



PD-Support for Daily Living

The information in this packet will guide you in the management of your disease

1. Websites that provide information and additional materials for your review
 - a. National Parkinson Foundation (www.parkinson.org)
 - b. Parkinson's Disease Foundation (<http://www.pdf.org>)
 - c. Davis-Phinney Foundation For Parkinson's (www.davisphinneyfoundation.org)
 - d. Weekly News Update (<https://nwpf.org>)
2. Parkinson's Support Group-Larimer County (<http://www.pdsupportlc.net>)
 - a. Larimer County Exercise Class Schedule
 - b. Parkinson's Advocacy Program
3. Classes help ease Parkinson's disease symptoms (Zapanta)
4. Parkinson's – Not Just a Motor Disease (Postuma & Christian Galatas)
5. Moving through Parkinson's (Gilbert)
6. Build Your Neurological Care Team (Giroux)
7. Improve your Medical Appointment-Return visit forms (Giroux)
8. Parkinson's Foundation Contact Information Card and Parkinson's Foundation Medical Alert Card
9. PWR (Parkinson's Wellness Recovery Program)
10. 25 Things People with Parkinson's disease can relate to (Smith)
11. Deep Brain Stimulation for Parkinson's Disease Fact Sheet
Recommended Book...Easy reading; order on-line
DBS - A Patient Guide to Deep Brain Stimulus
Giroux and Farris 2013
12. Participation in Research
Recommended Book...Easy reading; order on-line
Alter your Course...Parkinson's-The Early Years
Giroux and Farris 2014
13. Michael J. Fox Trial Finder (<https://foxtrialfinder.michaeljfox.org>)

www.centerformovement.org/books-resources

Home	Patients	Caregivers	Events	Resources	PSGLC	Donate	Contact Us
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**Parkinson's Support Group
in Larimer County
(PSGLC)**



In the United States, it has been estimated that more than 1 million people have Parkinson's Disease (PD). In Colorado the estimate is 15,000 and in Larimer County there are at least 900 suffering from this chronic disease.

The Parkinson's Support Group in Larimer County (PSGLC) has more than 100 members including PD patients, their caregivers, family and friends, health professionals and other interested parties.

The Larimer County Parkinson's Support meeting is held the first Wednesday of each month at the Fort Collins Senior Center, 1200 Raintree Drive, from 10:30am to 12:30pm.

Visitors and newcomers are always welcome. There is no admission charge.

September 2nd Meeting -- Jeff Caron, CLU, CLTC

The September 2nd meeting of the Parkinson's Support Group in Larimer County will have Jeff Caron as a speaker talking about supplemental insurance for people with Parkinson's Disease.

Jeff will be speaking about supplemental insurance benefits that cover both Home Health Care and Home Health Aides. Mr. Caron has spent the last 18 years working in Life Insurance, Long Term Care and Annuity businesses. During that time he served as manager and District Leader/Manager for New York Life, Mass Mutual and Genworth. He is currently a Certified Life Underwriter (CLU) and Certified in Long Term Care (CLTC).

The meeting will begin at 10:30am and will be followed by break-out sessions for patients and caregivers as time permits.

Donald Gaymon (Home Watch Caregivers) has volunteered to give a ride to our meeting if someone is not able to find a ride. His number is 970-227-9095.

Please note our bad weather policy: If schools close due to weather problems, we will not hold a regular support group meeting on that day.



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***Parkinson's Support Group
in Larimer County
(PSGLC)***

Our Monthly Meetings

Please join us the 1st Wednesday of each month from 10:30 - 12:30

- Monthly meetings are held at the Fort Collins Senior Center, 1200 Raintree Drive, Ft. Collins, CO
- At each meeting our members and guests enjoy a brief 15 minute social time with refreshments.
- 1 hour Speaker/Presentation/Webinar.
- 45 minute breakout session for patients and caregivers to meet separately.
- 12 sessions a year including one session for our Year End Holiday Party and one session for our summer picnic.



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------	----------	------------	--------	-----------	-------	--------	------------



**Parkinson's Support Group
in Larimer County
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2015 Exercise Class Schedule

Voice, Exercise, and Movement Classes for People with Parkinson's (PWP)

Come and join us for these dynamic and fun classes! You can come to one, two, or all for a great therapeutic combination. The tables below have information and contacts if you have questions or concerns or contact Chris Hageseth at (970) 222-1867.

Weekly Class Calendar

Monday	Tuesday	Wednesday	Thursday	Friday
Yoga for PWP 1:30 - 2:45	PD Vocal Exercise Class 2:15 - 3:15	Moving Through Parkinson's 2:30 - 3:30	PWRI Moves 1:00 - 2:00	Yoga for PWP 1:30 - 2:45
PWRI Moves 1:00 - 2:00	PD Music Therapy Exercise Class 3:30 - 4:30			



Yoga for PWP Class

Detailed Class Information

Class Name	Description	Location	Facilitator Contact Info	Suggested Donation
Moving Through Parkinson's	Through exercises and specific movement patterns, we work to improve balance, combat stiffness and rigidity, and improve spatial awareness and coordination. We will gain confidence to move with freedom and ease, improving our well-being as we interact, share, and move together.	Dance Wing* - Studio 102	Lisa Morgan, Movement Specialist Dave Jacoby, musical accompanist. Lisa Morgan: 482-4279 or lisa.morgan@colostate.edu	\$5.00
PD Vocal Exercise class	Designed for improving speech volume, articulation clarity, breathy voice quality and varied speech rate for individuals with Parkinson's Disease. Utilizes vocal and singing exercises. Therapists facilitate the class in a fun and encouraging group environment.	Music Therapy GAIT lab*	Blythe LaGasse, Asst. Prof., Music Therapy/ 491-4042 or BlytheLaGasse@colostate.edu	\$5.00
PD Exercise Class (restarts 8/25/2015)	Uses Neurologic Music Therapy and physical therapy techniques. Designed for improving strength, flexibility, walking and balance and overall independence.	Music Therapy GAIT lab*	Dr. Ruth Rice, PT Dr. Corene Hurt-Thaut Call 214-3352 or email ruth.rice@comcast.net CSU students from the Music Therapy and Physical Therapy programs assist participants. Center for Biomedical Research in Music	\$5.00
PWRI Moves	The exercises, fun and games apply "PWRI" ("Power" - Parkinson Wellness Recovery) strategies that are based upon research in neuroplasticity and designed to specifically	The Aspen Club, 1025 Garfield, Fort Collins	Hillary Beck-Gifford, Fitness Instructor 484-1724 or hbgtfpro@comcast.net or sign up with the Aspen Club at 495-8566 (sponsored by the Aspen Club Senior Outreach)	The class runs in two month blocks avg. cost \$5/week

	counteract limitations typically experienced by persons with PD.			
Yoga for People with Parkinson's and/or their Carepartners	Adaptive yoga class designed to support people with PD (and similar disorders), as well as their caregivers. Props such as chairs and bolsters are used to provide comfort, support and safety for gentle stretching, mindful movement, breathing and balancing. Every class concludes with a guided full-body relaxation. Classes are on-going and new participants can join anytime.	Raintree Athletic Club - Enlighten Studio 2555 S. Shields, Fort Collins	Please arrive early to your first session to sign appropriate paperwork. Contact instructor Jennifer Atkins at jayanti.yoga@yahoo.com or click here to view her webpage.	\$5.00 per session - accepted directly in the Enlighten Studio.
<p>* Meet at the CSU University Center for the Arts (the old Fort Collins High School building). The classes are held in the Gait Lab in the area referred to as The Center for Biomedical Research in Music (CBRM). You enter the building on the Southeast corner, there is a ramp and handicap accessible doors at the back of the building off Lake street.</p> <p>Parking - On-street parking is available on Lake Street. Handicapped parking is available in the parking lots on the east side of the building. The parking spaces along the dog park fence on the south east side of the parking lot are available for our participants as well. There is a ramp on the southeast corner of the building with handicap accessible doors. Parking Passes are available through your instructors - please ask if you need one!</p>				

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Zapanta: Classes help ease Parkinson's disease symptoms

FTC 12:48 a.m. MDT April 20, 2014



April is National Parkinson's Awareness Month, and our community has many exciting things to offer.

Parkinson's disease, or PD, is classified as a movement disorder. Larimer County is fortunate to have not only a viable support group for people with Parkinson's disease (PwPs) and their care partners, but also an array of exercise classes specifically designed to counteract Parkinson's symptoms.

The classes focus on overall fitness, voice, dance moves and yoga. The connections created in the support group and exercise class overcome the "lack of ease" in Parkinson's and provide community perseverance, inspiration and hope.

Colorado State University's neurologic music therapy exercise class is designed to improve movement using live music facilitation. It is based on the research of physical therapist Dr. Ruth Rice, neurologist Dr. Gerald McIntosh and Dr. Michael Thaut, a music therapy professor at CSU. Their research found that music in the form of rhythmic cueing improved walking patterns in patients with PD.

Sarah Johnson, a neurologic music therapist at CSU, leads a therapeutic singing class before the exercise class with the therapeutic goal for communication. Participants sing and perform voice drills to strengthen the muscles and mind required for speech. Both Rice and Johnson lead the neurologic music therapy exercise class at CSU weekly and describe "participants not only improve their speech and movement patterns, but their commitment and tenacity are a great inspiration to each other and to the two of us."

The Moving Through Parkinson's dance class is an extension of the music therapy program at CSU, designed for more advanced movement. Instructor Lisa Morgan choreographs movement, music and dance together to improve balance, combat rigidity, and improve body awareness and coordination.

"I have been so inspired by the people who come to my classes week after week," Morgan said. "There is a great desire to work hard, find new ways to fight the progress of the disease, and feel better in body and mind. I have learned a lot from each of the participants and appreciate their perseverance to maintain their level of movement, strength and balance."

Denis Day, diagnosed with PD in 2003, participates in the CSU exercise, singing and dance classes weekly and said they have helped him regain his life.

Aspen Club's Parkinson's wellness recovery class (PWR!Moves), led by Hillary Beck-Gifford, is an upbeat class incorporating high-intensity exercises designed by leading Parkinson's researcher Becky Farley, PT, Ph.D. Beck-Gifford observes that the people who attend the class want to take power back in their lives and come to class for the fun, social situation — and mostly because they feel better with consistent exercise.

The Parkinson's yoga class at the Raintree Athletic Club started after Jennifer Atkins was approached by one of her students, Chris Hageseth, MD, a retired psychiatrist diagnosed with PD in 2011. He adamantly reported that yoga greatly improved and even reversed his Parkinson's symptoms. He combines yoga with strenuous physical exercise and reports that most of his initial symptoms have disappeared without the use of medication.

With his optimism and balanced approach to physical activity, he offers three main points for patients with PD: First, "Change lifestyle in this moment for change in PD." Second, "Align oneself with a physical therapist who specializes in movement disorders." Third, "Pursue exercise regularly — it is a commitment for the rest of your life."

While working with patients with PD, Atkins feels honored to have the opportunity to know and help "these wonderful people. I have seen much improvement in those that have been attending regularly, and all have reported how they feel the positive effects of our practice. We also have quite a few good laughs."

Indeed, the Parkinson's community in Northern Colorado has united to help create a sense of "ease" and well-being with each other. Day describes his journey with PD over the past decade as a "blessing" — a blessing of being more aware of the physical, mental and spiritual aspects of his life.

He shares his exercise regimen with friends he meets outside and inside classes. Having PD has allowed him to also be involved in the community and strengthen his faith. "Don't be afraid to use your gifts. Take the risks to help, rather than worry about how others will react," Day said regarding a strong and giving attitude. "Every day is a gift. Don't worry about tomorrow. We have enough to worry about today."

Jerry Manning is both a care partner for his wife, Patsy, who has PD, and a leader of the Parkinson's Support Group of Larimer County, an organization that addresses needs of both PwPs and care partners.

Jerry recognizes the importance of communication and connection among care partners dealing with similar issues, stating, "We are all in this together." Care partnering for his wife also taught Jerry the importance of finding space and time for himself. By taking time for himself, he is able to care for his wife and community with dedication and compassion.

Advancements in research and success stories in the Parkinson's community are promising. For more information on Parkinson's disease research, exercise options and more information on an upcoming first Tai Chi and Qi Gong Awareness class for PD, visit ColPTs.com.

Dr. John Zapanta, PT, DPT conducts research in PD and was the guest columnist.

Parkinson's – Not just a motor disease

**Source: A Guide to the Non-Motor Symptoms of Parkinson's Disease by Ron Postuma & Christos Galatas*

Parkinson's disease (PD) is classically considered as a motor disease, with tremor, rigidity, bradykinesia and gait problems as the classic motor features. However, non-motor manifestations (NMM) of PD have become increasingly recognized – they can often be more disabling than the motor symptoms. Non-motor manifestations of PD result from neuronal degeneration in widespread areas of the brainstem. Unfortunately, NMM are often under recognized, and therefore, undertreated.

Most NMM fall into one of three major categories: autonomic dysfunction, cognitive and psychiatric symptoms, and sleep disorders. They can occur throughout PD; some of them, such as olfactory dysfunction, constipation, depression, and rapid eye movement sleep behavior disorder (RBD) can precede the motor symptoms of PD. Others, especially cognitive symptoms such as hallucinations and dementia, tend to occur late in PD.

Drooling

What is the prevalence? Approximately 10% of patients

What do patients experience?

When mild, drooling usually occurs during the night or at mealtimes, but as it progresses it can occur any time during the day. Other than the social disability involved, serious complications can include choking on saliva and aspiration pneumonia.

Olfactory & Taste Dysfunction

What is the prevalence? Olfactory loss affects up to 90% of patients

What do patients experience?

Olfactory dysfunction (hyposmia or anosmia) and sometimes taste alterations occur in PD. Since these changes occur gradually, it is difficult for the patient to recognize them. Hyposmia often precedes the motor symptoms of PD, and therefore, it may be useful in the future as a screening tool to identify those at risk for PD. These symptoms are not serious, but in some cases they may cause decreased appetite.

Dry Eyes

What is the prevalence? Greater than 50% of patients

What do patients experience?

People with PD may blink only 1-2 times per minute (normal is 16-18 times), leading to itching and burning. Also they may experience decreased sensitivity to contrast (color and brightness), making vision less sharp, caused by the loss of dopamine neurons in the eye's retina. Altered color vision, a sort of blue-yellow color blindness.

Pain

What is the prevalence? Approximately 33-66% of PD patients experience pain directly related to PD

What do patients experience?

Pain in PD presents as stiffness, cramps, spasms or muscle pain, usually occurring in the calves, neck or back. Both primary PD pain and secondary pain exist in PD. Primary pain often occurs during off periods (i.e. when antiparkinson medications "wear off" in patients who fluctuate). Pain can also be associated with dyskinesias and early morning dystonia. PD also can decrease pain thresholds, so that other secondary pain syndromes worsen in the presence of PD.

Weight Loss

Why does it happen?

Weight loss occurs in many neurodegenerative diseases, including PD. This weight loss is often independent of energy intake. Normally, the brain integrates information on nutrient stores and energy expenditure, and then alters energy intake. IN neurodegenerative diseases, this process may be affected. In PD, weight loss is related mainly to a decrease in fat tissue. Factors such as dyskinesia, swallowing dysfunction, altered smell and taste, nausea and vomiting, or other medication side effects can contribute to weight loss.

Cognitive Dysfunction and Dementia

What is the prevalence? Up to 70% of patients with PD will eventually develop cognitive impairment (either mild cognitive impairment or dementia)

What do patients experience?

Patients with early disease demonstrate subtle changes on neuropsychiatric tests of mental flexibility and executive function, but these changes are usually asymptomatic. Parkinson's Disease Dementia (PDD) usually occurs in patients in later stages that are above 65 years of age. Predominant symptoms include bradyphrenia (slow thought process), impaired memory (due to retrieval more than encoding problems), impaired attention, visuo-perceptual/visuospatial dysfunction, and dysexecutive syndrome (poor planning, rigidity, etc.).

Hallucinations

What is the prevalence? Up to 40% of patients have visual hallucinations

What do patients experience?

Hallucinations usually occur in later stages of PD. Auditory (whispers, music); gustatory, olfactory, and tactile hallucinations are uncommon in PD, while visual hallucinations are more common. These often occur in low-light settings or when one's conscious state is altered (i.e. sleep/wake transitions). Initially, illusions (misinterpretations of visual objects) are common – for example, a spot on a wall becomes a bug. As they progress, they become less dependent on the environment, more vivid, and often threatening. Initially, the patient usually realizes that the hallucinations are not real, but eventually, they may not be able to distinguish between reality and the imaginary.

Excessive Daytime Sleepiness

What is the prevalence? Approximately 50% of patients

What do patients experience?

Patients with EDS may fall asleep while driving, during a conversation, or in public places such as theatres. If the EDS is severe, the patient may experience sudden sleep episodes called “sleep attacks”. Naps are often unrecognized by patients, so caregiver input is essential.

Insomnia

What is the prevalence? Some insomnia affects up to 60-80% of patients

What do patients experience?

There are two major types of insomnias:

Sleep-onset insomnia: trouble falling asleep

Sleep-maintenance insomnia: trouble staying asleep and waking too early

In general, PD patients tend to be more troubled by sleep-maintenance insomnia. Many patients notice that they have become increasingly “early to bed, early to rise”.

REM Sleep Behavior Disorder (RBD)

What is the prevalence? Found in 50% of patients with PD

What do patients experience?

Rapid Eye Movement Sleep Behavior Disorder (RBD) is characterized by the absence of muscle atonia during REM sleep. Patients act out their dreams, resulting in talking, limb jerking or screaming during their sleep. Patients may fall out of bed, injure themselves, or hurt their bed partner. Patients often note that dreams have become more violent. In many cases RBD precedes motor symptoms and can be a marker of other problems, especially cognition.

Restless Leg Syndrome (RLS)

What is the prevalence? Approximately 30% of patients

What do patients experience?

The patient feels discomfort in their legs and feels the need to constantly move their legs. RLS usually occurs when sitting or lying down, and it is usually worse during the evening and night. RLS can be associated with periodic limb movements of sleep, which are involuntary limb movements that occur every 20-60 seconds while sleeping. It is unclear whether the prevalence of RLS is the same in the general population as it is in PD, but it is often more severe in PD. It is important (and difficult) to distinguish RLS from other leg symptoms that are common in PD such as pain due to off periods, cramps, and dyskinesia.

Depression

What is the prevalence? Approximately 20-50% of patients

What do patients experience?

Depression precedes motor symptoms in approximately 30% of cases. PD depression typically differs from depression in the general population – there are less expressed feelings of sadness, little tearfulness or guilt and a low suicide rate. On the other hand, there is prominent anxiety, anhedonia, and apathy. There are difficulties in diagnosing mild depression in PD because clinical features overlap with motor features of PD; hence clinicians should have a low threshold for diagnosing depression in PD.

Anxiety

What is the prevalence? Reported in 30-40% of patients, frequently co-occurs with depression

What do patients experience?

Symptoms can include panic attacks, phobias, or generalized anxiety disorder. Patients often find they ruminate excessively on upcoming events. Anxiety may precede diagnosis of PD. In some patients, anxiety can be related to drug-induced motor fluctuations. When patients with PD have depression, anxiety is commonly a prominent component.

Apathy

What is the prevalence? Reported in 12-16% of patients

What do patients experience?

Apathy is the lack of motivation, interest and emotion. The patient expresses indifference and has no goals for the future. Patients often note that they no longer enjoy elective activities. Caregivers often complain that the patient no longer participates in social or physical activity.

Sexual Dysfunction

What is the prevalence? Approximately 50% of patients

What do patients experience?

Sexual dysfunction (SD) in PD includes erectile dysfunction (ED), difficulty reaching orgasm, decreased libido, and decreased genital sensitivity. On the other hand, patients can occasionally have increased sex drive (hypersexuality), usually related to dopamine agonists. Sexual dysfunction is reported more commonly by men than women, perhaps because it is more easily identified in men.

Orthostatic Hypotension

What is the prevalence? Seen in 30-58% of patients

What do patients experience?

Orthostatic hypotension (OH) is formally defined as a drop in systolic blood pressure by >20 or diastolic pressure >10 from supine to standing. Due to cerebral auto regulation, many patients with OH are asymptomatic. Symptoms can include light headedness, fatigue, headache, shoulder-ache (coat-hanger pain) and cognitive slowing after standing up or occasionally after large meals. Falls and blackouts may occur if the OH is severe.

Choking and Swallowing Difficulties

What is the prevalence? Approximately 50% of patients

What do patients experience?

Although mild swallowing problems can be experienced early in the disease, severe dysphagia usually occurs only in advanced PD. The patient may have trouble swallowing food, liquids, or pills. Complications include malnutrition, aspiration pneumonia, and choking.

Nausea and Vomiting

What is the prevalence? Approximately 20% of patients

What do patients experience?

Patients can experience a sensation of abdominal bloating even without medications, or can present with nausea and vomiting when they start a new antiparkinson drug.

Constipation

What is the prevalence? Approximately 75% of patients

What do patients experience?

Constipation is defined as fewer than 3 bowel movements per week or straining to pass stools. Constipation often precedes motor symptoms. Aside from the distress it adds to daily life, complications include megacolon, pseudo-obstruction, volvulus, and bowel perforation. Therefore, severe constipation should not be neglected.

Fecal Incontinence

What is the prevalence? Uncommon (less than 10%)

What do patients experience?

Fecal incontinence is the involuntary loss of stool. It is a relatively rare non-motor manifestation, and it is usually seen with urinary incontinence.

Bladder Dysfunction

What is the prevalence? Over 50% of patients experience some form of bladder dysfunction

What do patients experience?

A diverse range of bladder symptoms are experienced by PD patients. The commonest are related to detrusor hyperreflexia, including nocturia, urinary urge, urinary frequency, and incontinence. Urinary retention/detrusor hyporeflexia is less common. Mild bladder symptoms are common in early PD – incontinence occurs in more advanced PD. In some cases, it is difficult to diagnose the nature of the impairment (or combination of impairments) on history alone – if this is the case, consider urodynamic studies.

Excessive Sweating

What is the prevalence? Approximately 30-50% of patients

What do patients experience?

PD patients sometimes experience excessive sweating. Usually, hyperhidrosis manifests in the axilla, the palms, the soles of the feet, and the face, but in PD it often also involves the whole body – “drenching sweats.”

Diplopia and Visual Abnormalities

What do patients experience?

Visual abnormalities in PD include diplopia, impaired color and contrast discrimination, and visuospatial defects. Impaired color and contrast discrimination may precede motor symptoms and patients can be unaware of these deficits. Impaired contrast sensitivity can impair driving, particularly at night. Diplopia is less common and usually occurs while reading.

Delusions

What is the prevalence? Approximately 5% of non-demented and 15% of demented patients with PD

What do patients experience?

Delusions are false beliefs that are not based on fact. They frequently are paranoid in nature, with feelings of persecution, jealousy, spousal infidelity and fears of impoverishment. Visual hallucinations can trigger delusions – a common delusion in PD is squatters living in attics, sheds, the garage, etc. which is directly related to vivid hallucinations of people.

Impulse Control Disorders

What is the prevalence? Approximately 10-15% of patients

What do patients experience?

Impulse control disorders (ICD) are characterized by failure to resist an impulse, drive or temptation to perform an act that is harmful to the person or to others. These include pathological gambling, hypersexuality, binge eating (eating abnormally large amounts of food or lack of control), excessive shopping, and punding (repetition of useless tasks). Unrecognized impulse control disorders can have devastating effects, resulting in bankruptcy and deterioration of close relationships. Dopamine Dysregulation Syndrome (DDS) is another form of ICD, which is experienced like an "addiction" to levodopa. Patients with DDS experience severe anxiety and irritation during off periods, and will take excessive medication to prevent any sign of an off period without their physician's approval.

Moving Through Parkinson's

Exercise List (Based on Brain Dance® by Anne Green Gilbert)

Prepare for the activity both physically and mentally. Taking five minutes to focus your mind and body on how you are feeling, what you will be doing. "Checking in" with your body will help you to benefit the most from your outing. Have you had a good meal? Water? Are you dressed accordingly? What's your plan? A walk around the block, meeting a friend, chores in the garden, etc. If you can take the time, sit in a chair and go through our warm up that we do every time we start class, you will enhance your activity and your body will thank you.

1. Breathe! Breathe in through your nose, out through your mouth, letting go of any tension in the shoulders or neck. Sense the breath sweeping through your whole body, checking in with your core as well as all extremities, their muscles and bones.
2. Tactile: Brush both arms, massage or pat arms and legs, "waking up" the nerve endings and soft tissue connections.
3. Head-tail: Curve the spine forward, head toward knees. Then extend the spine with head and neck reaching to the sky and tail bone reaching to the back of the chair – try this with your breath – exhale as you curve forward, head to knees.
4. Core-distal: Extend your arms over your head and out to the sides, feeling the connection to your core. Try the same with your legs (the BIG STAR). This helps to get the whole body moving together and in a "larger" space, with a connection to your power center.
5. Cross lateral: Connect your right hand to your left knee, change sides. Do this several times, then switch to your hip, shoulder, and foot. This helps to engage both sides of your brain and connect across the midline of your body.
6. Head/neck mobility: Gently roll your head from side to side, use your breath, close your eyes and come back to where you started. Finish with sitting tall and preparing to stand. If you haven't already gotten your shoes on, be sure to do some ankle rotations and squeeze and release your toes.

Standing and ready to go! Feet underneath your pelvis, with exhale, stand with power and strength and connection. If you can make it happen, after your activity, repeat this nice body/mind connection and sense how you feel, thank your body for getting out, being there for you and then have a big glass of water!



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Optimize Your Care Build Your Neurological Care Team

Rehabilitation therapy, nutritional and behavioral counseling can help you improve your abilities, adapt and adjust to changes and most of all enhance everyday life quality. Use this checklist to understand how these specialists can help you. Share the results with your medical provider to discuss if a referral is right for you.

Physical Therapy: Specializes in physical movement such as joint range of motion, muscle flexibility, balance and ambulation. Provides guidance toward home exercise programs for health and prevention at all stages of disease, reduce fall risk and help with caregiver needs.

A physical therapy evaluation could be helpful, if you have any of the following:

- Do you need an exercise program specifically for Parkinson's disease?
- Do you get out of breath easily when walking or feel tired most of the day?
- Do you have trouble getting out of a chair, getting out of your car or getting out of bed?
- Are you having trouble with walking, falling or fear of falling?
- Do you have problems with falling, balance, walking or freezing while trying to walk?
- Is your posture changing?
- Do you need a walking aid such as a cane or walker?
- Do you have exercise limitations?
- Does your carepartner need information and training how to best help you move?
- Do you have joint or muscle pain or spasms?
- Do you need help selecting the right wheelchair for improved independence?
- Do you have vision problems affecting your coordination or movement?
- Do you have trouble with bladder control?
- Are you changing or avoiding some of your daily activities due to mobility issues?
- Do you feel dizzy when you move?

Name:



Build Your Neurological Care Team (continued) page 2

Occupational Therapy: Specializes in the areas of self-care, medication management, home maintenance, community involvement including driving, alternative options for transportation, and resources for staying active with emphasis on safety. Along with these are programs for arm and shoulder strength, flexibility, fine motor, handwriting, and relaxation techniques (yoga and meditation). **An occupational therapy evaluation could be helpful, if you have any of the following:**

Do you have problems completing tasks or organizing your day?

Do you have problems completing tasks or organizing your day?

Do you need help assessing your home for safety needs?

Do you need some more information how to best organize your medications?

Do you need help or have more difficulty with dressing or bathing?

Is it taking you longer to complete task due to fatigue, pain, weakness, coordination or thinking problems?

Have you stopped doing tasks, chores, work or hobbies because of difficulties due to fatigue, pain, weakness, coordination or thinking problems?

Do you have trouble with your vision?

Do you have concerns about safety while in your home?

Do you have problems with freezing while trying to walk?

Are you fearful of falling or have fallen due to your condition?

Do you need help reviving your hobbies or other social interests?

Do you need an assessment for changes at your workplace to accommodate your neurologic or muscular condition?

Do you have trouble getting out of bed, chair or car?

Do you need help with stress management?

Do you need help with preparing a meal due to your neurologic condition?

Do you have trouble sleeping?

Are you or a family member concerned about your driving?

Name:



Build Your Neurological Care Team (continued) page 3

Speech Therapy: A comprehensive speech and voice evaluation is completed by a certified speech language pathologist. Therapy can help voice symptoms, swallowing difficulties, conversation and communication problems. **A speech or swallowing evaluation could be helpful, if you have any of the following:**

- Do you have problems swallowing food, liquid or pills?
 - Do you need to know which foods to avoid if you have a swallowing problem?
 - Do you have you lost more than ten pounds without trying over the past six months?
 - Do you have problems with your speech, being heard or difficulty communicating?
 - Do you have word finding problems?
 - Do you have excessive drooling?
 - Do you cough when you eat or drink?
 - Have you choked or worry about choking?
-

Nutrition Consult: A registered dietician is trained to provide diet and nutritional counseling to improve health with certain conditions such as neurologic conditions, diabetes, heart disease and kidney disease. **A nutrition consult could be helpful, if you have any of the following:**

- Are you having trouble eating food due to a swallowing problem?
- Are you having trouble keeping on weight?
- Are your meals interfering with your medication?
- Do you have food sensitivities, gluten sensitivity or celiac disease?
- Do you have diabetes or kidney disease?
- Are irritable bowel symptoms or constipation affecting your appetite and diet?

Name:



Build Your Neurological Care Team (continued) page 4

Psychology Evaluation: Specializes in the evaluation of mood changes, adjustment anxiety and support. A Neuropsychologist specializes in thinking problems and dementia. **A Psychology or Neuropsychology evaluation could be helpful, if you have any of the following:**

- Do you have do you have memory problems?
 - Do you have problems multitasking or decision making?
 - Do you experience confusion?
 - Do you have more down days than good days?
 - Do you have anxiety that interferes with your day to day activities?
 - Do you have thoughts or concerns that keep you awake at night?
 - Does your caregiver seem to be on edge lately?
 - Are you worried about your care-partner's stress levels?
-

Social Work Evaluation: Specializes in the evaluation of emotional support, community resources and adjustment to illness with an emphasis on improving quality of life. **A social work consultation could be helpful, if you have any of the following:**

- Do you need help located specific resources in your community or finding out what is available?
- Do you have questions regarding in home care or housing?
- Are you a caregiver in need of respite care?
- Are you interested in attending a support group for Caregivers or Patients?
- Do you have interest/hobbies you would like to pursue but don't know where start?
- Do you need help identifying ways of coping with the adjustment of living with your pain or neurologic condition?
- Are you having trouble effectively communicating with your spouse, family and/or friends?
- Are you feeling overwhelmed about what to do first or need help prioritizing your needs?
- Do you feel like you need a stronger support network?



Improve Your Medical Appointment

Better communication will improve your quality of care.

STEP 1: BEFORE YOUR APPOINTMENT

Write down your questions or concerns before your visit. Sometimes you may forget to ask important questions during your doctor's appointment. Writing them down will remind you to ask them during the appointment.

- Prioritize your questions with the most important one first as you may not have the time to address all in one visit.
- Allow space to write answers next to the question so you can look back at a later time to refresh your memory after the appointment. It also helps to bring someone along to write the answers for you.
- If you are a care-partner, your questions and concerns are important too! Remember to add these to the list.

Write down your goals for the appointment. It is very helpful to take some time and think about what is important to you. This will help you and set goals focus your appointment on what is meaningful to you.

- Write down your visit goals and share this with your doctor or healthcare provider.

Keep a record of any changes your doctor makes to your treatment for quick reference.

Important items to bring to your appointment include:

- Keep a dedicated notebook for your doctor visits and include the following:
 - Medications and side effects if any.
 - Copies of previous brain MRIs or CT scans.
 - Medical notes and addresses of previous doctors.

STEP 2: APPOINTMENT DAY

Optimize your time with your doctor or healthcare provider. This means more time for your doctor to listen and answer your concerns and questions. Planning ahead, arriving early and completing forms accurately will save time for you and your doctor. Begin by asking your doctor what information is needed from you for each visit to help take care of your symptoms. Ask questions that are important early during your appointment; don't wait until the end.

Complete patient care questionnaires. These forms have questions that your doctor or healthcare provider feels are important for your visit. Completing these forms improves communication, provides information for your record, allows your doctor to spend more time on you, and reduces errors and mistakes. This is especially true when keeping track of your medications. Medications are the main treatment for many neurological disorders. Medication accuracy can greatly affect how well your doctor can manage or control your symptoms.

- Arrive for your appointment at least 20 minutes early to complete patient questionnaire forms.
- Ask for extra copies of forms for future visits. Store them in your notebook and complete them at home before your next appointment.
- Bring a complete list of medications to reduce errors that may occur from one visit to the next. Do not use statements like, "no changes", "same as last visit", or "the doctor knows what I am on". This is how errors occur.

Ask questions and learn about your condition. The importance of writing your questions down is outlined in Step One on the previous page. Important questions to ask include:

- What are the symptoms or problems that are related to my PD and what symptoms should I look for?
- Do I need medication and if so, what should it treat or change?
- What are the side effects of the medication?
- What symptoms or side effects should be reported immediately?
- How often should I make appointments?
- Where can I find more information about my symptoms?
- When should I see a physical therapist, occupational therapist, speech therapist, counselor or other specialist?

STEP 3: AFTER THE APPOINTMENT

How often do you leave your doctor's office trying to remember what just happened? Do you have trouble following through with your treatment plan? The following suggestions will help you stay on track between appointments.

- Bring a care-partner, family member or friend to write down instructions and help you keep track of your next steps.
- Review your appointment information with others and involve them in your treatment.
- Keep a journal or a calendar of your goals for the week and steps you have taken to reach them.
- If you made changes in your treatment, write down what did and did not work to review at your next appointment.

APPOINTMENT CHECKLIST

The following information will be helpful to you and your doctor over time. You can download and print a copy of these forms from this site for your use.

- ✓ Complete your doctor's appointment questionnaire or use the one included on this website.
- ✓ Keep a list of medications to include name, strength, timing, generic or trade. A medication log is available for your use.
- ✓ Keep a list of prior medicines that were tried and not effective or caused side effects so that they are not used again.
- ✓ Keep a list of all your treating doctors to include name, address, and FAX #.
- ✓ Keep a list of any changes that result from calls to your doctor or new symptoms experienced between appointments.
- ✓ Keep track of medication refill needs before you run out.
- ✓ Make a list of questions to ask before your visit.
- ✓ Define your goals for your appointment and the steps needed to reach these goals. Write this information down on the Goal Summary sheet and review it often.
- ✓ Ask your doctor, "what information is important for you to bring to each visit so that you can work together as a team?"

These steps take work. However, they will help you gain the most you can out of your medical visits.

Name: _____ Date of Birth: _____ Date: _____

Please rate the severity of each symptom below by *filling in* the appropriate bubble:

Fine Motor Skills	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Handwriting	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Bathing and/or dressing	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Fatigue	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Motivation	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Anxiety	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Depression	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Hallucinations	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Swallowing	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Swelling	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Sleep Problems	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Dizziness or lightheaded	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Bladder problems	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Constipation	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Sexual function	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Chest pain or palpitations	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Cough or sore throat	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Rash or bruising	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Headache	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Heartburn or stomach pain	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Seizures	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Double or blurred vision	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Shortness of breath	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Joint pain	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Muscle pain	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Hearing loss	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Leg swelling	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe



MOVEMENT &
NEUROPERFORMANCE
CENTER COLORADO

Parkinson's Symptom Diary

Name _____ Date: _____

1. **Medications:** place an x under the hour that you took your medicine; draw a line through the hours that you are asleep.
2. **Dyskinesia:** use the following scale to indicate the severity of involuntary movement (do not include tremor).
 0= no extra movement
 1 = mild extra movement
 2 = Moderate movement
 3 = Severe disabling movement
3. **Freezing:** place an x during the times when you are freezing.
4. **Offs:** use the following scale to indicate the severity of off symptoms.
 0 = Feeling no symptoms
 1 = Mild tremor, stiffness or slowness without disability
 2 = Moderate tremor, stiffness or slowness, occasionally requiring assistance
 3 = Severe tremor, stiffness or slowness requiring total assistance
5. **Falls:** place an x to indicate when you fell.

	A M		6		7		8		9		10		11		A M		12	
	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Medications																		
Dyskinesia																		
Freezing																		
OFFs																		
Falls																		
Time																		

Complete a diary for 3 days and bring to your appointment.



Tremor Symptom Diary

MOVEMENT &
NEUROPERFORMANCE
CENTER, COLORADO

Name _____ Date: _____

Rate your tremor severity for each body part and activity below.

0 = no tremor - not bothersome

1 = mild tremor – not interfering with movement, mildly bothersome

2 = Moderate tremor – interfering with movement and moderately bothersome

3 = Severe disabling tremor – impossible to perform activity

Body Part		Rate how bothersome your tremor is when doing the following activities:								
Face or chin		Eating	Drinking	Cooking	Pouring	Working	Dressing	Hygiene	Speaking	Writing
Voice										
Head/Neck										
Right hand		Draw a line from point to point below with your dominant hand								
Right arm		<div style="display: flex; justify-content: space-between; align-items: center; height: 100px;"> • * </div>								
Left hand										
Left arm										
Right foot										
Right leg										
Left Foot										
Left Leg										

Draw a spiral with the right hand and left hand

Right Hand Unsupported

Left Hand Unsupported

Complete a diary for 3 days and bring to your appointment.

MEDICAL ALERT

I have **PARKINSON'S DISEASE**
which could make me move slowly and
have difficulty standing or speaking.

I AM NOT INTOXICATED.

Please call my family or physician for help.



**NATIONAL PARKINSON
FOUNDATION**

1.800.4PD.INFO (473-4636)

www.parkinson.org

Important Medical Information for Health Care Professionals

- To avoid serious side effects, Parkinson's patients need their medication **on time, every time** – do not skip or postpone doses.
- Do not stop levodopa therapy abruptly.
- If an antipsychotic is necessary, use quetiapine (Seroquel[®]) or clozapine (Clozaril[®]).
- **Special Alert:** Drugs such as benzodiazepines, muscle relaxants, bladder control medications and other medications used for sleep and pain may lead to confusion, hallucinations and other symptoms.

Turn this card over for a list of contraindicated medications & important considerations if the patient has a brain device & needs a MRI/EKG/EEG.

MY NAME _____

HOME ADDRESS _____

PERSON TO CALL _____ PHONE _____

PHYSICIAN _____ PHONE _____

ALLERGIES/OTHER MEDICAL CONDITIONS

Medications that may be Contraindicated in Parkinson's Disease

Safe Medications:	Medications to Avoid:
ANTIPSYCHOTICS quetiapine (Seroquel [®]), clozapine (Clozaril [®])	avoid all other typical and atypical anti-psychotics
PAIN MEDICATION most are safe to use, but narcotic medications may cause confusion/psychosis and constipation	if patient is taking MAOB inhibitor such as selegiline or rasagiline (Azilect [®]), avoid meperidine (Demerol [®])
ANESTHESIA request a consult with the anesthesiologist, surgeon and Parkinson's doctor to determine best anesthesia given your Parkinson's symptoms and medications	if patient is taking MAOB inhibitor such as selegiline or rasagiline (Azilect [®]), avoid: meperidine (Demerol [®]), tramadol (Rybix [®] , Ryzolt [®] , Ultram [®]), droperidol (Inapsine [®]), methadone (Dolophine [®] , Methadose [®]), propoxyphene (Darvon [®] , PP-Cap [®]), cyclobenzaprine (Amrix [®] , Fexmid [®] , Flexeril [®]), halothane (Fluothane [®])
NAUSEA/GI DRUGS dopramperidone (Motilium [®]), trimethoprim-benzamide (Tigen [®]), ceciliansetron (Zofran [®]), dolasetron (Anzemet [®]), granisetron (Kytril [®])	prochlorperazine (Compazine [®]), metoclopramide (Reglan [®]), promethazine (Phenergan [®]), droperidol (Inapsine [®])
ANTIDEPRESSANTS fluoxetine (Prozac [®]), sertraline (Zoloft [®]), paroxetine (Paxil [®]), citalopram (Celexa [®]), escitalopram (Lexapro [®]), venlafaxine (Effexor [®])	amoxapine (Asendin [®])

MRI, EKG and EEG Warning

If you have a Deep Brain Stimulation device (DBS):

- MRI Warning: MRI should not be performed unless the hospital has MRI safe experience and a neurologist/programmer turns the DBS device to 0.0 volts. The MRI should never be performed to Image structures below the head

(neck, chest, abdomen, arm, legs). The MRI should never be performed if the pacemaker is placed below the clavicle (abdomen) as dangerous heating of the lead could occur.

- EKG and EEG Warning: Turn off the DBS device before conducting EKG or EEG.
- Diathermy should be avoided.

Parkinson Wellness Recovery | PWR!

About PWR! Pwr4life.org/about/

Innovating the treatment of Parkinson's through research-based exercise

Parkinson Wellness Recovery | PWR! is a nonprofit 501(c)(3) founded public charity and contributions are tax-deductible. PWR! got started when Dr. Farley, after years of research saw compelling data that **proved that exercise has serious benefits for people living with Parkinson's**. But research does no good if it stays inside the lab. PWR! advocates changing our present treatment paradigms and incorporating the translation of research-based neuroplasticity concepts into proactive programming with daily access throughout the ENTIRE continuum of care which starts at diagnosis with rehab and then doesn't stop, but is actually a cycle of rehab to community and back. PWR! is about changing the status quo to offer the latest cutting edge research exercise programming at diagnosis for life.

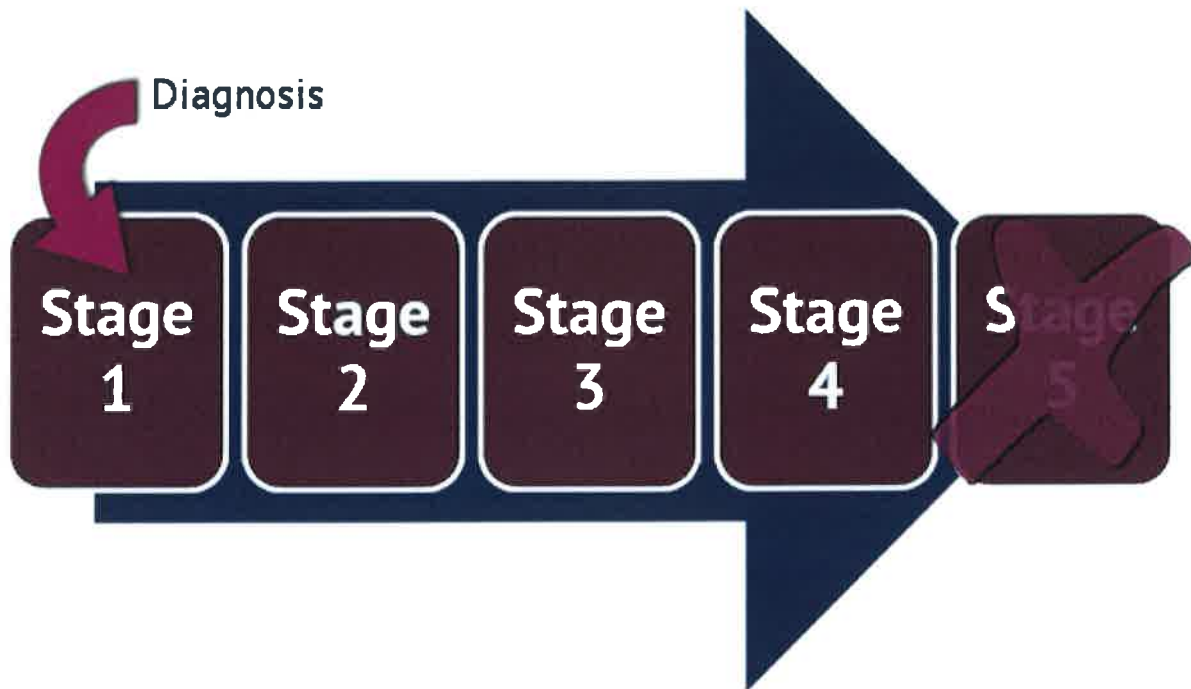
Dr. Farley teamed up with Sally Michaels, PT, CCM and officially debuted the mission and activities related to the PWR! project at the World Parkinson Congress in Glasgow, Scotland in 2010. By 2012, with the goal to increase the availability of PD-specific research-based exercise that adhere to Exercise4BrainChange® principles of practice Dr. Farley and Sally Michaels, PT, CCM opened the PWR!gym®, a NeuroFitness Center of Excellence in Tucson, AZ.

PWR!Vision

Communities where all individuals with Parkinson disease receive research-based exercise programming beginning with diagnosis and throughout their lives in order to increase longevity and quality of life so that end stage Parkinson disease is eradicated!

Since 2010, PWR! has trained over 3,000 professionals in how to implement PD-specific exercise and treated over 600 people through their exercise programs in Tucson, AZ.

Exercise from diagnosis! Stamp out chronic, end-stage Parkinson disease!



Stage 1

Unilateral involvement only, usually with minimal or no functional disability.

Stage 2

Bilateral or midline involvement without impairment of balance.

Stage 3

Bilateral disease: mild to moderate disability with impaired postural reflexes; still physically independent.

Stage 4

Severely disabling disease though still able to walk or stand unassisted.

Stage 5

Confinement to a bed or wheelchair unless aided.



25 Things People with Parkinson's Disease Can Relate To

Posted by Allison Smith, January 16, 2015



Guest blogger Allison Smith describes herself this way: "I am a medical anomaly, advocate for people, freakishly smart, believer of unicorns, self-proclaimed addict of frozen yogurt, secretly a ninja, and personally planning the assassination of Barbie... Oh and I have Parkinson's disease. If I could describe myself in one sentence, I wouldn't be blogging!" Find more of her entertaining posts at [The Perky Parkie](#).

Now readers, before I get started, I want to remind you that my blog is strictly for entertainment purposes and is not meant to diagnosis or treat any medical illness. I am not a doctor, and although I am freakishly smart, you should probably follow-up with someone a little more serious than myself.

1. Being frozen does not necessarily mean that you are cold.
2. You know that if you are seeing unicorns and believe that your car is made out of skittles, you're probably taking a dopamine agonist.
3. You can play the fun game of, "What symptoms will I have today?"
4. At the grocery store staring at the gum, you take 20 minutes to pick a flavor, only to return moments later to exchange it.
5. You start 10 projects at home and haven't finished one.
6. Everyday you'll have to eat candy, or someone will get hurt.
7. You'll wear a mask, even if it's not Halloween.
8. You have hidden stashes of Sinemet in your purse, gym bag, key chain, glove box, wallet, and in the flowerpot on your patio.
9. You do a perfect imitation of a garden statue.
10. You can cry almost on cue.
11. You have perfected the dance move called Dyskinesia.
12. You stayed up all night organizing your family photos, and then decide to clean out the garage.
13. Multi-tasking sounds like too much work, so you don't do it.
14. It doesn't matter how cold it is, you are somehow sweating.

15. Shaving can be hazardous to your health.
16. When you walk, one arm goes on strike and decides not to swing.
17. No, you don't smell the dog poo you just stepped in.
18. You will never need to buy an electric toothbrush every again.
19. Your ability to balance decided to take a vacation to Fiji and hasn't even sent a postcard.
20. You know that Dystonia is not a city in Estonia.
21. You will always win a staring contest.
22. You have been pulled over for drunk driving, but haven't even had a drop of booze.
23. You know that an abduction by aliens is not necessary to get Deep Brain Stimulation.
24. You would pay top dollar for Dopamine on the black market.
25. Bloodhounds are jealous of your ability to drool.

<https://www.michaeljfox.org/mobile/news-detail.php?25-things-people-with-parkinson-disease>

National Institute of Neurological Disorders and Stroke

Deep Brain Stimulation for Parkinson's Disease Information Page

Condensed from [Deep Brain Stimulation for Parkinson's Disease Fact Sheet](#)

What is Deep Brain Stimulation for Parkinson's Disease?

Deep brain stimulation (DBS) is a surgical procedure used to treat several disabling neurological symptoms - most commonly the debilitating motor symptoms of Parkinson's disease (PD), such as tremor, rigidity, stiffness, slowed movement, and walking problems. The procedure is also used to treat essential tremor and dystonia. At present, the procedure is used only for individuals whose symptoms cannot be adequately controlled with medications. However, only individuals who improve to some degree after taking medication for Parkinson's benefit from DBS. A variety of conditions may mimic PD but do not respond to medications or DBS. DBS uses a surgically implanted, battery-operated medical device called an implantable pulse generator (IPG) - similar to a heart pacemaker and approximately the size of a stopwatch - to deliver electrical stimulation to specific areas in the brain that control movement, thus blocking the abnormal nerve signals that cause PD symptoms.

Before the procedure, a neurosurgeon uses magnetic resonance imaging (MRI) or computed tomography (CT) scanning to identify and locate the exact target within the brain for surgical intervention. Some surgeons may use microelectrode recording - which involves a small wire that monitors the activity of nerve cells in the target area - to more specifically identify the precise brain area that will be stimulated. Generally, these areas are the thalamus, subthalamic nucleus, and globus pallidus. There is a low chance that placement of the stimulator may cause bleeding or infection in the brain.

The DBS system consists of three components: the lead, the extension, and the IPG. The lead (also called an electrode) - a thin, insulated wire - is inserted through a small opening in the skull and implanted in the brain. The tip of the electrode is positioned within the specific brain area.

The extension is an insulated wire that is passed under the skin of the head, neck, and shoulder, connecting the lead to the implantable pulse generator. The IPG (the "battery pack") is the third component and is usually implanted under the skin near the collarbone. In some cases it may be implanted lower in the chest or under the skin over the abdomen.

Once the system is in place, electrical impulses are sent from the IPG up along the extension wire and the lead and into the brain. These impulses block abnormal electrical signals and alleviate PD motor symptoms.

Advantages

Unlike previous surgeries for PD, DBS involves minimal permanent surgical changes to the brain. Instead, the procedure uses electrical stimulation to regulate electrical signals in neural circuits to and from identified areas in the brain to improve PD symptoms. Thus, if DBS causes unwanted side effects or newer, more promising treatments develop in the future, the implantable pulse generator can be removed, and the DBS procedure can be halted. Also, stimulation from the IPG is easily adjustable—without further surgery—if the person's condition changes. Some people describe the pulse generator adjustments as "programming."

Prognosis

Although most individuals still need to take medication after undergoing DBS, many people with Parkinson's disease experience considerable reduction of their motor symptoms and are able to reduce their medications. The amount of reduction varies but can be considerably reduced in most individuals, and can lead to a significant improvement in side effects such as dyskinesias (involuntary movements caused by long-term use of levodopa).

In some cases, the stimulation itself can suppress dyskinesias without a reduction in medication. DBS does not improve cognitive symptoms in PD and indeed may worsen them, so it is not generally used if there are signs of dementia. DBS changes the brain firing pattern but does not slow the progression of the neurodegeneration.

Research

National Institute of Neurological Disorders and Stroke (NINDS), a part of the National Institutes of Health (NIH), supports research on DBS to determine its safety, reliability, and effectiveness as a treatment for PD. NINDS supported research on brain circuitry was critical to the development of DBS.

Researchers are continuing to study DBS and to develop ways of improving it. A two-part study funded by the NINDS and the Department of Veterans Affairs first compared bilateral DBS to best medical therapy, including medication adjustment and physical therapy. Bilateral DBS showed overall superiority to best medical therapy at improving motor symptoms and quality of life. The second part of the study, involving nearly 300 patients, compared subthalamic nucleus (STN) DBS to globus pallidus interna (GPI) DBS. The two groups reported similar improvements in motor control and quality of life in scores on the Unified Parkinson's Disease Rating Scale.

On a variety of neuropsychological tests, there were no significant differences between the two groups. However, the STN DBS group experienced a greater decline on a test of visuomotor processing speed, which measures how quickly someone thinks and acts on information. Also, the STN DBS group had slight worsening on a standard assessment of depression, while the GPI DBS group had slight improvement on the same test. The importance of these two differences is not clear, and will be scrutinized in follow-up research.

In addition, NINDS-supported researchers are developing and testing improved implantable pulse generators, and conducting studies to better understand the therapeutic effect of neurostimulation on neural circuitry and brain regions affected in PD. For more information about current studies on brain stimulation and Parkinson's disease, see www.clinicaltrials.gov and search for "deep brain stimulation AND Parkinson AND NINDS." For information about NINDS- and NIH-supported research studies in this area, see the NIH RePORTER (Research Portfolio Online Reporting Tools) at <http://projectreporter.nih.gov> and search for "deep brain stimulation AND Parkinson."

The Brain Initiative for Advancing Innovative Neurotechnologies (BRAIN) initiative, announced in 2013, offers unprecedented opportunities to unlock the mysteries of the brain and accelerate the development of research and technologies to treat disorders such as Parkinson's disease. For more information about the BRAIN initiative, see www.nih.gov/science/brain.

Where can I get more information?

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

"Deep Brain Stimulation for Parkinson's Disease Fact Sheet," NINDS. Publication date July 2014.

NIH Publication No. 14-5648

Prepared by:
Office of Communications and Public Liaison
National Institute of Neurological Disorders and Stroke
National Institutes of Health
Bethesda, MD 20892

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Last updated July 27, 2015

EVERY CLINICAL TRIAL
NEEDS VOLUNTEERS.
FOX TRIAL FINDER KNOWS
WHICH TRIALS NEED YOU.

[Learn More](#)



FIND A TRIAL

- I have Parkinson's or am registering for someone who does
- I do not have Parkinson's but would like to volunteer for a trial

I am located in

Please choose a country

Postal Code

[GET STARTED](#)

ABOUT FOX TRIAL FINDER

Fox Trial Finder was created by the Michael J. Fox Foundation to help increase the flow of willing participants — both people with Parkinson's and control participants who do not have Parkinson's — into the clinical trials that need them, accelerating the Parkinson's drug development process.

Clinical trials are a final and crucial step on the path to developing better treatments for Parkinson's patients today. Around the world, between 40% and 70% of trials face delays because of a lack of volunteers.

Fox Trial Finder will not only list ongoing PD clinical trials and research studies, but will match registrants to the trials that need them and are best-suited to their specific traits. Fox Trial Finder also has a secure and anonymous messaging system, making it much easier to find and act on suitable opportunities to get involved.

JOIN THE **49,210** CLINICAL TRIAL
VOLUNTEERS WHO HAVE ALREADY STEPPED UP.

INTERNATIONAL COLLABORATION

The Michael J. Fox Foundation is collaborating with international leaders in PD research to expand Fox Trial Finder in Austria, France, Germany, Italy and Spain.

FROM MICHAEL J. FOX

"The answer is truly in all of us, working together. International collaboration is essential for speeding a cure for the 5 million Parkinson's patients worldwide."

— **Michael J. Fox**

TRIAL TEAMS



Do you need volunteers for your clinical trial? Find them with Fox Trial Finder!

[Learn More](#)

Wednesday, March 24, 2010

How Music Helps to Heal the Injured Brain

Therapeutic Use Crescendos Thanks to Advances in Brain Science

By: Michael Thaut Ph.D., and Gerald McIntosh M.D.

The use of music in therapy for the brain has evolved rapidly as brain-imaging techniques have revealed the brain's plasticity—its ability to change—and have identified networks that music activates. Research has shown that neurologic music therapy can help patients who have difficulty with language, cognition, or motor control, and the authors suggest that these techniques should become part of rehabilitative care.

Editor's note: The use of music in therapy for the brain has evolved rapidly as brain-imaging techniques have revealed the brain's plasticity—its ability to change—and have identified networks that music activates. Armed with this growing knowledge, doctors and researchers are employing music to retrain the injured brain. Studies by the authors and other researchers have revealed that because music and motor control share circuits, music can improve movement in patients who have suffered a stroke or who have Parkinson's disease. Research has shown that neurologic music therapy can also help patients with language or cognitive difficulties, and the authors suggest that these techniques should become part of rehabilitative care. Future findings may well indicate that music should be included on the list of therapies for a host of other disorders as well.

The role of music in therapy has gone through some dramatic shifts in the past 15 years, driven by new insights from research into music and brain function. These shifts have not been reflected in public awareness, though, or even among some professionals.

Biomedical researchers have found that music is a highly structured auditory language involving complex perception, cognition, and motor control in the brain, and thus it can effectively be used to retrain and reeducate the injured brain. While the first data showing these results were met with great skepticism and even resistance, over time the consistent accumulation of scientific and clinical research evidence has diminished the doubts. Therapists and physicians use music now in rehabilitation in ways that are not only backed up by clinical research findings but also supported by an understanding of some of the mechanisms of music and brain function.

Rapid developments in music research have been introduced quickly into neurologic therapy (see sidebar) over the past 10 years. Maybe due to the fast introduction, the traditional public perception of music as a 'soft' addition, a beautiful luxury that cannot really help heal the brain, has not caught up with these scientific developments.

But music can. Evidence-based models of music in therapy have moved from soft science—or no science—to hard science. Neurologic music therapy does meet the standards of evidence-based medicine, and it should be included in standard rehabilitation care.

Where We Started

While the notion that music has healing powers over mind and body has ancient origins, its formal use as therapy emerged in the middle of the 20th century. At that time, music therapists thought of their work as rooted in social science: The art had value as therapy because it performed a variety of social and emotional roles in a society's culture. In this early therapy, music was used, as it had been through the ages, to foster emotional expression and support; help build personal relationships; create and facilitate positive group behaviors; represent symbolically beliefs and ideas; and support other forms of learning. In the clinic, patients listened to music or played it together with the therapists or other patients to build relationships, promote well-being, express feelings, and interact socially.

Because early music therapy was built upon these laudable and important but therapeutically narrow concepts, many in health care, including insurers, viewed it as merely an accessory to good therapy. For decades it was difficult to collect scientific evidence that music therapy was working because no one knew what the direct effects of music on the brain were. Now, however, the approaches that are central to brain rehabilitation focus on disease-specific therapeutic effects, demonstrated by rigorous research.

Neuroscience Steps Up

During the past two decades, new brain imaging and electrical recording techniques have combined to reshape our view of music in therapy and education. These techniques (functional magnetic resonance imaging, positron-emission tomography, electroencephalography, and magnetoencephalography) allowed us for the first time to watch the living human brain while people were performing complex cognitive and motor tasks. Now it was possible to conduct brain studies of perception and cognition in the arts.¹

From the beginning of imaging research, music was part of the investigation. Scientists used it as a model to study how the brain processes verbal versus nonverbal communication, how it processes complex time information, and how a musician's brain enables the advanced and complicated motor skills necessary to perform a musical work.

After years of such research, two findings stand out as particularly important for using music in rehabilitation. First, the brain areas activated by music are not unique to music; the networks that process music also process other functions. Second, music learning changes the brain.

The brain areas involved in music are also active in processing language, auditory perception, attention, memory, executive control, and motor control.² Music efficiently accesses and activates these systems and can drive complex patterns of interaction among them. For example, the same area near the front of the brain is activated whether a person is processing a problem in the syntax of a sentence or in a musical piece, such as a wrong note in a melody. This region, called Broca's area after the French neurologist from the 19th century who described it, is also important in processing the sequencing of physical movement and in tracking musical rhythms, and it is critical for converting thought into spoken words. Scientists speculate, therefore, that Broca's area supports the appropriate timing, sequencing, and knowledge of rules that are common and essential to music, speech, and movement.³

A key example of the second finding, that music learning changes the brain, is research clearly showing that through such learning, auditory and motor areas in the brain grow larger and interact more efficiently. After novice pianists have just a few weeks of training, for example, the areas in their brain serving hand control become larger and more connected. It quickly became clear that music can drive plasticity in the human brain, shaping it through training and learning.⁴

Researchers in the field of neurologic rehabilitation have described parallel results. They found that the brain changes in structure and function as a result of learning, training, and environmental influences. Exposure and experience will create new and more efficient connections between neurons in the brain in a sort of "rewiring" process.

This discovery fundamentally changed how therapists developed new interventions. Passive stimulation and facilitation were no longer considered effective; active learning and training promised to be the best strategy to help rewire the injured brain and recover as much ability as possible. Further clinical research has strongly confirmed this approach.⁵

By combining these developments—brain imaging, insight into plasticity, and finding that musical and non-musical functions share systems—therapists finally could build a powerful, testable hypothesis for using music in rehabilitation: Music can drive general reeducation of cognitive, motor, and speech and language functions via shared brain systems and plasticity. Once used

only as a supplementary stimulation to facilitate treatment, music could now be investigated as a potential element of active learning and training.

First Steps with Movement

To explore this hypothesis, in the early 1990s we began to extract and study shared mechanisms between musical and non-musical functions in motor control. One of the most important shared mechanisms is rhythm and timing.

Timing is key to proficient motor learning and skilled motor activities; without it, a person cannot execute movement appropriately and skillfully. Rhythm and timing are also important elements in music. Rhythm timing adds an anticipation component to movement timing. The necessary harness for all elements of musical sound architecture, rhythm is also important in learning the appropriate motor control in order to play music.

We hypothesized that by using musical rhythms as timing signals we might improve a person's motor control during non-musical movement. To test this idea, we used rhythmic auditory cues to give people an external "sensory timer" with which they could try to synchronize their walking.

When we tried it with patients with stroke or Parkinson's disease, their improvements in certain areas were instantaneous and stunning. By following the rhythmic cues, patients recovering from stroke were able to walk faster and with better control over the affected side of their bodies. Some of the more complex measures of movement control, such as neuromuscular activation, limb coordination, angle extensions, and trajectories of the joints and centers of body mass, also became significantly more consistent, smoother, and flexible.⁶ For those with Parkinson's disease, it was interesting to see that music and rhythm could quicken their movements and also serve as an auditory trigger to keep the movements going and prevent "freezing" (the sudden halt of all movement), which occurs frequently in Parkinson's patients.⁷

These improvements held up over long-term training and also proved to be superior in comparison with other standard physical therapy interventions.⁸ We then applied the same concepts to arm therapy, with similar success. Since then, other studies have confirmed and extended our research. The therapy created from it, rhythmic auditory stimulation, now is considered part of the state-of-the-art repertoire in motor therapies.

Our results added weight to the idea that music could shape movements in therapy by accessing shared elements of musical and non-musical motor control (rhythm, timing) and thus powerfully enhance relearning and retraining in a clinical environment. In a recent study that utilized brain imaging in patients with stroke, arm training with auditory rhythm triggered brain plasticity, as predicted. Additional areas in the sensorimotor cortex and the cerebellum were activated by the training. In comparison, standard physical therapy did not result in any evidence of new changes in brain activations.⁹

Reaching for Speech and Cognition

Clinical research studies in the past 10 years have extended the use of music from motor therapy to the rehabilitation of speech, language, and cognitive functions. Scientists wondered if they could design therapeutic music exercises that would affect general cognition and speech and language functions via plasticity in shared brain systems the way they had for motor therapies.

It wasn't as clear from the outset, though, exactly what advantage music would show over other methods of retraining impaired cognition or language functions. It was easier to see that music has advantages over other types of therapies for motor control because of its rhythmic patterns that drive priming and timing of the motor system, and the rich connectivity between the neurons in the auditory system and those in the motor system. One can picture the auditory neurons responding to rhythmic stimuli and firing in patterns that spread via connecting nerve fibers into motor neurons, activating them in synchronicity. How music could facilitate cognition and language training was initially less obvious.

Two insights from research help to bridge this gap. The first extends the idea that the brain systems underlying music are shared with other functions. Evidence suggests that music may activate these systems differently than speech or other stimuli do and might enhance the way the systems work together.¹⁰ For example, music tends to activate brain structures either bilaterally—in both hemispheres simultaneously—or in the right hemisphere more than the left. For injuries on one side of the brain, music may create more flexible neural resources to train or relearn functions. Aphasia rehabilitation is a good example. Singing—which relies mainly on right-hemisphere brain systems—can bypass injured left-hemisphere speech centers to help people produce speech.¹¹ We have shown in a memory study that learning word lists in a song activates temporal and frontal brain areas on both sides of the brain, while spoken-word learning activates only areas in the left hemisphere.¹² Music also can activate the attention network on both sides of the brain, which can help overcome attention problems caused by stroke or traumatic brain injury.¹³

The second helpful insight was the development of the auditory scaffolding hypothesis.¹⁴ This model proposes that the brain assigns nearly everything that deals with temporal processing, timing, and sequencing to the auditory system. This process works because sound is inherently a temporal signal, and the auditory system is specialized and highly sensitive for perceiving time information. For example, short-term auditory verbal memory (in spoken words) is better than short-term visual memory (in written words). Similarly, people can track and remember auditory tone sequences better than visual or tactile ones. And people who are deaf also often have trouble developing non-auditory temporal skills. Cognitive abilities such as language, learning and remembering, attention, reasoning, and problem-solving require complex temporal organization. Experiences with sound may help bootstrap—or provide a kind of scaffolding for—developing or retraining such abilities. As music may be the most complex temporal auditory language, it may offer superior auditory scaffolding for cognitive learning.

Using these two insights, researchers could make a case for trying music as therapy in speech, language, and cognitive rehabilitation. Evidence from the research that ensued supports the clinical effectiveness of music and has identified the brain processes that underlie these effects.

For example, various studies have shown that therapeutic music exercises can help improve verbal output for people with aphasia, strengthen respiratory and vocal systems, stimulate language development in children, and increase fluency and articulation. Music therapy can retrain auditory perception, attention, memory, and executive control (including reasoning, problem-solving, and decision-making).¹⁵

Next Frontier: Mood?

The extended shared brain system theory and the auditory scaffolding theory provided a new theoretical foundation for the therapeutic use of music in motor, speech and language, and cognitive rehabilitation. In the future, new theories may help us understand the other effects of music, and point the way to new types of rehabilitation.

For example, how can we harness the ability of music to evoke and induce mood and emotion to help retrain the injured or depressive brain? We know that the capacity for memory improves when people are in a positive mood. We also know that rational reasoning in executive control requires integrating and evaluating both logic and emotion. In this context, one question is whether emotions evoked by music can contribute to executive control training in rehabilitation, and if so, how. The problem is that we still do not know the exact nature of these emotional responses and whether they relate to those that we experience in everyday life. If we find answers to questions like these, we might someday use music to retrain emotional and psychosocial competence—not in the traditional music therapy sense of improving well-being, but rather as a functional goal in cognitive ability.

Biomedical research in music has come a long way to open new and effective doors for music to help reeducate the injured brain. Of course, much still needs to be done: More professionals need specialized training, and other possibilities for rehabilitation require further research and clinical development. Scientists need to better understand what dosages work best, to

pay more attention to research that will benefit children, and to focus on disorders in which neurologic music therapy lacks rigorous study so far, such as autism, spinal cord injury, cerebral palsy, and multiple sclerosis. In addition, the effects of brain injury can be complex, and researchers must take individual factors into account and adapt to individual needs. Neurologic music therapists share those aims with practitioners in other rehabilitation disciplines.

What no longer requires confirmation is the premise that music in therapy works, in principle and in practice. It is a fact: Music shows promise for helping to heal the brain. Research has identified specific areas in which music is an effective therapeutic approach. Neurologic music therapy now meets the standards of evidence-based medicine, is recognized by the World Federation of Neurorehabilitation, and should be a tool for standard rehabilitation care.¹⁶ Insurance companies must become familiar with the research evidence and reimburse patients who have conditions for which the evidence supports its effectiveness.

Neurologic music therapy is a specialized practice, but it is based on elements and principles of music and brain function that can be integrated by all rehabilitation professions. In this way, it offers a strong foundation for interdisciplinary teamwork that will benefit patients.

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- See more at:

http://dana.org/Cerebrum/2010/How_Music_Helps_to_Heal_the_Injured_Brain__Therapeutic_Use_Crescendos_Thanks_to_Advances_in_Brain_Science/#sthash.uZ3XNm37.dpuf



Essential Tremor (ET)

Coping Tips

for everyday living

Essential tremor (ET) can turn daily tasks into a test of ingenuity, perseverance and self-esteem. Writing a letter, dressing and eating can cause frustration and lead to stress that temporarily increases tremor. Try these coping tips to make tasks easier to accomplish.

General Suggestions

- Maintain a positive, upbeat attitude and put a smile on your face. It will reduce tension and lighten your mood.
 - Stress exacerbates tremor. Use deep breathing exercises or meditation to help reduce stress levels and remain calm.
 - Learn to use your tremor-free hand for as many activities as possible, including writing.
 - Use your tremor-free hand to steady your trembling hand and use two hands when possible.
 - Keep your elbows close to your body when performing tasks as a way to help control hand tremor.
 - Use travel mugs with lids. When on the go, use lids for purchased beverages whenever possible.
 - Carry straws with you. You can find sturdy, thick, plastic straws in many housewares sections of stores if thin plastic straws are too flimsy.
 - Avoid caffeine, mahuang, ephedra, and other over-the-counter medications and herbs containing ingredients that increase heart rate. They can cause a temporary increase in tremor.
 - Carry and use weighted pens and eating utensils with large handles.
 - Talk to people about ET and explain what it is. Education raises awareness and fosters understanding.
 - Don't be afraid or embarrassed to ask for help. Tell others you have ET and ask them to help you reach for groceries on high store shelves, ask cashiers in cafeterias to help bring the tray to your table, or ask relatives or friends to cut meat or lettuce for you.
 - Before doing fine, detailed tasks with your hands, avoid heavy lifting or strenuous activity.
 - When reading, place the newspaper or book on a table rather than holding it.
 - Tear paper using a sharp-edged ruler or use scissors while holding your hands close to your body.
 - Do tasks slowly. Try to focus and concentrate on the task at hand.
 - Take an active role in your local support group. Ask if you can assist the leader in any way. Sometimes when we help others, we end up helping ourselves.
-

Writing

- Print rather than write script.
 - Write in small letters—it's easier than writing in large letters.
 - Rest the heel of your palm on the writing surface and your forearm on a table while writing.
 - Make sure your writing surface is level.
 - Hold the pen between your index and middle finger.
 - Place writing paper on a newspaper, envelope or heavyweight paper to help control shaking movements and avoid ripping the paper.
 - Use a ruler as a guide under your palm to keep lines straight.
 - Use a pen or pencil with a thick, rubberized grip.
 - Rather than writing, carry a recording device with you to record notes.
 - When possible, type messages rather than writing them.
 - Do math on a calculator rather than on paper.
-

Head Tremor

- Hold your chin in your hand(s) or toward your chest, or turn your head to the side to steady your head.
 - When conversing, hold your head to the side, not straight ahead. Also, turn your body slightly and turn your head toward the other person.
-



Eating, Drinking and Food Preparation

- Use heavier glasses and mugs with lids instead of light-weight cups. Soup mugs are also a good choice for drinking.
- When holding a mug or small glass, place your thumb along the rim and place your fingers across the bottom.
- Fill cups, mugs and glasses half full.
- Use dishes that have vertical sides or buy rubber bumper guards from a medical supply store to place around the edges of your plates so food is easier to scoop.
- Use covered ice-cube trays.
- Get a rubberized placemat that sticks to the table so plates do not slide.
- When pouring or measuring liquids or solids into an eating or storage container, put the container in the sink and pour down into it. For instance, when measuring ground coffee, put the grounds into a measuring cup in the sink and pour them into the basket or filter.
- If necessary, use a bib or napkin to prevent food from soiling clothes.
- Put your microwave on a countertop or low table so you can easily place food inside and remove it.
- Use Chinese soup spoons which have a larger bowl and are heavier than standard spoons.

Restaurants

- Request that your meat be cut in the kitchen before being served.
- Order finger foods to eliminate the need for utensils.
- Ask that your soup be served in a mug.
- Request that your drinking glass or mug be filled only half full.
- Ask for a straw or carry some with you.
- Avoid buffets or have someone assist you when going through the line.
- Add crackers or pieces of bread to a thin soup to thicken it and make it less likely to spill.
- Order mashed potatoes so you can move smaller pieces of food (peas, etc.) into the potatoes to make them easier to pick up.
- Use two hands to hold cups, soup bowls, etc.

Business and Banking

- Use a signature stamp when possible to sign your name. (Check with your banking institution to ensure they will accept a stamp on your financial documents.)
- If possible, sign forms using your initials rather than your full name.
- Carry a strip of self-adhesive address labels, to use when asked for contact information.
- Fill out deposit and withdrawal slips at home before going to the bank.
- Use online banking to pay your monthly bills.
- Use credit or debit cards instead of writing checks.
- If you write checks, do them all on a "good" tremor day.
- When paying with cash, ask the cashier to put the coins in your hand and the bills on top so the coins won't fall.
- Ask receptionist or teller to help you fill out forms.
- Print personal business cards listing your name, address, phone/cell numbers, e-mail address, etc.
- When speaking before audiences, keep your hands and arms close to your side or keep your hands in your pockets. Explain to the audience you have ET. Insert paper notes into plastic sheets and put them in a loose leaf notebook so they won't rattle.

*Be who you are and say what you feel,
because those who matter don't mind,
and those that mind, don't matter.*

-Dr. Seuss

Telephones

- Use a telephone with large buttons. Avoid phones with speed dial and redial buttons too close to the number buttons.
- Use a speakerphone, headset or Bluetooth® device when using phones.
- Keep a small recording device next to the phone so you can record information when talking on the phone.
- Use voice-activated dialing, if available, on your cell phone.
- Adjust the touch screen interface on your Android phone or iPhone in order to use features that will better accommodate your ET.

When you become detached mentally from yourself and concentrate on helping other people with their difficulties, you will be able to cope with your own more effectively. Somehow, the act of self-giving is a personal power-releasing factor.

-Norman Vincent Peale

Computers

- Set your computer to omit double-strikes and repeat characters on the key board and double-clicks and tracking speed on the mouse. If you use a PC, go to your computer's Control Panel and click on the Ease of Access Center to set these options. On a MAC, go to your System Preferences.
- Rest the heel of your palms on the surface in front of the keyboard.
- Go to a store selling a number of different types of computer mouse. Try them out and choose the one that works best for you.
- Check into speech-recognition software. Some computers are pre-loaded with this.

Other Technology

- Ask your security alarm representative to give you a remote to turn your system on and off.
- When choosing a digital camera, pick one with image stabilization technology.
- Use a tripod or camera stand when taking pictures.
- When using a digital camera, use the optical viewfinder so that you can hold the camera close against your body.
- For unattended parking garages where you must insert a thin cardboard ticket into a slot: slip the ticket into a firm plastic card protector and extend the ticket an inch or so outside the plastic cover. If necessary, exit the vehicle and brace your arm against your body. Place the exposed ticket end into the slot and retract the plastic cover as the ticket is pulled into the slot.

Airport Security

Getting through airport security can be especially difficult for people with ET. It can be a frustrating, intimidating experience. That's why it is important to be prepared.

- Give yourself plenty of time to arrive well before your flight so that you do not have to rush through security.
- When dressing for air travel, wear slip-on shoes that are easy to remove and easy to put back on afterwards.

Before entering security:

- Have a plastic bag ready so you can place everything you usually carry in your pockets, such as coins, keys and cell phone, into it.
 - Take your belt off (or don't wear one).
 - Have your ID and other travel documents together and in your hand.
-

Dental Visits

- Ask for adrenaline-free anesthesia shots.
- Notify your dentist of all medications you are taking.

Head tremor only

- Request that your dentist stop periodically so you can massage and rest your jaw and head.
- Ask your dentist whether a bite block will help steady your jaw during dental procedures.
- Talk with your dentist about having a person in addition to the dental assistant help with your procedure. The third person can gently hold your head to help control tremor.

Personal Care

- Use an electric razor when shaving.
- Have a manicurist care for your nails.
- Have a cosmetologist wax or pluck your eyebrows.
- Use disposable floss holders when flossing your teeth.
- Hire a seamstress to do your mending, or find a volunteer to sew on buttons, thread needles and pin fabrics.
- Use Velcro® fasteners rather than buttons.
- Use a buttoning aid (a pencil-like device) with a wire hook at the end.
- Use an electric toothbrush or a child's toothbrush for better control when brushing your teeth.
- Put toothpaste on a toothbrush by laying the tube on the counter and push from the bottom of the tube onto the bristles.
- To put drops into your eyes or nose, hold your elbow with your other hand, or try lying flat.

Applying Makeup and Putting on Jewelry

- Apply mascara by resting your elbows on the countertop. Put the wand in one hand and use the other hand to keep the wand steady.
- Apply eyebrow pencil, mascara, eyeliner or lipstick by resting your finger or the palm of your hand on your face to steady your hand.
- Put on earrings by resting your elbows on a table.
- If you have head tremor, place your chin on an upended facial tissue box to steady your head.

Cheerfulness is the best promoter of health and is as friendly to the mind as to the body. -Joseph Addison

Thank you to the Northbrook, IL Support Group and our IETF members for providing these helpful tips. Email your coping tips to info@essentialtremor.org.

This information is not intended to replace your current medical therapy. Discuss your difficulties with your physician or other healthcare professional in order to help develop a well-rounded treatment plan that is right for you.



International
Essential Tremor
Foundation

Your Voice for Essential Tremor

Our Mission:

The IETF funds research to find the cause of essential tremor (ET) that leads to treatments and a cure, increases awareness, and provides educational materials, tools, and support for healthcare providers, the public, and those affected by ET.