

Parkinson's Disease, MUSIC AND MYSTERY

What effects does music have on people living with Parkinson's disease? What mysterious thing happens to us when we are exposed to or even participate in song?

When you sit back and listen to music, say Samuel Barber's Adagio for strings; something happens. What is that something? Your heart rate synchronizes with the music, your mind quiets and your thoughts melt away into melodies. Your whole being transcends time and space and you float on the harmonies and gentle rhythm of the piece. If you listen to say, Buddy Holly's That'll Be The Day, again, something happens. Your pulse quickens, and you begin tapping your feet to the rhythm, you break into a smile and memories of dancing and happy times flood into your consciousness. Wherever you were, whatever you were doing, suddenly you are transported somewhere else and you feel the change. If you have ever sung in a group or been part of a choir, you have experienced firsthand the surge of serotonin and the uplifting feeling that blending your voice with other voices all singing the same song brings.

So perhaps all this has something to do with why music therapy is so good

for people living with Parkinson's disease. Music is complex, music is dynamic; and it operates on many levels. It lifts the mood and lifts the spirit. Parkinson's is also a complex disease. It is more than a tremor, stiffness and gait disturbance,



Continue on page 2

Featured Articles	
Parkinson's Disease, Music and Mystery	Pages 1 & 2
Glossary of Parkinson's Terms	Page 3
Help Yourself by Exercising	Page 4
Parkinson Place Center	Page 5
Rock Steady Boxing for Parkinson's Disease	Page 6
Yoga for Parkinson's Disease	Page 7
Help Us Help Others - Donate Today	Page 8



more than a lack of dopamine in the substantia nigra, more than then alpha-synuclein, the mitochondria or the cell surfaces or the chaperone molecules within the cells. Music in all its complexity seems to harmonize with the complexity of Parkinson's disease. Taking what may be a depressed mood and turning it into happier thoughts and perhaps a lighter mood.

Music is one area that although it can be quantified into individual parts, is; as Aristotle commented "The whole is greater than the sum of its parts". It is a process, Music's effects on the human psyche and the variability of those effects defy explanation. Reducing disease to cellular function can explain the cellular function or "mis-function" and the interactions between the cellular relationships. It can show the how and what of the disease process, but it cannot tell us the why. Parkinson's is a dynamic system, with many effects changing from moment to moment. Sometimes it is the "whole", sometimes it is just a "part".

Adding music therapy to the treatment for Parkinson's disease is bringing two dynamic systems (really many more) together to change the course of yet another. Exactly how music calms the Parkinson's beast has yet to be determined. Yet more important is the fact that it is all a process, not an endpoint - the complexity of both dynamic systems interacting to bring the human state or the disease state to the edge of that creative process, to the edge of energy and potential and to stimulate new dynamic processes.

In complex systems, such as music and disease, there will always be missing information, and unanswered questions. Part of the process knows there are limits: there are things perhaps we cannot qualify or "know". Life is still, and hopefully will always be a mystery. It is releasing and letting go, accepting those limits and allowing "magic" to happen. Music is magic... and mystery and what a sweet mystery it is!



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Glossary of Parkinson's Terms

Atypical Parkinsonism - Disorders related to PD in that they are characterized by bradykinesia and sometimes rigidity, and balance problems, but have other clinical features and other pathology. Tremor is less common in these disorders.

Basil Ganglia - The interconnected cluster of nerve cells that coordinate normal movement, made up in part of the substantia nigra, striatum, subthalamic nucleus and globus pallidus.

Blepharospasm - forced closure of the eyelids.

Bradykinesia - gradual loss of spontaneous movement; slowness of movement. This is often the most disabling of symptoms.

Carbidopa - a drug, used with levodopa, to block the breakdown of levodopa to dopamine in the intestinal tract and in the blood.

Cognitive function - the ability to think, remember, plan and organize information.

Deep Brain Stimulation - electrical stimulation of certain parts of the brain to treat Parkinson's disease.

Dopamine - the primary chemical messenger of the basal ganglia; it is reduced in Parkinson's disease.

Dysphagia - difficulty with or abnormality in swallowing.

Dystonia - in Parkinson's disease, tightness, spasm, or cramping of muscles; may also involve twisting or posturing of muscles.

Festination - a symptom characterized by small, quick forward steps.

Freezing - inability to move or getting "stuck", as with the feet appearing to be glued to the floor.

Gait - the manner in which a person walks.

Hypomimia - the mask-like expression typical of Parkinson's disease.

Lewy body - a ball of proteins lodged within cells, visible microscopically and usually present in Parkinson's disease.

Motor fluctuations - the complications of the treatment of Parkinson's disease affecting the ability to move; examples are wearing off of dose, on-off phenomenon and dyskinesias.

Orthostatic hypotension - a significant drop in blood pressure on changing position (going from lying to sitting to standing), often accompanied by lightheadedness or passing out.

Pallalia - stuttering or stammering speech in Parkinson's disease.

Parkinsonism - a term referring to a group of conditions that are characterized by four typical motor problems - tremor, rigidity, postural instability and bradykinesia.

Propulsion - propelling forward as the patient accelerates with rapid, short steps.

Rigidity - a tightness or increase in muscle tone at rest or throughout the entire range of motion of a limb; it may be felt as stiffness by the patient.

Substantia nigra - movement control center in the brain where the loss of dopamine-producing nerve cells triggers the symptoms of Parkinson's disease; substantia nigra means "black substance" so called because the cells in this are dark.

Tremor - shakiness or trembling, often in a hand, which in Parkinson's disease is usually most apparent when the affected part is at rest.

Wearing off effect - the tendency, following long-term levodopa treatment, for each dose of the drug to be effective for shorter and shorter periods.

HELP YOURSELF by EXERCISING

Although exercise will not reverse the symptoms of Parkinson's disease (PD), it retains your functioning potential for a longer period of time. Exercise can also help prevent complications due to long-term immobility, such as contractures. Regular exercise is one of the most important self-help strategies for those living with PD. The phrase "use it or lose it" definitely applies. Exercise is just as important as medication in helping to manage the symptoms of PD.

Exercise will slow the progression of symptoms, improve balance, increase mobility, strengthen muscles, increase circulation, improve quality of life, increase the ability to function independently for longer, improve emotional state and help lift depression.

What Type of Exercise Should I Do?

All types of exercise help. Your choice depends on your symptoms, your age, your physical strength and your interests. The best program is one that combines a number of different activities and allows you to change as symptoms and capabilities change. It is important to choose a form of exercise that you enjoy or your tendency might be to quit.

A Formal Exercise Group

Some people find that an exercise group helps them adhere to consistent exercise. In a class setting, people with varying levels of ability can be accommodated when each participant competes only with themselves, supports each other and works within their personal limits.

Beginning an Exercise Program

When you begin to exercise, make sure that your expectations are realistic. You may not be able to perform at the same level as you did before PD. Exercise helps you to maintain a better quality of life and gives you a sense of control and accomplishment. Your goal should be to work at your personal best.

How Much Should I Exercise?

An ideal goal is to perform some form of exercise every day. However, because of the nature of PD, there may be some days when this is not possible. Accept this and return to exercise when you are able.

**Last but not least -
HAVE FUN!**



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ROCK STEADY BOXING FOR PARKINSON'S DISEASE

Rock Steady Boxing is a unique exercise program based on training used by boxing pros and adapted for people with Parkinson's disease. The program involves regular exercises such as stretching, dexterity drills, hand & eye coordination, balancing and non-contact boxing led by experienced trainers/coaches. Rock Steady Boxing serves both men and women of all ages and levels of ability.

The Rock Steady Boxing Method was developed in Indianapolis over the course of seven years. In 2012, the Training Camp was launched to share the Rock Steady Boxing Method with other people who are fighting back against Parkinson's. The Rock Steady Boxing headquarters and training center is located in Indianapolis.

Various studies support that rigorous exercise, emphasizing gross motor movement, balance, core strength, rhythm and hand-eye coordination improves range of motion, flexibility, posture, gait and the ability to perform activities of daily living. Studies at the Cleveland Clinic suggest that forced exercise, such as boxing, is neuroprotective and may actually slow disease progression.

"We have always believed in the Rock Steady Boxing Method," said Rock Steady Boxing, Inc. Executive Director Joyce Johnson. "When evidence began to emerge that our program had a

very positive impact on the "boxers" our mission became clear – to share our knowledge and experience with all people living with Parkinson's. That is why we decided to make our training available worldwide. To train as many as we can so together we can improve the care of people with Parkinson's everywhere."

Additional information about Rock Steady Boxing Inc. www.rocksteadyboxing.org.

Become a member at Parkinson Place Center for All Movement Disorders at www.ParkinsonPlace.org and take free Rock Steady Boxing classes online or in person. We look forward to seeing you soon.



YOGA

for Parkinson's Disease

*Lynn Burgess, Registered Yoga Teacher (RYT)
500 & E-Registered Yoga Teacher (RYT) 500*

Yoga is an ancient Indian science that has been used for centuries to create physical health, mental peace and intellectual clarity. In recent years, yoga's popularity in Western countries has been on the rise. People are now realizing its therapeutic benefits for managing many chronic diseases, including Parkinson's disease (PD).

Yoga involves the practice of various asanas (yoga postures) and pranayama (modulation of breath). BKS Iyengar, one of the world's leading authorities on yoga, has created variations of key yoga postures which help individuals with specific medical problems reap full benefits from the practice. Iyengar's variations often utilize "props" (blocks, blankets, etc.) which make it possible for everyone, including those with major physical and

physiological limitations, to perform the postures.

For example, yoga poses that target the torso help prevent rigidity and foster a sense of balance. Stiffness in the body's core is one of the most debilitating symptoms of PD because it hampers a person's ability to walk across a room or simply stand upright. Poses that strengthen the trunk tend to reduce stiffness and improve mobility. They give participants the energy needed to counteract insomnia and the lethargy that often occurs with Parkinson's disease.

Yoga induces relaxation which helps control tremors, activates muscle groups and can be a steady reminder of where your body should be and how it should move.



“Help Us Help Others - Donate Today”

Without ongoing contributions from generous donors like you, the **PARKINSON RESEARCH FOUNDATION** would be unable to fund **EDUCATION, RESEARCH, and FREE SERVICES** for the millions of people living with Parkinson's disease around the world.

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Wills, Bequests and Planned Gifts

Please give serious consideration to the designation of PRF in your Will, Charitable Trusts, Life Insurance, Appreciated Securities and Real Estate as this offers preplanned giving opportunities that will serve the Parkinson community for years to come. Please call Lynne Henry (941) 893-4389 at the Parkinson Research Foundation, today, for personal assistance in initiating this effort.

The following language has been reviewed and is deemed a legally acceptable form for including such a bequest in a will:

“I give and bequeath to the Parkinson Research Foundation,
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for discretionary use in carrying out its aims and purposes,
(the sum of \$_____) OR (a sum equal to _____% of the value of my gross
estate at the time of my death under this will or any codicil hereto).”

The Parkinson Research Foundation Federal ID number is 20-0205035

Memorial and Honor Giving

Honor a family member, friend or special event by donating to PRF. Pay tribute to someone you love whose life has been impacted by Parkinson's disease. In lieu of flowers, please consider designating Parkinson Research Foundation as your charity of choice.

Workplace Giving: Launch a Giving Campaign

Please consider leading a team at work by encouraging your colleagues and staff to join together to help those living with Parkinson disease. Launch a workplace giving campaign today.

Ask about Matching Gifts

Many gracious employers double even triple charitable donations made by individual employees. Some companies will match gifts made by retirees and/or their spouses. Contact your employees for matching gift eligibility as this allows you to maximize your personal donation.



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