studies showing that people turn, on average, about a thousand times a day.”

Dr. Okun added, “If you’re having problems with walking or balance or freezing, it’s important to discuss internal cueing and assistive devices with your neurologist and physical therapist. Different folks will respond to different cues, and those cues can change because Parkinson’s is a progressive disease. So don’t get discouraged.”



Portions of this article courtesy of Brain & Life.

10 EARLY SIGNS OF *Parkinson's Disease*

It can be hard to tell if you or a loved one has Parkinson's disease (PD). Below are 10 signs that you might have the disease. No single one of these signs means that you should worry, but if you have more than one sign you should consider making an appointment to talk to your doctor.

1. TREMOR

Have you noticed a slight shaking or tremor in your finger, thumb, hand or chin? A tremor while at rest is a common early sign of Parkinson's disease.

What is normal? Shaking can be normal after lots of exercise, if you are stressed or if you have been injured. Shaking could also be caused by a medicine you take.

2. SMALL HANDWRITING

Has your handwriting gotten much smaller than it was in the past? You may notice the way you write words on a page has changed, such as letter sizes are smaller and the words are crowded together. A change in handwriting may be a sign of Parkinson's disease called micrographia.

What is normal? Sometimes writing can change as you get older, if you have stiff hands or fingers or poor vision.

3. LOSS OF SMELL

Have you noticed you no longer smell certain foods very well? If you seem to have more trouble smelling foods like bananas,

dill pickles or licorice, you should ask your doctor about Parkinson's.

What is normal? Your sense of smell can be changed by a cold, flu or a stuffy nose, but it should come back when you are better.

4. TROUBLE SLEEPING

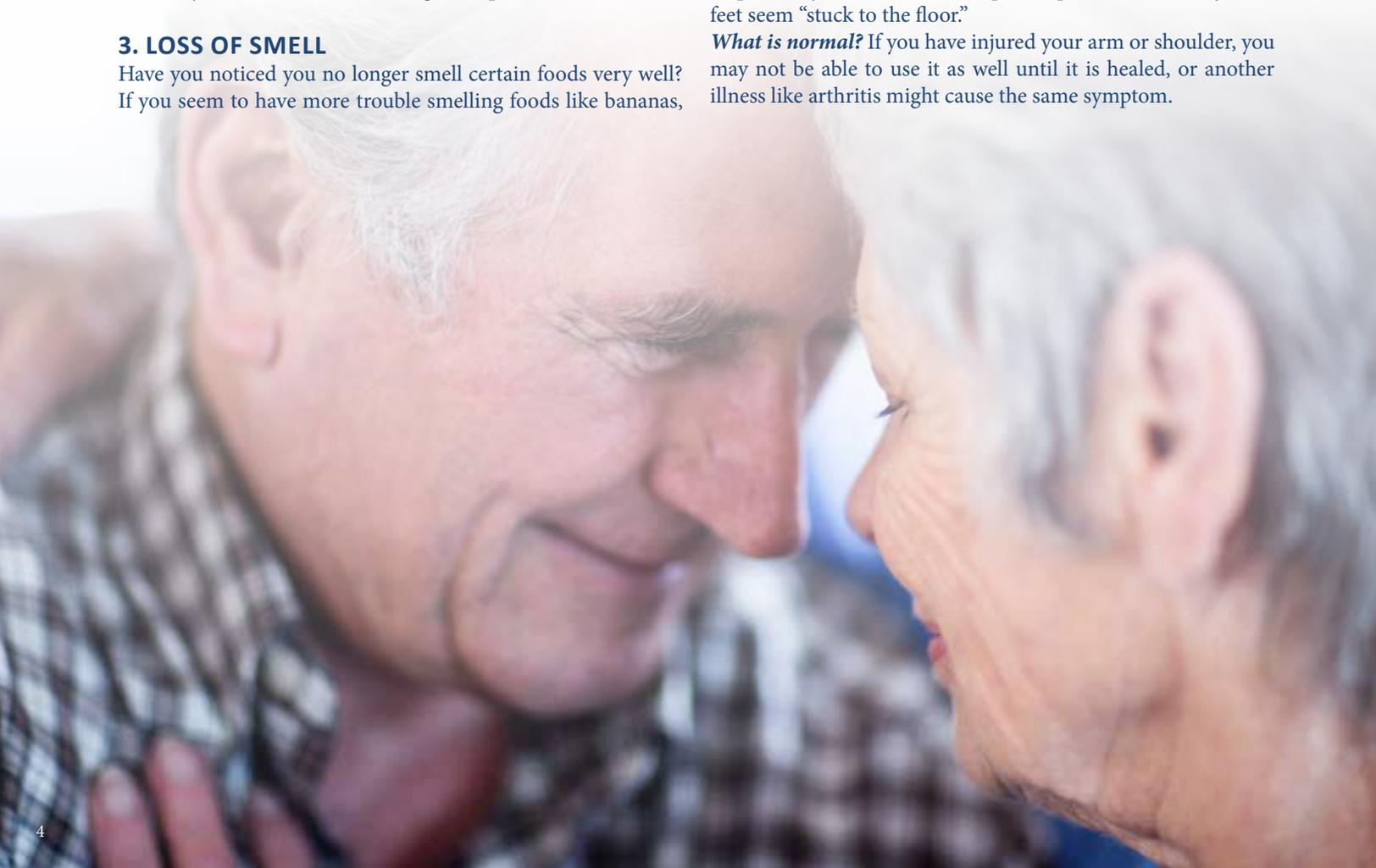
Do you thrash around in bed or act out dreams when you are deeply asleep? Sometimes, your spouse will notice or will want to move to another bed. Sudden movements during sleep may be a sign of Parkinson's disease.

What is normal? It is normal for everyone to have a night when they 'toss and turn' instead of sleeping. Similarly, quick jerks of the body when starting to fall asleep or when in lighter sleep are common and often normal.

5. TROUBLE MOVING OR WALKING

Do you feel stiff in your body, arms or legs? Have others noticed that your arms don't swing like they used to when you walk? Sometimes stiffness goes away as you move. If it does not, it can be a sign of Parkinson's disease. An early sign might be stiffness or pain in your shoulder or hips. People sometimes say their feet seem "stuck to the floor."

What is normal? If you have injured your arm or shoulder, you may not be able to use it as well until it is healed, or another illness like arthritis might cause the same symptom.



6. CONSTIPATION

Do you have trouble moving your bowels without straining every day? Straining to move your bowels can be an early sign of Parkinson's disease and you should talk to your doctor.

What is normal? If you do not have enough water or fiber in your diet, it can cause problems in the bathroom. Also, some medicines, especially those used for pain, will cause constipation. If there is no other reason such as diet or medicine that would cause you to have trouble moving your bowels, you should speak with your doctor.

7. A SOFT OR LOW VOICE

Have other people told you that your voice is very soft or that you sound hoarse? If there has been a change in your voice, you should see your doctor about whether it could be Parkinson's disease. Sometimes you might think other people are losing their hearing, when really you are speaking more softly.

What is normal? A chest cold or other virus can cause your voice to sound different, but you should go back to sounding the same when you get over your cough or cold.

8. MASKED FACE

Have you been told that you have a serious, depressed or mad look on your face, even when you are not in a bad mood? This is often called facial masking. If so, you should ask your doctor about Parkinson's disease.

What is normal? Some medicines can cause you to have the same type of serious or staring look, but you should go back to the way you were after you stopped the medication.

9. DIZZINESS OR FAINTING

Do you notice that you often feel dizzy when you stand up out of a chair? Feeling dizzy or fainting can be a sign of low blood pressure and can be linked to Parkinson's disease.

What is normal? Everyone has had a time when they stood up and felt dizzy, but if it happens on a regular basis you should see your doctor.

10. STOOPING OR HUNCHING OVER

Are you not standing up as straight as you used to? If you or your family or friends notice that you seem to be stooping, leaning or slouching when you stand, it could be a sign of Parkinson's disease.

What is normal? If you have pain from an injury or if you are sick, it might cause you to stand crookedly. Also, a problem with your bones can make you hunch over.

WHAT CAN YOU DO IF YOU HAVE PARKINSON'S?

Work with your doctor to create a plan to stay healthy. This might include the following:

- A referral to a neurologist, a doctor who specializes in brain disorders
- Care from an occupational therapist, physical therapist or speech therapist
- Meeting with a medical social worker to talk about how Parkinson's will affect your life
- Start a regular exercise program to delay further symptoms.
- Talk with family and friends who can provide you with the support you need.

Article courtesy of Parkinson's Foundation and University of Florida, a Parkinson's Foundation Center of Excellence.



National Caregivers Day is February 18

National Caregivers Day is observed on the third Friday in February — on February 18 this year. The day honors individuals who selflessly provide personal care, and physical and emotional support to those who need it most.

There are different types of caregivers who are not just limited to the health sector. The types are: family caregiver, professional caregiver, independent caregiver, private duty caregiver, and informal caregiver.

Some of them are not always paid, which is why it is essential to appreciate and thank them for their long-term commitment.

Alzheimer's Effect on Eyesight

PRACTICAL TIPS ON HOW TO HELP YOUR LOVED ONE

Alzheimer's and related disorders can cause a continual decline in visual and cognitive functioning. Your loved one will struggle to make sense of the world around them and it can be a profoundly distressing and lonely experience. Caregivers, however, can promote a safe, supportive, and calming atmosphere by making some changes to the physical surroundings.

PERIPHERAL FIELD LOSS

Individuals are unable to see things that are on the side, top or bottom, making something as simple as moving around the home without tripping or bumping into things difficult. This deficit may contribute to an inability to detect motion as well.

How to help: Place objects directly in front of the person. Eliminate clutter from floors and tabletops. Use simple adapted devices like large button phones and TV controls, large print calendar, talking clocks, tactile markers on appliances, and adapted kitchen tools, to foster independence and enable activities they can still enjoy.

LOSS OF CONTRAST SENSITIVITY

Individuals may experience difficulty seeing objects of the same color (e.g., an all-white bathroom).

How to help: Use high contrast colors as much as possible (place white mashed potatoes on a dark plate on a light placemat). Change color in a room to help define objects and make it easier to navigate. A dark colored sofa on a light-colored carpet will stand out more. A toilet is easier to see if there is contrast with the wall behind it. Painting baseboards with contrasting color on the walls may help distinguish where the wall ends and the floor begins.

DIFFICULTY WITH DEPTH PERCEPTION

Individuals will have a harder time judging how far an object is, understanding changes in elevations, and differentiating between three-dimensional objects and flat ones – so the person may feel and look off balance. Differences between flooring (carpeting that connects to a tile floor) may be perceived as a step up or down, or your loved one may try to pick up the flowers in the print of a tablecloth.

How to help: Keep areas well lit; place brightly colored tape on the edge of stairs. Eliminate glass and other shiny surfaces.

GLARE

Caregivers need to be mindful of reducing glare in a setting. Floors that are shiny may be painful to look at or perceived as wet by a person with Alzheimer's.

How to help: Consider placing a small, non-slip mat on a tile floor. Close window blinds. Cover mirrors in a room as your loved one with dementia may perceive a person and become startled. Monitor too much background distraction, including television and complex patterns in upholstery and wallpaper.

*Portions of this article courtesy of
Alzheimer's Association and Alzheimer's TODAY*



JOIN US FOR ONE OR MORE OF OUR FREE

Educational Classes

CAREGIVING 101

This 6-week class covers the basic aspects of caregiving for a loved one with dementia: activities of daily living, environment, safety, medications, and behaviors.

STRESSBUSTING FOR THE CAREGIVER™

We know caregiving can be stressful! This 9-week class will teach stress management techniques, relaxation, and coping strategies.

TOTAL MEMORY WORKOUT

For the cognitively well senior. 8 Easy Steps to Maximum Memory Fitness in a 4-week class. Learn brain-healthy lifestyles.

WARNING SIGNS OF DEMENTIA

Join us to learn what the warning signs of dementia are vs. normal aging. 1-hour presentation.

COMPASSIONATE TOUCH

A holistic approach that combines skilled touch with compassionate presence to enhance quality of life for those in the later stages of life. 1-hour class.

THE DEMENTIA EXPERIENCE

This training will aid family and professionals alike to become sensitized to the needs of those suffering with dementia or other memory issues. The dementia experience is a scientifically proven method designed to build sensitivity and awareness about dementia. The experience is for anyone seeking to understand the physical and mental challenges of those with dementia and to create a community of acceptance and support for those grappling with Alzheimer's and related neurological diseases.

Call us for more information about the educational seminars and workshops we offer, led by specialists in the fields of memory and movement disorders.

Our annual Day of Hope Caregiver Conference and Parkinson's Awareness Conference are held each winter and have featured speakers like Teepa Snow, one of the world's leading advocates and educators for people living with dementia and their caregivers.

Call us at 772-563-0505 to find out more about our caregiver education classes and conferences.



Susan Micheel, Alzheimer & Parkinson Association Education Coordinator, with volunteers and staff of Vero Beach Magazine



WALK TO REMEMBER

On November 13, 2021, hundreds of supporters and friends gathered at Riverside Park in Vero Beach to take part in our signature fundraiser – the annual WALK TO REMEMBER. To date, we have raised more than \$214,000 as a result of the impressive fundraising efforts and work done by dedicated families, friends, supporters, and our amazing Walk Volunteer Ambassadors, led by Eileen O'Donnell. What is

perhaps just as important is that all of these funds will stay local, supporting our vital programs that serve people with memory and/or movement disorders in Indian River County. Special thanks to our Presenting Sponsors: Walter Borisenok Family Foundation; Coastal Concierge Services; and George E. Warren Corporation.





Photo by Will Garin

SUCCESSFUL AGING LUNCHEON

Featuring bestselling author
of *Under the Tuscan Sun*
FRANCES MAYES

Thursday, March 17, 2022 • 12 noon
Vero Beach Museum of Art
3001 Riverside Park Drive, Vero Beach

Frances Mayes has always adored houses, and when she saw Bramasole, a neglected, 200-year-old Tuscan farmhouse, it was love at first sight. Out of that instant infatuation has come six marvelous, and hugely popular, books. The #1 bestseller *Under the Tuscan Sun* remained on *The New York Times* bestseller list for two and a half years and was later made into a popular film starring Diane Lane. All of Frances Mayes' books are about taking chances, the pleasures of food, books, wine, gardens, and "the voluptuousness of Italian life."

TICKETS \$200 per person • \$2,000 for a reserved table of 10

A book signing will take place after the luncheon.

CONTACT Judith Lemoncelli at 772-563-0505 ext. 107 or judyl@alzpark.org to make your reservation

The Alzheimer & Parkinson
Association of
Indian River County
is proud to present
its annual event
featuring iconic speakers
who celebrate
successful aging!

Frances Mayes' appearance
is made possible by
the generosity of:

Sandy & Randy Rolf

Nancy & Bob Puff

Emilie & Bob Burr

Becky & Bob Allen

Michelle & Walter Borisenok

MARK YOUR *Calendar*

MEMORY

MONDAYS

- **Vero Social Respite Group:** 9 am - 3 pm, Vero Beach
- **Gifford Social Respite Group:** 1:30 - 4 pm, Gifford Community Center
- **Artful Engagement:** 1 pm - 2 pm, Vero Beach

TUESDAYS

- **Vero Social Respite Group:** 9 am - 3 pm, Vero Beach
- **South County Social Respite Group:** 9 am - 3 pm, Intergenerational Center
- **3rd Tuesday of each month**
- **Support Group for those with loved ones in facility:** 1 pm - 2 pm, Zoom

WEDNESDAYS

- **Vero Social Respite Group:** 9 am - 3 pm, Vero Beach
- **Island Social Respite:** 9 am - 3 pm, Indian River Shores Community Center
- **Island Movement in the Moment:** 11:30 am, Indian River Shores Community Center

THURSDAYS

- **Vero Social Respite Group:** 9 am - 3 pm, Vero Beach
- **Sebastian Social Respite Group:** 9 am - 3 pm, Yacht Club
- **Gifford Educational Classes:** 1:30 pm - 4 pm, Gifford Community Center
- **COPES Support Group:** 10:30 am, Zoom
- **2nd Thursday of each month**
- **AD Support Group:** 2 pm, Vero Beach
- **Gifford Caregiver Support Group:** 2 pm, Gifford Community Center
- **Last Thursday of each month**
- **Evening Support Group:** 7 pm, Zoom

FRIDAYS

- **Vero Social Respite Group:** 9 am - 3 pm, Vero Beach
- **Island Social Respite:** 9 am - 3 pm, Indian River Shores Community Center
- **Movement in the Moment:** 1 pm, Zoom and Vero Beach Social Respite
- **First and third Friday of each month:**
- **Men's Support Group:** 10:30 am - 11:30 am, Vero Beach

SATURDAYS

- **First and third Saturday of each month:**
- **Weekend Respite:** 9 am - 3 pm, Vero Beach

MOTION

MONDAYS

- **Land and Sea:** 11:30 am, The Brennty
- **PD Exercise:** 2:30 pm, Vero Beach Movement Room
- **Last Monday of each month:**
- **Movement Disorders Individual Support Group:** 1:30 pm, Vero Beach Movement Room and Zoom
- **3rd Monday of every month:**
- **Memory Fitness for PD:** 1:30 pm on Zoom

TUESDAYS

- **Qigong:** 1:30 pm, Vero Beach Movement Room and Zoom
- **PD Exercise:** 2:45 pm, Vero Beach Movement Room
- **Last Tuesday of each month:**
- **PD Caregiver Support Group:** 2:45 pm, Vero Beach Office and Zoom

WEDNESDAYS

- **Chair Yoga:** 3 pm, Vero Beach Movement Room and Zoom

THURSDAYS

- **Qigong:** 1:30 pm, Vero Beach Movement Room and Zoom
- **Balance Class:** 2:45 pm, Zoom

FRIDAYS

- **Tremble Clefs:** 2 pm, Vero Beach Movement Room
- **VBMA Movement Class:** 3 pm, Vero Beach Movement Room

**CONFIDENTIAL MEMORY SCREENINGS
AVAILABLE BY APPOINTMENT.
CALL 772-563-0505**

Janet and Bob Wood enjoy one of our many movement classes.



SUPPORT GROUPS

AD CAREGIVER GROUP

For caregivers of loved ones with Alzheimer’s or other dementias.

Vero Beach- 2nd Thursday at 2 PM

Indian River Estates – 4th Wednesday of each month at 2 PM
(Call 772-562-7400 for more information)

COPEs

(Caregiver Ongoing Practical Education & Support)

This is a support group for all caregivers available via Zoom.

Vero Beach – 2nd and 4th Thursday at 10:30 AM via Zoom

Sebastian – 1st and 3rd Thursday at 10:30 AM via Zoom

MEN’S GROUP

A support group for male caregivers to share their challenges and lessons learned.

Vero Beach, 1st and 3rd Friday at 10:30 AM

MOVEMENT DISORDER SUPPORT GROUP

A support group for those with movement disorders to discuss challenges and share experiences.

Vero Beach, last Monday of each month, 1:30 PM

Indian River Estates, 4th Wednesday of each month at 10:30 AM (Call 772-562-7400 for more information)

PARKINSON’S CAREGIVER SUPPORT GROUP

A support group for family and caregivers of loved ones affected by Parkinson’s disease or related movement disorders.

Vero Beach, last Tuesday of each month at 2:45 PM

CAREGIVER SUPPORT WHEN YOUR LOVED ONE IS IN A FACILITY

3rd Tuesday of each month at 1 PM via Zoom.

EVENING SUPPORT GROUP

Last Thursday of each month at 7:00 PM, via Zoom

GIFFORD CAREGIVER SUPPORT GROUP

Second Thursday of each month at 2:00 PM, Gifford Community Center



Save the Dates!

February 14 & 15 from 10 am to 2 pm

FIRST PRESBYTERIAN CHURCH • 520 Royal Palm Boulevard, Vero Beach
\$20 per day (includes lunch) • **Call 772-563-0505 to make a reservation today!**

Parkinson's Conference

Monday, February 14

*An educational conference on
Parkinson's disease featuring:*

**CRISTA ELLIS, BS, RYT-200, Parkinson's Foundation
and JOHN SAMMARTANO, JAS Fitness LLC**



Day of Hope

Tuesday, February 15

*An educational conference on Alzheimer's disease
and other dementias featuring:*

**PAM BRANDON
Founder & CEO, AGE-u-cate® Training Institute**



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