

Living with Parkinson's: Strategies for Patients

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Disclaimer: The proceeding information is for educational purposes and acts as a guide to help patients understand possible therapeutic approaches to living with Parkinson's Disease. This information does not substitute for direct medical advice, service, or treatment by a licensed health care practitioner. The reader understands that the author is not rendering therapeutic or medical advice or engaging in professional service of health care. The reader should consult his or her licensed health care provider(s) before adopting any of the suggestions found in this manuscript or attached appendices.

This guide is provided for and in relation with *Never Surrender To Parkinson's, Inc.*

Introduction/Philosophy

The *Never Surrender* philosophy and mission is to help those individuals currently struggling with the disease live with more freedom and autonomy. *Never Surrender* founder Paul Green has opined that individuals should seek to be active in regular physical activity and exercise. His instinctual theories and personal experiences of managing Parkinson's with vigorous exercise have strong merit within the scientific community. These theories and methods are only the beginning as we will discuss five important strategic topics including: 1.Posture/Body Structure 2.Exercise 3.Nutrition 4.Mentality 5.Medicine/Surgery

Sufferers of PD often find performing routine daily activities physically, emotionally and socially challenging. This summary provides ideas for Parkinson's patients that may help ease these challenges. It must be understood that the suggestions presented are simply recommendations based upon treatment experiences, exercise science and neurology principles. It is not claimed that this information will provide immediate results or therapeutic answers for each and every specific patient. However, it is believed that if these strategies are followed consistently it will result in improved function, personal freedom and quite possibly slower progression of the disease.

Posture/Body Structure

Perhaps the most overlooked aspect of managing PD is how to maintain and strengthen body structure. The fact that many PD patients suffer from the distinct postural deformity of severe forward head carriage, increased curvature of the upper back and forward flexed arms is not by coincidence. This "stooped" posture is caused by many factors including spinal rigidity, loss of normal subconscious posture control, poor balance, and a loss of normal proprioception (movement sensation of the joints).



Normal



Hyper-Kyphosis

The structure of the spine is the foundation of posture. Normal spinal structure most often equates to a healthy posture while an abnormal, or decayed, spine is associated with unhealthy postures. Abnormal posture causes and worsens disc decay, causes pain, contributes to spinal arthritis, and is associated with many forms of disability. Poor posture is associated with many health conditions such as limited range of motion, breathing difficulties, cardiovascular disease, headaches, poor balance, jaw pain, shoulder/arm pain, and numbness/tingling. Specific to PD, there are two areas of the spine that are often deformed. The cervical spine (neck) and the thoracic spine (upper/middle back) are regions greatly stressed due to the development of “hyper-kyphosis.”

Oftentimes, PD patients stand similar to the picture on the right. If you have suffered from Parkinson’s for some time you may have a posture resembling this picture- termed hyper-kyphosis. Many people in the general population display a hyper-kyphotic posture. There are various reasons why a person may develop this posture but for our purposes we will limit our discussion to what is most relevant to PD.

Perhaps the most startling and vitally important fact regarding the development of hyper-kyphosis is that this posture is directly related to early morbidity and mortality. The hyper-kyphotic posture is not only physically stressful but it potentially shortens lifespan. Many large scale studies have shown that the more a person looks like the picture on the right, the greater the chance of early death, specifically due to heart and cardiovascular problems. Clearly, this is very important for patients to understand as this is the classic postural deformity seen with the disease.

Most of us can have good posture if we *force ourselves to stand up tall*, but we will inevitably resort back to our original position once our effort ceases. It is critical to understand that posture is a subconscious state. Therefore, any methods aimed to rehabilitate posture must focus on subconscious mechanisms and not simply attempt to

exercise the body from a bad position to a better one. The keys to improving subconscious control are to use repetitive movements with medium to long contraction times (10seconds-1 minute), involve whole body movements, and to challenge balance/stability. These methods are inherently more difficult for patients with PD because the areas of the brain that help control posture are simply deficient. The best way for Parkinson's patients to help induce subconscious learning is to perform therapeutic exercises along with strong concentration and cognitive thought- and do it over and over again. Think of the first time you tried a new activity- a sport, game, hobby, or musical instrument. You probably had to concentrate very hard to get it right in the beginning. As time passed with more practice and participation the activity became easier and easier until you could do it "with your eyes closed" or "in your sleep" as the sayings go. In other words, the activity became "reflexive." PD patients must utilize concentration or "cognitive" activity to compensate for the lack of reflexive control resulting from the disease. An analogy of this concept is driving a "standard" automobile instead of an "automatic." The "automatic" car shifts gears on its own (reflexive) but in a "standard" the driver must know when to shift to make the car move efficiently (cognitive). The importance of concentration and mindfulness cannot be underestimated as it relates to learning, exercise, and brain activity.

There are various strategies to help prevent, manage, and possibly reverse hyper-kyphosis deformity. Examples include specifically prescribed therapeutic exercise programs and a unique method of rehabilitation called Clinical Biomechanics of Posture[®] (see www.idealspine.com for information and list of practitioners).

In the next section we will introduce new and novel ways that help to retrain and reeducate posture controls. We will also discuss more specifically the importance of physical exercise for PD patients.

Exercise

One of the most important aspects of health is that of exercise and body movement. Consistently, we find exercise to be a solution to many of humankind's ills. Heart disease, diabetes, obesity, cancer, arthritis and osteoporosis are all conditions that are improved by exercising. What is more is that new information not only suggests, but undoubtedly proves, that exercise helps to relieve mental stress, depression, and dementia. PD patients who participate in regular exercise can improve body strength and endurance, thus helping to prevent injuries and falls sustained during daily activities. Furthermore, exercise improves blood flow (oxygen) to the brain and actually creates new neuron (nerve cell) branches. These new discoveries of the past 15-20 years support and enhance the long held understanding of the importance of cardiovascular exercise on health. They have also resulted in rapid developments of physical exercise strategies that are meant to strengthen not only the body but also the brain itself.

The *Never Surrender* philosophy encourages vigorous exercise in various forms. “Vigorous” will vary from person to person within specific physical limitations and safety. But, it must be emphasized that to make improvements we must challenge the body’s capabilities to create healthy adaptations in blood flow, breathing, strength, flexibility, balance, and stability. As with any form of learning, exercise adaptation and improvement is primarily a direct result of increased neurological activity and efficiency. Once neurological learning (“plasticity”) is accomplished the overall benefits of exercise will soon follow. The ultimate goal is to enhance autonomy and improve the ability to function during daily activities, hobbies, family activities, etc.

Suggestions of exercise programs include cardiovascular activity (various choices such as biking and rowing), therapeutic exercise (muscular stability, neurological exercises, balance training), strength training, stretching classes, tai chi, yoga, gait training and others. If financially able, it is recommended that a person or team be assembled as health advisors/guides to maintain safe and effective exercise programs- examples include exercise physiologists, physical therapists, personal trainers, and chiropractors. Since not all professionals are trained to care for specific populations it is always prudent to check each person’s education and qualifications to ensure quality care and skill.

The most important aspect of exercise is choosing activities that are enjoyable and/or challenging. Creating enjoyment during exercise will improve compliance and help to make exercise a part of life and not a chore.

Cardiovascular Exercise

- Stay within your limits
- 30 minutes-1hour of continuous aerobic exercise
- Calculate **Target Heart Rate** between 50%-70% of Maximum
220-age = Maximum Heart Rate
Target = Maximum x .50
Maximum x .70

Example: 60 year old Male/Rowing
220-60 = 160
Target = 160 x .50 = 80 bpm
160 x .70 = 112 bpm

If you know your Resting Heart Rate you can be more specific

220-age = Maximum Heart Rate
Maximum Heart Rate – Resting Heart Rate = Heart Reserve
Target = Heart Reserve x .50 + Resting Heart Rate
Heart Reserve x .70 + Resting Heart Rate

Example: 60 year old male/Rowing, Resting Heart Rate 74
220-60 = 160
160 - 74 = 86
Target = 86 x .50 + 74 = 117 bpm
86 x .70 + 74 = 134 bpm

It is important to be able to challenge the body safely. A good rule of thumb is that you should be able to hold a casual conversation while exercising. If you find that you cannot speak to someone exercising near you or you experience labored breathing, the intensity is too high. Please see the Rating of Perceived Exertion(RPE) below as a guide of exercise intensity (0-10). For most PD patients the accepted rate should be within 3-7:

Taken from Borg RPE Scale ©Gunnar Borg 1998

Category-Ratio Scale

0	Nothing
.3	
.5	Extremely Weak
1	
2	Weak
2.5	
3	Moderate
4	
5	Strong
6	
7	Very Strong
8	
9	
10	Extremely strong
**	Absolute Maximum

Therapeutic Exercise

Therapeutic exercise may include cardiovascular, strength, flexibility, balance, and stability training. Most often exercise protocols are prescribed and supervised by a health care professional such as a physical therapist. However, with proper instruction and education the PD patient may incorporate therapeutic exercise independently into their daily routines and regular exercise programs. Various examples of balance and stability exercises are pictured in the PD Exercise Program.

Metronome Therapy

A metronome can be used very effectively with therapeutic exercises. A metronome is a simple audio device that beats at an adjustable rate and rhythm. PD patients can use the metronome to match body movements with sound. Exercise research suggests coordinating body movements with metronome rhythm can improve coordination, balance, and walking ability. Some examples of metronome exercises are 1) walking in sync to the rhythm of the metronome 2) moving eyes back and forth in sync while standing with feet together 3) exercising upper and/or lower limbs in sync with the metronome.

Virtually any movement or exercise can be modified to the metronome including many in the attached PD Exercise Program.

Metronome therapy is an effective way to utilize the concept of exercising the brain and body simultaneously. The idea of using concentration to help improve learning and create “plasticity” is the premise of this novel exercise technique.

Nutrition

Similar to exercise, nutrition can be directly or indirectly attributed to nearly all disease processes. Specific to PD, there is no need to deviate from accepted nutritional guidelines. Plenty of fruits and vegetables, whole grains, lean meats, adequate water, and limited processed food intake are the standard recommendations of nearly all health care and nutrition authorities. More detailed suggestions and specific diets are debatable with little evidence of any one dietary program providing superlative benefits (i.e. vegetarian, blood type, high protein, low fat, etc.).

One aspect of nutrition (and of health in general) that has gained incredible support over the past few years is that of inflammation. The body responds to any injury whether it is a physical trauma or a sickness in the same basic way- by inflammation. Think of stubbing your toe and seeing the toe swell afterwards. The swelling is caused by inflammation. Now think of having a cold and having a runny nose and stuffed sinuses. This is also caused by a form of inflammation. Many other disease processes that we don't necessarily see or feel are also caused by minor forms of inflammation. Chronic inflammation has been linked to many disease processes including heart disease, cancer, auto-immunity, fibromyalgia, and pain syndromes. Alzheimer's and Parkinson's have also been linked to chronic inflammation. Many medical and nutritional therapies are now focusing exclusively on limiting (or preventing) chronic inflammation of the body. It is recommended that the PD patient follow the dietary recommendations that will limit inflammation. These include the basic recommendations reviewed above and will emphasize an alkaline (non-acidic) diet. The human body maintains a gentle balance of acid-base in its cells and bloodstream. Current knowledge suggests that if the body becomes too acidic-even mildly so- it promotes an inflammatory environment.

A chronic inflammatory environment will cause cellular damage. Cellular damage eventually results in disease and dysfunction.

Suggestions to limit inflammation and create alkalinity

- If you are overweight, start a plan to lose the excess weight.
- Avoid any foods or environments that you may allergic to. If you are not sure if you have allergies, ask your doctor to be tested for food/environmental allergies.
- Supplement with high quality fish oil, flaxseed oil, or oil blends.
- Hydration- Water intake (consume half of body weight in ounces/day).
Example: 170 pounds = 85ounces = about 3 quarts
- Limit animal foods, especially high saturated fat such as beef.
- Eat many different colors (vegetables, fruits), especially green.
- Vegetable juicing.
- Limit sugar and processed foods.
- Increase fiber intake (whole grains, nuts, firm fruits-apples, pears).
- Maintain oral health, including flossing and regular dental visits.
- Recover- Be sure to maintain a regular sleep schedule as best you can.

There are some interesting supplements that are involved in protecting brain cells from inflammation, injury, and malfunction. Some have shown promise while others have failed to show any significant results in improving PD symptoms. The two most notable to show positive results are Coenzyme Q10 (CoQ10) and Glutathione. The most popular supplement form of Glutathione is N-Acetyl Cysteine (NAC) due to its higher digestive and absorption qualities. Clinically, these two substances help to improve cellular brain function. CoQ10 helps to regulate energy production of the cell and use oxygen more efficiently. Hence, it has been shown to help neuron (nerve cell) survivability- an obvious important benefit. Glutathione is a very powerful anti-oxidant (a substance that prevents damage from overuse and inflammation). In fact, it is reportedly the most potent anti-oxidant of the brain. Currently, neuron metabolism, energy use, and cell life-span are popular topics of brain research. CoQ10 and Glutathione supplements have been studied in animals and patient populations to have positive benefits. More research is currently being investigated.

Mentality

Before any action can be taken, whether it is posture correction, exercise, or a nutritional change there has to be a decision to make a difference- to try. The person with PD is the only one that truly understands what it is like to live with Parkinson's. Only that person can decide to make the effort to improve function. Obviously, it will be more difficult for some than others. It is suggested that a support system be in place to help maintain focus, encouragement, and a positive mentality. We all need a coach, mentor, or partner when times are hard on us. Being that most PD patients are probably in their fifth or sixth decade of life, maintaining function may seem like a lot of tiring work that is hard to sustain on a daily basis. This may be true. However, it is suggested that with some effort the benefits will greatly enhance living with Parkinson's. Tom Landry, the famous football coach, once said "A coach is someone who makes you do what you don't really want to do in order for you to become what you want to become." Your coach could be a professional therapist, a family member, your spouse, a friend- someone who is able to help you not only physically but mentally and emotionally. Keep in mind it is not against the rules to have more than one coach. In fact, a team or "Board of Directors" is encouraged.

Medicine/Surgery

As stated earlier, the mission of *Never Surrender* is not to find a cure for PD but to help people living with the disease function better now. Many support and fundraising organizations are working to develop a medical cure- and perhaps someday this will occur. Until that day, a proactive philosophy is passionately suggested.

Currently, the popular medications aim to treat the dopamine deficiency at the receptor level of the basal ganglia, which is of course the source of the disease. There are basically two mechanisms of drugs that help to improve dopamine levels. The first kind are the dopamine agonists, which increase the dopamine that is being made and/or trick the body into acting as if more dopamine was actually being produced. The second group of drugs tries to help the dopamine that is made last longer and/or be recycled. This has a similar effect as if the body was producing more dopamine. Fortunately, these drugs work well for most patients in managing their symptoms. Unfortunately, for some patients on long term dopamine based medication a side effect of increased movements/tremors occurs. The excess involuntary movement is called *dyskinesia* and is typically evident by faster more abrupt tremors than the classic PD resting tremor. Dyskinesias can be a frustrating experience for PD patients as they severely limit normal activities of daily living.

Pharmaceutical research projects are ongoing and new treatments are constantly being investigated. One such project is investigating the role of calcium channel blockers and PD progression. Early findings show promise and patient trials are beginning. *Never Surrender* encourages any safe pharmaceutical intervention that may improve the function and freedom of patients- especially if it enhances participation in the various physical activities suggested.

Deep Brain Stimulation

A procedure being utilized for PD patients with unremitting symptoms is Deep Brain Stimulation (DBS). DBS is a surgical procedure that uses a stimulator implanted into one of the structures of the basal ganglia, usually the pallidum or the subthalamic nucleus. The stimulator is analogous to a heart pacemaker and is not thought to negatively affect healthy brain tissue. DBS has been successful in decreasing tremors, rigidity, and stiffness. More research is needed to determine long term efficacy and potential side effects.

Conclusion

Various aspects of health including posture, exercise, nutrition, mentality, and medicine have been reviewed in an effort to educate and encourage PD sufferers and their families to embrace a proactive lifestyle. Committing to daily activity and to the therapeutic approaches suggested will provide greater probabilities of maintaining autonomy, stimulating brain activity, lessening disability, and slowing progression of the disease. New information will surely surface as researchers uncover innovative ways to treat PD. While researchers work to develop new strategies, patients need not wait at rest. Health awareness, a positive mentality, and physical activity can empower patients to strive to live a vivified life. Do what you can. *Never Surrender.*

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