



## How to be a Parkinson's Patient

**This booklet expresses only the personal opinions of the authors and is not intended to offer medical advice. Always consult your personal physician for medical advice.**

This booklet is distributed by National Parkinson Foundation Central & Southeast Ohio Chapter, a non-profit organization serving those afflicted with Parkinson's Disease, their partners and families. The society publishes a monthly newsletter with information for both patients and caregivers as well as establishing local support groups. Completing the form inside the back cover will add your name to the list of those of us fighting Parkinson's disease. If you reside in central or southeast Ohio, we can put you in contact with a nearby support group.

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So you've just been diagnosed with Parkinson's disease? Welcome to the club. We are not an exclusive lot. There are more of us with Parkinson's than those with Muscular Dystrophy, Multiple Sclerosis, and Lou Gherig's disease combined. Our group crosses all the lines of race, gender, age, wealth, and fame. Muhammad Ali, former Olympic and Wold Heavyweight Champion, has it, the Reverend Billy Graham, former President George H. W. Bush, Michael J. Fox, and Senator Clairborne Pell. Many remain active and working for years. You, too, can learn to come with Parkinson's.

It's especially important that you learn how to be a Parkinson's patient. First, since you are going to be a Parkinson's patient for the rest of your life, you may as well be good at it. Secondly, and most important, Parkinson's is unlike most other afflictions. Many diseases can be positively diagnosed by a blood test or something similar. Parkinson's can only be positively diagnosed by microscopic examination of brain tissue at autopsy. Many diseases can be monitored scientifically, such as blood pressure readings with hypertension and blood sugar measurements with diabetes. It is not possible to measure dopamine levels in the brain for Parkinson's. The physician will depend on you for guidance in titrating your medication and making other adjustments in your treatment. If you are going to maximize your quality of life from now on, you are going to have to learn how to be a patient.

Fighting Parkinson's disease for a better quality of life is going to involve much more on your part than taking some pills. You are going to have to put forth the effort to exercise and remain active, and you will have to become a student of your own body and how it reacts to different drugs and circumstances.

This monograph is designed to help, as are others in this series. Actual patients, sometimes in conjunction with doctors, write these monographs.

Now, what do you need to know to best fight this disease and maximize your quality of life? What follows is a series of points and suggestions. This is probably not an exhaustive list. We welcome your suggestions and additions.

## Take Responsibility

Newly diagnosed patients often go through a period of denial. After you have accepted the fact that you have Parkinson's, you will have many decisions to make. You will have to decide whom you will tell. If you are still working, you will have to decide when it is appropriate to tell an employer. Your diagnosis may force changes in your plans for retirement and where you plan to live. This, and many other aspects of your new life, will require a number of tough decisions.

Sometimes patients will avoid responsibility for these decisions by retreating into a "poor me" shell and expect their partner to take care of them and make all the decisions. This is unfair to your partner. It's your disease, your body, and you know best what you can still do and what you can't. The best decisions are going to be those that are jointly made by you, your partner and family with you taking the lead.

Similarly, don't dump all responsibility for your treatment on your physician. Only you will be able to decide when a medication is working and when it is not. When doctors prescribe a dosage of a drug they are typically going by guidelines. You will have to decide whether it is too much or too little and then work with your doctor to determine the right amount of the right drug. "Right" is what works for you. No lab test can tell you what is right. You must decide.

## Learn the Language

Remember, there isn't very much your doctor can measure scientifically about Parkinson's disease. He or she is going to have to depend on you to describe your symptoms and problems. If you learn the medical terms associated with Parkinson's, you will be able to be more effective and clear in this communication. You will also be better equipped to understand your doctor and better able to read and understand articles written about the disease and the research into cures and prevention.

First learn the terms that are used to describe the basic symptoms, such as bradykinesia, akinesia, dyskinesia, tremor, and so forth. The Society has available a complete listing of Parkinson's terms. Get a copy and study it until you are familiar with the vocabulary.

Let me give you an example of the importance of understanding the vocabulary of Parkinson's. Recently we heard about a newly diagnosed woman. Her doctor wasn't completely positive that she had Parkinson's. The woman's chief complaint was a tremor in her right arm. To help the doctor determine for certain that it was indeed Parkinson's, he prescribed Sinemet, a drug that delivers levodopa to the brain. Unfortunately, he prescribed too large a dose. Too much levodopa in the brain produces dyskinesia. Dyskinesia is defined as various involuntary movements that include twitches, jerks, twisting or writhing movements, or simple restlessness. After a few days her doctor checked back with her to see how the Sinemet was doing. The woman told him that it made her condition worse. The doctor responded by increasing the dosage of Sinemet. The woman went through a very unpleasant period before the doctor figured out what was happening.

## Keep Records, Write Things Down

Don't depend on your memory for remembering questions you want to ask your doctor on the next visit. Write them down. As you begin to take various medicines to control the symptoms of the disease, keep a written log of when you took the medicine, when you ate, what you ate, and the effect the medicine had. This will help you and your doctor develop a strategy and a dosage regimen that does the most good.

Drugs affect people differently. There is no one medication strategy. You will have to work with your doctor to determine what works for you. Good records will speed the process. From time to time you will have to adjust and change your medicines and dosage. Keeping good records will minimize the difficulties in transition.

## Find a Physician With Whom You are Comfortable

While you should always be comfortable with any physician you use, it is especially important for tracking the progression of your Parkinson's disease. You will be depending on your physician for many years and numerous visits. It is important that the doctor spends time listening to you as you describe problems and your responses to medication. You must be able to discuss intimate details of your life such as constipation, sexual difficulties, and mood. Most long-term Parkinson's patients say that it is important that the physician be knowledgeable about Parkinson's. The diagnosing physician may not be your choice for long-term care. Be assertive and do not settle for someone that you are less than completely comfortable with or who does not enjoy your complete confidence.

Be certain your doctor understands your wishes in regard to your caregiver. Most patients will want their caregivers present at routine visits. Some doctors are reluctant to answer caregivers' questions. Explicitly notify your physician of your wishes so that medical confidentiality will not be a barrier to effective communication.

## **Establish Support Systems**

Joining a Parkinson's support group will provide contact with other Parkinson's patients who have "been there" and "done that". They can answer questions and make suggestions based on actual patient experience. You will find this invaluable.

Usually Parkinson's support groups meet once a month, but members are always available by phone to answer questions and suggest strategies. There are also support groups for caregivers. Don't overlook the need of your "significant other" to obtain support for the difficult job of supporting you. In Ohio, you can contact the Ohio Parkinson group for the names of nearby support groups.

There are other support mechanisms such as Internet discussion groups that put you in contact with other patients. We can provide Internet addresses for those with a personal computer and Internet access. Here again, there are also caregiver groups.

## **Begin a Routine Program of Stretching and Exercise**

If you're like me, you find exercise boring. While I don't enjoy exercise as some do, I stretch and exercise at least three times a week. If I don't exercise routinely, my rigidity gets worse, my energy level goes down, walking gets more difficult, and I simply don't feel as good. By forcing myself to a fixed schedule, I maintain the discipline I need to stick with it.

I'm not disciplined enough to do my stretching and exercise at home. I go to a commercial facility three days a week where I stretch, do strengthening exercises using various machines, and do aerobic conditioning. My health insurance covered a limited number of visits to a physical therapist for the purpose of establishing a series of stretches and exercises that are appropriate for me. Check our coverage to see if similar consultations are covered for you. After a year or so, you will recognize what strengthening you should be emphasizing at any point.

Being elderly or having limited mobility does not excuse you from routine exercise. It is important that you do something. Try “mall walks” where you window shop in an enclosed mall. Try walking around the block. Exercise with your caregiver. Everybody should do something. Unused muscles quickly atrophy. Joints need to move through their entire range of motion every day or they will become rigid.

## **Maintain a Healthy Diet**

Constipation is usually a continuing problem for Parkinson’s patients. The usual measures for dealing with constipation often are not effective for us. You should be aware that constipation could be a life-threatening problem. Bowel impaction/megacolon can be fatal.

A diet that includes plenty of fruits and vegetables and is high in fiber will go a long way toward ameliorating this problem. Your diet should also include drinking four to eight glasses of water a day even if you don’t feel thirsty.

When you eat can also be important. Protein interferes with the absorption of levodopa. Scheduling your medication in relation to your meal schedule is a topic for you and your doctor to discuss.

## **Change Your Environment**

As the disease progresses you may begin to experience balance problems, rigidity, and a “shuffling” walk. Don’t wait until you experience a fall before you modify your living space to eliminate hazards such as slippery floors, stairs, steps without hand rails, and so forth. Pay special attention to areas around the bath that tend to be slippery anyhow.

It was important for me to keep things I use in places where I can get to them without leaning and throwing my body out of balance. Once I get out of balance, it is very hard for me to recover without falling.

There are catalogs of various devices to help you in dressing yourself, eating, and tending to your other personal needs. Contact COPS for a list.

## **Learn About the Drugs You are Taking and be Aware of Drug Interactions**

Many prescription and non-prescription drugs in our world today interact with medications we may be taking for another medical problem. Always disclose all medications you are taking, even those taken occasionally, to all of your doctors. But ultimately it is going to be your responsibility to be aware of what you are taking, why you are taking it, and which drugs have other drugs that are contraindicated (should not be taken together).

Taking certain pain medications such as Demerol with the Parkinson's drug Eldepryl can be fatal. Other physicians treating non-Parkinson's problems may not be aware of this. Recently a member of my support group had surgery for another problem. He carefully explained to his physician that he was taking Eldepryl for Parkinson's and should not be given Demerol. This was even noted on his hospital chart. The evening following the surgery a nurse appeared in his room to give him a shot. His wife asked what the shot was and, you guessed it, it was Demerol.

Be responsible and observant. Ask what you are being given and know what can be dangerous.

## **Maintain a Positive Attitude**

Depression or melancholia is prevalent in Parkinson's patients. You can fight Parkinson's disease and still have a good life. Mental attitude can make all the difference in the world. Remaining active and a part of the outside world is important. You need not be ashamed of your walk or tremor and should not stay out of the public eye. Thanks to the Americans with Disabilities Act, the outside world is friendlier to us than was ever the case in the past. This law also gives us certain job rights, which are very important.

Since depression may reflect a chemical imbalance, the right attitude may not be enough. In that case, there are drug therapies for depression that are very effective. Don't be hesitant to ask your doctor about them.

## **Help others; Get Involved in the Search for the Cure**

There is hope. Scientists are working on several approaches that could lead to a cure or prevention. Your involvement in one of the Parkinson's groups and your financial and moral support for research in finding the cause and cure is important. You can help.

## **A Doctor's Viewpoint**

In all our monographs written by patients, we ask a physician trained in Parkinson's to read what the patient has written and make any comments or observations they see fit.

Dr. George Paulson is eminently qualified as a reviewer. A prolific writer on Parkinson's disease himself, Dr. Paulson is not only a practicing neurologist with a special interest in Parkinson's, but he has been chairman of the Neurology Department at The Ohio State University and Co-Director of the NPF/Madden Parkinson's Disease Center of Excellence at OSU.

Dr. Paulson comments:

*Self-help, self-education, and personal effort all are important in health and medical care. Indeed at the very time prophets of doom state that individual responsibility is being ignored, support groups, associations and societies have taken on the task of encouraging both the healthy and the sick to go beyond the doctor as authority.*

*Common sense, advice of the experienced, lay literature, etc., can all teach a person more than one can expect from an impatient medical doctor. The Central Ohio Parkinson Society is launching a series of information bulletins for families and patients. Let us hear if they help, suggest topics for the future, and keep us struggling along with you.*

*Yes, adaptation is required to be a successful patient. No one, not even the most experience "Parkinsonologist", can predict the future. Every patient is different. It is predictable that initial uncertainty about the diagnosis may lead to several consultants. Unwillingness to accept a diagnosis for which there is no specific laboratory test and no cure may be associated with denial or followed by despair. Most patients, almost all, do very well and essentially all show sustained courage in the face of a process that tends, fortunately very slowly, to worsen. Remaining physically active is as important as any exact dosage of medication.*

*Exercise is more likely to be useful if it is, or becomes, fun. Swimming, walking, dancing, and gardening are all good. Formal physical therapy helps some. Even more find stretching exercises useful. Depression is an accompaniment of PD for many, and who wouldn't be depressed when, "I was never sick a day in my life before this". The depression is often a biochemical one, tied in with the biochemical changes that lead to PD. Since it is biochemical, not just "reactive", medications can often help. As in every other feature of the disease, patients can help themselves with depression: forcing a mood change, remaining active, talking with dear ones, etc.*

*It is often hard to know what the terms do mean, even if you read a dictionary. Dyskinesia (literally abnormal movement) means a twisting trunk, finger movements, or lip pursing and, in contrast to tremor, is not so regular and not limited primarily to the hands. The distinction between tremor and dyskinesia is the sort of thing you can discuss with your doctor, if you are unsure.*

*Yes, you do have to learn how to be a person with Parkinson's disease, but you don't have to do it alone.*



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Do you belong to a Parkinson's Support Group?  Yes  No

If not, would you be interested in joining?  Patient Support Group

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Parkinson Patient's Family

As an MD

Nursing Staff

Other

*The National Parkinson Foundation Central & Southeast Ohio Chapter does not charge annual dues, relying instead on donations. Our services are freely given to any patient or caregiver requesting help without any consideration of income. Many patients are elderly and on fixed incomes with high prescription expenses and cannot afford to give. We need your help.*

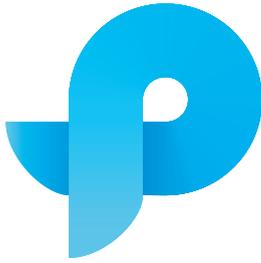
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