

PD SENTINEL

CONNECTICUT PARKINSON'S WORKING GROUP

SUMMER 2017

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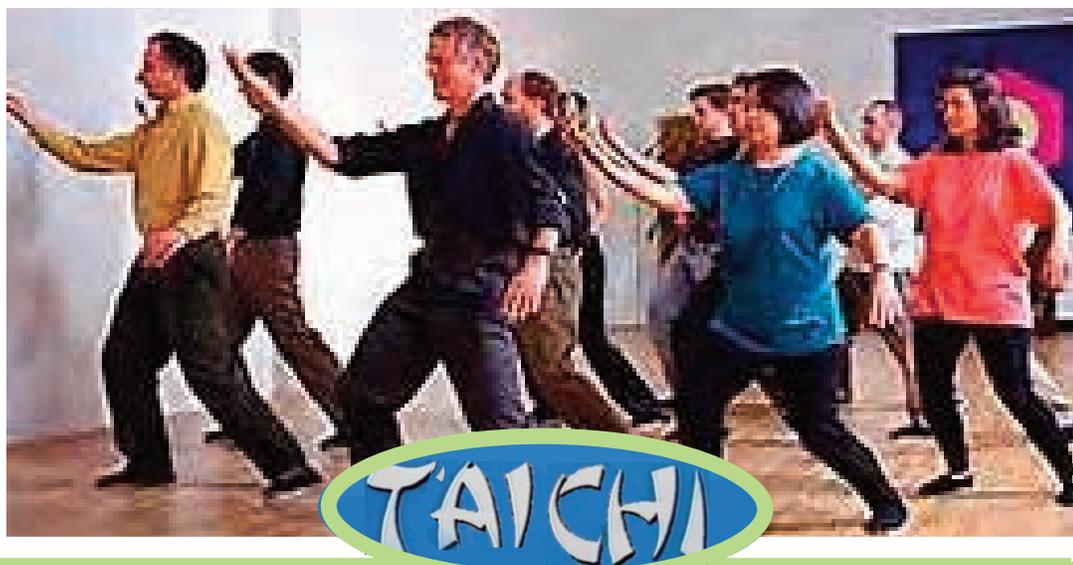
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Benefits for Patients With Parkinson's

Tai Chi, an ancient martial art characterized by slow, flowing movement and meditation, helps improve balance and movement control for people with Parkinson's Disease.

The finding, published in *The New England Journal of Medicine*, is the latest study to show the benefits of Tai Chi for people with chronic health problems. Past studies have shown that Tai Chi reduces falls and depression among the elderly, and lessens pain for patients with arthritis and fibromyalgia.

In the latest research, 195 people with movement and balance problems caused by Parkinson's Disease were recruited from four Oregon cities. The patients were divided into three exercise classes that met for an hour a day, twice a week. One group took part in an extensive stretching class, another was taught resistance training, and the third group performed Tai Chi.

After six months, patients in the Tai Chi
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LIVING WITH PD NATURALLY

Some Supplements For Parkinson's Disease

By Martha Jaffe



.You should always check with your doctor before trying new supplements especially when you take prescription medication.

This article lists some of the supplements that I take to help with my Parkinson's symptoms. You should always watch for adverse reactions when you start a new supplement, and stop taking it immediately if you suffer from one. If you seem to be tolerating the supplement, take it for at least 1 or 2 months to see if it makes any difference since most supplements need time to work.

Magnesium: is a mineral that's involved in over 300 biochemical functions in the body including helping neurotransmitter functions. A magnesium deficiency can cause noticeable negative symptoms including muscle aches or spasms, poor digestion, anxiety, trouble sleeping and restless legs. Many of us with PD do not get enough magnesium from the foods that we eat, and absorption can be blocked by a number of different things. I recommend supplementation with either Magnesium Citrate (an added benefit of this can be relief of constipation), Magnesium Glycinate or Chelated Magnesium, as all these forms are more easily absorbed than others. If you have trouble taking pills (these tend to be rather large) you could try Magnesium Oil or Spray which can be absorbed transdermally. I actually use both supplements and a spray. (I use AllVia Magnesium Topical Spray, as recommended by my acupuncturist.) Magnesium spray can be a bit itchy at first so I mix it with carrier oil (e.g., sweet almond oil, fractionated coconut oil, jojoba oil, etc.) so it won't irritate my skin.



Glutathione and N-Acetyl-Cysteine (NAC): glutathione is an antioxidant that protects cells from toxins such as free radicals. Your body creates

amino acids as building blocks. Those amino acids are cysteine, glycine, and glutamine. Out of the three, cysteine is usually in the shortest supply in your body, and can be increased by taking N-Acetyl-Cysteine (NAC). Make sure you take it with plenty of vitamin C to prevent kidney stones. I started taking NAC at the advice of my naturopath about 4 years ago, and added glutathione over a year ago. I found that after about a month taking the glutathione my cognition and both my short and long term memory seemed to improve. Now I remember a great deal of my past and don't forget things as easily as I had been. I use Vitacost brand N-Acetyl-Cysteine and Jarrow Reduced Glutathione.



Turmeric/Curcumin and Ginger Root: both these supplements reduce pain and inflammation. Since my body tends to get used to supplements after a while, I like to switch between these two supplements occasionally to increase their effectiveness. When I'm looking for turmeric, I try to find either a liposomal one or one that includes piperine (aka bioperine) to improve the absorption. I usually take either supplement 2 or 3 times a day.

Omega-3 Fatty Acids: research shows that omega-3 fatty acids can dramatically reduce inflammation. They are highly concentrated in the brain and are vital for memory and mood. I can't eat fish and can't stand the fishy burps that a lot of supplements give me so I use Jarrow Formulas Max DHA. I take 2 capsules 2 or 3 times a day.



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Board MEMBER SPOTLIGHT

Honoring Our Proud History

By Judy Grasso



My name is Judy Grasso. My husband and I have been members of CPWG for three years.

I was recently asked to serve on the CPWG Board of Directors. While I had read the recent CPWG newsletters, I embarked on a mission to read all the newsletters written since 2000 in order to fully understand and appreciate the history of the organization. The founders of this organization were an impressive and visionary group of people. The mission of CPWG has always been to provide education and support to people with Parkinson's

formation about new drugs in the research pipeline, suggestions about how to manage common symptoms experienced by many patients, and announcements about educational and fund-raising activities occurring throughout the state. Additionally, the newsletter always contained a funny or heartfelt story about a personal experience of a CPWG member. These real-life stories reminded us that we will all have times when we will not have total control of our bodies, and that it is better if we can laugh about it. There also were some lovely stories about the importance of family support. There are many fine examples of the actions that our leaders have taken over the years to enhance CPWG programs. When the results of clinical trials began showing that exercise, including dancing, was the only way to slow down the progression of Parkinson's Disease, CPWG initiated "Dancing with Parkinson's" classes in New London and Middletown. In order to keep these important dance classes ongoing, Jackie Dorwin, president of CPWG at that time, seized the unique opportunity to partner with The Neighborhood Music School (NMS) in New Haven. NMS was already operating a similar class, and was the natural organization to carry the program forward. The only requirements were that CPWG would be able to find a free space for the class and that NMS would supply the instructor.

These old newsletters were inspiring to me. They clearly demonstrated the dedication to the Parkinson's community by the founders of CPWG. As these people move on to other endeavors, we now have the challenge of how to move forward without them. We need new members to step up with fresh ideas about how we can maintain our commitment to the Parkinson's community.



Disease and their families. They accomplished this goal by inviting physicians and other practitioners to speak at meetings. Each newsletter provided in-

**Paraphrased from article published by Michael J. Fox Foundation,
Rachel Dohhum, M.D., on staff, Movement Disorder Specialist.**

Sharing in your loved one's journey with Parkinson Disease (PD) means integrating the diagnosis together into your lives, adapting your routine and supporting him or her as the disease progresses — essentially, establishing a care partnership. This can sometimes be challenging; from learning about the disease and how best to help your loved one, to remembering to also care for yourself. There are steps you can take to help adjust to your new role as a care partner while maintaining a healthy and supportive relationship with your loved one



How Can I Help Manage My Loved One's Care?

Become an integral part of your loved one's responsibilities associated with the disease, including doctor appointments, therapy

sessions, medication administration, household duties or any activity that's more difficult to perform because of Parkinson's disease. People with Parkinson's will desire different levels of assistance, and some wish to maintain as much independence as possible. You won't know if a person wants help unless you ask, but then respect their response. Communication about these issues is key to understanding how best to help your loved one. Care partners play a major role on the team of people treating Parkinson's. You offer an outside view of how your loved one has been doing in the interim since the last visit. You may also recognize new symptoms or subtle changes that the person experiencing Parkinson's doesn't. For example, your loved one's mood or behaviors may have changed, and he or she may be more withdrawn. These could be signs of depression, which is a clinical symptom of PD and is treatable with medication. A person with Parkinson's might otherwise dismiss this as a reaction to the diagnosis of PD or not even mention it to the doctor. You may also have noticed that your loved one's speech has become softer or more monotone. This may impact

your ability to communicate and therefore also impact your relationship. Speech therapists can prescribe exercises to improve voice control.

As a caregiver, keeping track of all the details associated with medical care can be overwhelming. Here are some tips to help.

❌ Stay organized with a calendar that you can take on doctor visits. Note doctor and therapy appointments, start and stop dates of medicines, and any side effects you notice.

❌ Keep a list of all doctor's phone numbers and addresses in case of an emergency. Keep a separate and updated list of all prescription medications, their dosages and instructions and prescribing provider. Note allergies or medication intolerances as well.

❌ Familiarize yourself with the terms of your loved one's medical insurance. Know what services, including prescription medication coverage and therapy session benefits, are included. Talk with your physician about the long-term needs of your loved one, and make sure his or her current medical plan will meet those needs. Engage the services of a social worker if you need help navigating these issues.

❌ Know your rights in terms of disability coverage, family leave and elder rights. If possible, **consult a movement disorder specialist**, a neurologist specially trained in Parkinson's disease and other movement disorders. Before appointments, prepare a list of your questions for the doctor. You do not need special medical training to help with any but the most advanced stages of the disease. Most caregivers are primarily called on to aid with daily tasks that may become difficult or impossible for someone with Parkinson's, and to provide ongoing emotional support. One exception: if Parkinson's causes trouble swallowing and therefore increases the risk of choking, knowing the Heimlich maneuver can be life-saving



How Will Parkinson's Affect My Relationship?

Parkinson's disease can place stress on a marriage or relationship. The fatigue and motor difficulties of the disease can cause changes in your partner's appearance, and influence their contribution to household chores. Cognitive and mood changes may make it hard to initiate and follow through on everyday tasks, which can be frustrating for both of you. Effective communication is vital for the long-term health of your marriage. As with any other important development that affects the lives of two people who are close, Parkinson's Disease should be discussed openly and honestly. Do not consider your own concerns as a caregiver less important.



Can I Care for Myself?

Caring for a person with a chronic illness full-time can be overwhelming. Put together a list of friends and family members whom you trust and can call upon to relieve you for a few hours or in case of an emergency. Consider seeking outside, professional help for in-home assistance if you can afford it. Don't forget your own interests and your life outside of Parkinson's Disease. Schedule regular social activities and time for yourself. For Parkinson's patients who require constant care, check out local programs that will take care of them on a temporary basis (sometimes called "respite care"). Support groups offer the opportunity to share experiences and information with empathetic ears.



There are groups for Parkinson's patients and their loved ones to attend together, and separate groups just for caregivers.

FYI FOR YOUR INFORMATION

Healthy Ideas

Laughter has been proven to be therapeutic. It enhances your intake of oxygen, stimulates your heart, lungs and muscles, and increases the endorphins that are released by your brain.

It can relieve your stress response. The result? A good, relaxed feeling. Laughter can also stimulate circulation and aid muscle relaxation, both of which help reduce some of the physical symptoms of stress and of course Parkinson's Disease. "Always find a reason to laugh. It may not add years to your life but will surely add life to your years".

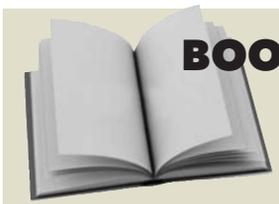
Simple tips for increasing your production of dopamine: keep a checklist for small tasks, create something, exercise, get a streak going (e.g. finish multiple small jobs), listen to music, and, finally, meditate.

Three 10-minute bouts of exercise may be as good as a single 30-minute bout so when you can't seem to get motivated to do a big exercise routine, just try to do 10 minutes and see where it leads.

Forgive yourself if there is a goal you do not achieve.

Be selfish with your time and yourself...since fatigue can be an issue, you will want to say NO to things that might take the time you'd rather spend doing things that are important or fun for yourself and family.

Keep Doing things you like to do, and look for other things as well...at the end of the day you will feel more rewarded if have done things that make you happy.



BOOK REVIEW

By Judy Grasso

A Parkinson's Primer by John M. Vine (Paul Dry Books, Philadelphia, 2017)

My husband recently brought home a book titled "A Parkinson's Primer". While we have read many books and articles about Parkinson's Disease, this book particularly caught my husband's eye because the author, John M. Vine, had been a student at Amherst College during some of the years my husband was also a student there. He remembered John Vine as an intelligent and thoughtful person, and wanted to know more about his perspective on living with Parkinson's Disease. Once I started reading the book, I could not put it down.

Vine, who continues to work as a practicing attorney even in his seventies, writes a powerfully honest book about the realities and challenges of living with Parkinson's Disease for the past twelve years. His 149-page book is a readable, helpful, and non-technical guide written from his personal experiences. Vine agrees with the image of Parkinson's as a "snowflake" disease because just as no two snowflakes are identical, no two Parkinson's patients have identical symptoms. For this reason, and with his own instincts as an attorney, he decided to interview several people with Parkinson's so that his book could capture the different symptoms patients experience and the various ways they have learned to cope with them. In the interviews, many people reported being misdiagnosed because they did not present with the usual motor symptoms of Parkinson's. Instead, they reported persistent problems with sleep, concentration, and other executive brain functions such as calendar issues. One person reported, "I am never sure what day it is". Another woman said her husband used to be a "take-charge guy", and now "he puts matters off."

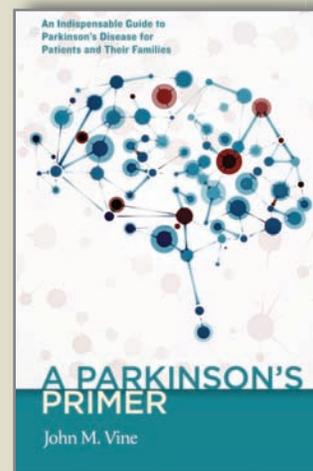
Vine's recounting of the interviews he did with people with Parkinson's was meaningful to me because it was so personal. People knew he understood their challenges, and willingly shared their lived experiences of Parkinson's Disease with him. One woman stated that, "freezing is a bitch"; she cannot walk or continue walking, and feels as if her feet are glued to the floor. Vine writes that patients are often able

to break a freeze by imagining a line or mark on the floor and trying to step over it, or by using a cane or walker equipped with a laser pointer that projects a line to step over. Vine self-reports that he walks, eats, dresses and organizes his office much more slowly than in the past. "Rather than resigning myself to being constantly late and under stress I allow more time to get things done".

Vine's honesty is apparent throughout his book. Although he discusses nonmovement symptoms in detail in Chapter 5, he states that he covered these symptoms because these are the symptoms he never wants to have. Even so, Vine goes on to report, "I often find it difficult to carry on a conversation at the same time" as walking. "Parkinson's seems to make it more difficult for me to switch my attention from one task to another. It seems to draw on the same pool of limited energy".

John Vine's highly informative book is especially well-suited for people with Parkinson's and their families who may continue to be overwhelmed and shocked by the diagnosis of the disease and its progression. In layman's terms, the book reviews medications used to help manage the disease, physical and speech therapies, exercise, the benefits of support groups, financial concerns, and myths and misconceptions about Parkinson's Disease.

While he makes it clear that each patient has a unique journey, Vine also describes many common-sense approaches for managing the symptoms of the disease and improving quality of life that were gleaned from individual patient interviews and his personal experiences of living with this disease. It is the personal accountings that make this book unique.



Tai Chi Benefits ... *Continued from page 1*

group performed better on a number of measures related to strength, movement control, balance, stride length and reach. Resistance training also offered some benefits, and both the Tai Chi and resistance training groups had fewer falls than the stretching group.

Why Tai Chi helps people with Parkinson's isn't entirely clear but it may be that practicing Tai Chi trains the parts of the brain that control balance and movement to adapt more quickly in response to the motor control challenges of Parkinson's. It could also be because Tai Chi movements rotate the human body in about 95% of the ways the body can move when a long form is practiced. This is far beyond what other exercise offers, and in fact the closest would be several swimming strokes, which together would only rotate the body in about 65% of the ways it can move. For PWP's, or anyone for that matter, this would indicate that by "using" 95% of the body's possible motion several times a week, the possibility of "losing" the ability to do so diminishes accordingly.

Preliminary research has shown that Tai Chi can lower blood pressure; about one-third of Americans (roughly over 90 million) have hypertension. Tai Chi can also boost immune function profoundly; a study cited at drkoop.com indicates that a Tai Chi-practicing group was twice as resistant to the shingles virus,

and researchers believe this would carry over to other viral resistance as well. Tai Chi can dramatically reduce falling injuries by about a half; complications from falling injuries in older Americans is the sixth leading cause of death for seniors.

In addition to the above, Tai Chi may very well relieve depression, anxiety, and mood disturbance. There are indications that Tai Chi may greatly reduce or even eliminate chronic pain conditions, lessen allergic and asthmatic reactions, and improve overall respiratory function.

The Parkinson's Society of Canada recommends Tai Chi for Parkinson's patients, suggesting, "Tai Chi may prevent or at least slow down the onset of degenerative diseases; in the long run. The Neurology Channel reported, "The slow flowing movements of Tai Chi help maintain flexibility, balance, and relaxation."

CPWG helped to sponsor a free 8 week Tai Chi class led by Tom Cushing. CPWG has just learned that Tom is in talks with the Village at South Farms to bring a Tai Chi class back. Due to the tremendous success of his initial set of classes, Tom has been asked to do it again. For more information contact Tom at **860-345-3838** or visit his website at Tcush@snet.net.

Some supplements ... *Continued from page 6*

B Vitamins: among other things, B vitamins help improve your overall energy level and help regulate your mood. Many of us are prone to deficiencies in folic acid, B12, and B6. I take 2 capsules of Emerald Laboratories B Healthy CoEnzymated brand since it contains the natural form of vitamins. Because it's enzymated, it doesn't need to be converted by your body in order for it be useful.



Probiotics: The friendly bacteria in your intestinal tract—probiotics—form the front line of your immune defense. You might be surprised to learn exactly how powerful your gut bacteria actually are in preventing and fighting inflammation. I found one that really helps me with constipation: Hyperbiotics Pro-Bifido Probiotic support for ages

50+. I order this from Amazon via their "subscribe and save" program.

Vitamin D3: aka the sunshine vitamin. Benefits listed for this vitamin include immune system support, and nutrition for your brain. I find that it also helps me by reducing fatigue and depression in the winter. In any case, many of us are deficient in this vitamin especially in the winter, so supplementation is important. Vitamin D3 (aka Cholecalciferol) is the most absorbable form of vitamin D. I take at least 5000iu in the winter and 2000iu or more in the summer depending on how much sunlight I get.





**CONNECTICUT
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Disclaimer: The content of this newsletter is offered to our readers solely on an informational basis and is not intended to support any medical treatment or advice. You are encouraged to review information regarding treatment with your physician. The opinions expressed are those of the writer or presenter and do not constitute an endorsement or approval by the CPWG Board or Newsletter staff.

Calendar

CPWG Activities:

Regular 3rd-Saturday-of-the-Month Meetings, 10:00a.m.-Noon. The Village at South Farms 645 Saybrook Road, Middletown, CT Visit us at www.cpwg.org.

August 19 – Dietician from Hartford Hospital will present “Nutrition Matters”, focusing on the Mediterranean and DASH diets to promote healthful eating.

September 16 - A speech therapist will feature a presentation about the LSVT Big and Loud program now being offered at Middlesex Hospital.

Events:

The 4th Annual MADPA Summer Symposium Saturday, July 29, 2017 8:30 a.m. to 3 p.m. University of Saint Joseph The Carol Autorino Center, Bruyette Athenaeum 1678 Asylum Avenue West Hartford, CT 06117.

**Morning: Prominent Parkinson's Experts Lunch and a MADPA Tote Bag too!
Afternoon: Breakout Sessions.**

To register for the symposium, send name, email address and phone number of each person attending to Susan Pelchat at sgpelchat@sbcglobal.net or call 860-489-1677 by July 26, 2017.

This is a free event sponsored by the Make a Difference Parkinson's Alliance.