

*Dear Friends
and Family...*

A Guide To
Providing Support for
Parkinson's Disease Patients

MISSION STATEMENT

National Parkinson Foundation Orange County Chapter

To serve the Parkinson community of Orange County through education, awareness, care, and support of research.

To provide resources through fund-raising endeavors that will contribute to the research effort to find a cure for Parkinson's disease.

Dear Friends and Family...

A Guide To
Providing Support for
Parkinson's Disease Patients

THE NATIONAL PARKINSON FOUNDATION
ORANGE COUNTY CHAPTER
355 PLACENTIA AVENUE, # 302
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Dear Friends and Family,

By now you may have heard that I have recently been diagnosed as having Parkinson's disease. Obviously the onset of any illness is very traumatic, and it has been for my immediate family and me. I didn't know very much about Parkinson's before the doctor confirmed that was my problem, but I've certainly tried to learn about it ever since. I would like to share some of what I have learned with you, and maybe answer some questions you might have about changes that could occur in my life.

Some of you have asked if there is anything you can do to help. The answer is "Yes," and I would like to talk to you about that too. But first let me tell you a little bit about Parkinson's disease.

My Diagnosis...

For several months I have known that something has been wrong with my body, but I didn't know what it was...and for quite a while doctors didn't know either. You see there really is no test for Parkinson's disease. At one time there was even a thought that I might have had a brain tumor. But when the tests I did take ruled out other causes, I was then referred to a neurologist who confirmed that I have Parkinson's disease. One of the things that delayed my diagnosis is the fact that so far I don't have any tremors. Although most people associate tremors with Parkinson's disease, and some patients have tremors, some never will.



What were some of my symptoms?

There were several, and that helped the neurologist to make a determination. Several months ago my handwriting began to shrink. It still looked like my writing, but it was much smaller. Now I understand that is a symptom of Parkinson's disease, and I also know that gradually my writing may become impossible to read.

I have always been a happy person, and love to smile and get your smiles back in return. I love it that you still smile at me, and I want you to know that internally I'm returning every one of those smiles. But you might not see it. Another characteristic of the disease is a "masked face" that shows little or no emotion. Don't think that I'm not interested or that I'm depressed. I'm still me, but it's a bit harder to show it.

When I walk, my arms don't swing freely. I didn't realize that; they tend to just hang by my side. That may be one of the reasons why I have difficulty with my balance, a problem that I have been told will probably get worse. Someday I may need a walker or even a wheelchair, but not yet. I know that physical activity and exercise are important to my treatment, as important as the medications I now take faithfully. But there really is no way that I can reverse the loss of manual dexterity or muscular stiffness that contributes to slowness of movement. Parkinson's disease is a progressive degenerative disorder. I can only hope that the progress will be slow. Already I am having difficulty with fine motor activities like fastening buttons and handling eating utensils.

What is being done to treat my illness?

There is no known cure or prevention for Parkinson's disease, but I now follow a very precise regimen of medications. There are many Parkinson's disease drugs on the market. As I have tried to explain, this is a very "individualized" illness, and treatments – including medications – have to be just as individual in nature. Although the common cause is a deficiency of the brain chemical *dopamine*, medications that are perfect for one person may do nothing for another. Sometimes a single drug works; at other times a whole combination may be necessary. As the illness progresses, I understand that my drug needs will invariably change. It will be very important for me to monitor those changes so my neurologist can vary my prescriptions as needed. Those that



are helping me now may not work as effectively in a year or two as medications need to be adjusted on an ongoing basis.

Physical exercise will be important to me. I know that I will have to stay active and keep my muscles in tone in order to avoid physical atrophy. I have been told that tai chi may also be beneficial in this regard. In addition, some occu-

pational therapy will probably be necessary to help me with the fine motor tasks that I mentioned earlier have been difficult for me.

A third therapy will probably begin shortly also. Speech therapy will help me to address both speaking and swallowing difficulties that have recently surfaced. About one-half of all Parkinson's disease patients experience difficulty speaking. At times there is a tendency to mumble or repeat syllables. That hasn't happened to me, but I have been losing vocal power. I know I have always had a soft voice, but lately my volume has been decreasing as I near the end of sentences.

With a little help from my friends...

I truly am grateful for the number of friends who have asked how you can help. Your love and understanding are the best medicine I could hope for. I have tried to help you understand how Parkinson's disease has affected me. While I hope I have been open and honest, I have to admit that I do feel self-conscious and awkward about the changes that are occurring, as well as fearful of what the future may hold. But I am fortunate to have a wonderful support system. As part of that system, here are some things you should know.

Parkinson's disease is not contagious. It's not unusual that I should have acquired Parkinson's disease at this stage of

life. Although there is a variation called Young Onset Parkinson's (YOP), the incidence increases with age and is uncommon in people younger than forty. Parkinson's disease affects both men and women across all ethnic lines. There are an estimated 1,500,000 people in the United States afflicted by it, and a new case is diagnosed about every five minutes.

One of the most troubling things about Parkinson's disease is the inconsistency that occurs. When you see me one day I may seem fine, but there might be a major difference the next time we are together. That does not necessarily mean that I am getting worse. It could mean that, but symptoms may be nonexistent one minute only to suddenly reappear for no clear reason. They will not only vary from



day-to-day but even moment-to-moment. This is why I may not be able to make a long-term commitment to social plans, or might have to change plans at the last minute. There is nothing you can do about that except understand how fickle this illness is. Please give me a “rain check.” If I can’t join you one day, another time might not be a problem. And it is important for my mental health that I sustain the wonderful friendships that have been developed through the years. Sometimes your presence might also give my caregiver a break in order to “recharge.” That’s really not a luxury but a necessity, for there is stress on all of us.

Changes in my daily health might be due to Parkinson’s

disease, or – ironically – they may be a response to my medications. That can be very frustrating. Initially nearly all symptoms respond to treatment, including medications. But there may be side effects. They could include mood swings, hallucinations, speech slurring, drowsiness, or even increased tremors. As I mentioned earlier, dosages have to be monitored as drugs can lose their effectiveness.

Please understand that no matter how familiar you may be with Parkinson’s disease that my illness may be very different from another friend or family member’s condition. There are so many different symptoms, and very rarely does any patient experience ALL of those symptoms.

Practical Suggestions...

A few of you asked for specific ways that you could help. Remembering that my needs may vary frequently, here are some practical suggestions that could really assist me.

While I can still do many things, I really can't do anything in the same time that I once could. I need extra time to do just about everything from eating meals to arriving at a location like a theater. If we plan on that extra time, it will not only enable me to complete the task, but it will reduce the frustration I feel when I think that my illness is impeding others and their activities.

I cannot hurry. When I try to, it only increases the likelihood that I will lose my balance. I have fallen a few times, and I



worry about the possibility of breaking bones. If we have extra time, I won't feel the need to hurry. I know that I appear to be moving in slow motion sometimes, but I can't help it. My gait often involves small, shuffling steps, and sometimes when I stop walking, I can't start again. It is as if my feet are frozen to the floor. It seems to be worse when I approach doorways or enter small areas like a bath-



room. It takes so much energy to overcome this problem that it can really wear me out. You can help by holding my arm or hand as I walk, but please remember that I have to set the pace. It is easier, though, if I know I won't fall because you have provided your physical support.

It is also very difficult to rise from a seated position. Not only will your

assistance help me to stand, but it will also ease the worry that I will knock something down when I struggle to get up. The most embarrassing thing for me is the difficulty I can experience in a public restroom where it is awkward to seek help from strangers. If we are out together, please accompany me, and don't hesitate in this setting – or any other case – to ask what help I might need.

My inability to write legibly is frustrating. There are times when it would really be helpful if someone could take notes or jot down information for me. This difficulty scares me because I know it's important to keep my mind working with pleasurable activities rather than allowing myself to be frustrated by thoughts about my illness.

As long as we are talking about communication skills, let me expand on my earlier reference that I might have to begin

speech and swallowing therapy. My voice “loses steam” as I come to the end of sentences. You can help here by repeating the portion of my sentence that you have understood. If I know what was heard, I can repeat only the remaining words from my original sentence, enabling the entire message to be understood both by the person offering assistance and others in the social group. Please be patient. Additional time is just as important here as it is in physical movement. It takes me longer to express my thoughts. Sometimes it is very hard to retrieve specific words from memory. If you see me floundering, it’s okay to offer suggestions so two-way conversation can be enhanced.

When I was tested by the speech therapist, she also checked my swallowing. Sometimes people have difficulty eating because their ability to swallow has been impaired. If

food collects in the mouth or the back of the throat, it can result in choking or coughing. This may be scary, but you might wish to become familiar with the Heimlich maneuver in the event of a choking episode.



This might be the time to address the unthinkable – death. While a patient does not die from Parkinson’s disease, the illness does create an environment for other problems including pneumonia. To try to guard against such consequences, I have established a series of regular visits with my neurologist who specializes in treating movement disorders. I know I am the most important person in my own treatment, but friends and family can make my life so much easier by helping in some of the ways we have been discussing.

Most Importantly...

Talk with me, and don’t hesitate to ask me questions. Sometimes I might feel as if I am imposing, but if I know you want to help, it will make it easier for both of us. Sometimes I get discouraged because adverse changes seem to be happening so quickly. When I know that you want to continue to involve me in a wide range of activities, that is great emotional medicine. I want to maintain control over Parkinson’s disease and not let it control me. I can’t do it alone. Support groups have been helpful, but the most valuable support comes from my family and friends. Thank you for being here for me.

If you want to learn more about providing support for Parkinson's patients, contact NPFOCC about "We Are There," a manual developed by caregivers for others who are involved on a daily basis.

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