



Title: Am I Really Ready to Cope with PD?  
Date: March 3, 2009  
Time: 8:00 PM, Eastern Standard Time (GMT-5:00 New York)  
7:00 PM, Central Standard Time (GMT-6:00 Chicago)  
6:00 PM, Mountain Standard Time (GMT-7:00 Phoenix)  
5:00 PM, Pacific Standard Time (GMT-8:00 San Francisco)

Faculty: **William Marks, MD**  
Associate Professor of Neurology, University of California,  
San Francisco  
Medical Director, UCSF Center for the Surgical Treatment of  
Movement Disorders  
Director, Parkinson's Disease Research, Education, & Clinical  
Center, San Francisco VA Medical Center



**Susan Health, RN, MS, CNRN**  
Movement Disorder CNS  
Parkinson Disease Research Education Clinical Center, San  
Francisco VA Medical Center



**Judith Hibbard, DrPH**  
Senior Researcher, Institute for Policy Research and  
Innovation  
Professor, Department of Planning, Public Policy &  
Management, University of Oregon



Link to the Webinar: <https://wemove.webex.com/wemove/onstage/g.php?d=555046127&t=a>  
Copy and paste this link into the address bar of your Web browser, For detailed instructions, please see the next page.

Password: Tigger

*WE MOVE gratefully acknowledges GlaxoSmithKline and Tercica, Inc., for an unrestricted education grant that made this Web event and syllabus possible.*

## WHAT IS A WEBINAR?

A Webinar is a web-based seminar that you can see (slides) and hear (lecture).

## HOW DO I TAKE PART IN THE WEBINAR?

To have the best experience, you will need a computer hooked up to a high-speed Internet connection. If you don't have a computer or don't want to watch the slide presentation, please call the toll-free number listed below to listen to the audio portion of the Webinar.

1. Please be sure to allow plenty of time to complete the log-in process. Depending on what programs are running on your computer and the speed of your Internet connection, this process may take from 5 to 30 minutes to complete.
2. Before the meeting's start time, copy and paste or type this address into the address line of your Web browser: <https://wemove.webex.com/wemove/onstage/g.php?d=555046127&t=a>
3. Enter only your first name, your email address, and the meeting password (the password is **tigger**), and then click *Join Now*.
4. You will now be in the meeting room. Turn up the volume on your computer's speakers and sit back and enjoy the program. You're now taking part in the WE MOVE Webinar!

## DO YOU HAVE ANY ALTERNATE OPTIONS FOR CONNECTING TO THE WEBINAR?

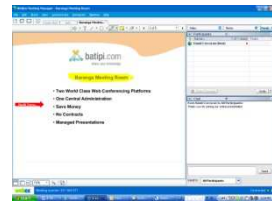
If you are unable to use the link provided above, go to [www.webex.com](http://www.webex.com) and click the *Attend Meeting* tab on the upper right-hand corner of your screen. Enter the meeting number **555 046 127** and click *Join Meeting*. On the next screen, type **tigger** in the password field and press enter.

## WHAT IF I DON'T HAVE A COMPUTER?

If you are unable to access the Internet or can't hear sound from your computer, call toll-free from the US or Canada: **866-469-3239**. When asked for the meeting number, enter **555 046 127#**.

## WHAT WILL THE WEBINAR LOOK LIKE?

If you are connected with your computer, your screen will have two parts. The main window, on the left-hand side of the screen, will have the slides that will be used to give the lecture. Another box on the right-hand side will have a list of all of the people who are attending the Webinar and a smaller box in which you can type your questions. (Keep in mind that everyone attending the Webinar will be able to see everything that you type into this box.) WE MOVE staff members will be watching for questions. We will copy these questions and make a list to give to Dr. Hibbard, Dr. Marks, and Ms. Heath during the third part of the webinar.



## WHAT WILL HAPPEN DURING THE WEBINAR?

1. The first part is the lecture: *Am I Really Ready to Cope with Parkinson Disease?*
2. During the second part of the Webinar, Dr. Hibbard, Dr. Marks, and Ms. Heath will answer questions that people sent in when they registered for the Webinar.
3. After they finish answering the preregistered questions, Dr. Hibbard, Dr. Marks, and Ms. Heath will answer the questions that people submit during the Webinar.

## WHERE CAN I GET MORE INFORMATION ON THIS TOPIC?

Many people submitted questions during the registration process. During the Webinar, Dr. Hibbard, Dr. Marks, and Ms. Heath will try to answer all of the preregistered questions that are about coping with a diagnosis of PD. If your question is not answered, please go to the WE MOVE Discussion Forum at [www.wemove.org](http://www.wemove.org) and click on the *Discussion* tab located at the top of the page. Once you have registered to take part in the forums, you can post your questions in the *Parkinson's disease* Forum and interact with others who have similar concerns.

## ***Introduction***

Dr. Judith Hubbard and her colleagues at the University of Oregon have coined the term *activation* to describe people who have the knowledge, skills, and confidence to manage their own health and healthcare. The knowledge passed on to you today may help you to have the confidence to make decisions that are right for you. For example, you may need to make choices about what to do if you experience a side effect of a medication and whether you need to visit your doctor or other healthcare professional. When you are ready and willing to make choices that support your wellness, you are on your way to achieving positive self-management. When you have the tools and information about what are symptoms of PD and even what are not symptoms of PD, what treatment options are available for PD, and what your role is in managing your disease, you are activated to do the best that you can for today—to take charge of your healthcare.

## ***Why Does It Matter if I Can Manage my Health and Health Care?***

Research has shown that people with chronic diseases such as PD who can self-manage their health and health care are more likely to

- Take medications properly
- Have increased functioning
- Have improved health-related status
- Have less pain
- Incur lower healthcare costs
- Be hospitalized less often
- Have lower levels of stress and emotional distress related to the condition

## ***How Do I Become More Activated?***

People with chronic diseases can acquire specific skills to effectively take on the on day-to-day management of their care. They must be able to recognize emotional responses and manage these emotions, have healthy and positive ways of coping with problems and stresses as they arise, and have well-honed problem-solving skills.

## ***Managing Emotions***

When you received the diagnosis of PD your emotions may have run the gamut from shock to withdrawal to sadness and, for some people, relief to finally know what was wrong. You may have even experienced all these emotions in a few days and sometimes swung back and forth among a variety of emotions. Depression, anxiety, anger, fear, worry, and a loss of a sense of control are examples of normal emotions in response to receiving a diagnosis of a chronic illness. When these negative emotions are not recognized and dealt with and not replaced with healthy positive emotions, they can create barriers to taking in new information and to making changes related to living with PD.



For example, a doctor's office is an anxiety-provoking setting for most people. If you are feeling anxious, which would be normal, you are less likely to be able to remember what your doctor tells you about a new diagnosis, your condition in general, or instructions for taking a new medication. You could manage your anxiety in this situation by preparing for your appointment, including writing down a list of questions for your doctor and, perhaps, bringing along someone to help you write down the answers to your questions. Organizing all of your medical information into a Care Notebook can help you to be more on top of things and less anxious.



Another example of a negative emotion is a sense of powerlessness or lack of control. Oftentimes, people who feel powerless seek to control those around them—usually in a negative way. Receiving a new diagnosis of PD knocks most people for a loop, frequently causing them to feel as if they have no control over their bodies or even their lives. True, you don't have control over the fact that you have PD, but you do have control over how you deal with it. One way to take control over how you can deal with your PD today is to decide to increase activities that support your health and your sense of wellbeing—and to include these activities in your life every day. This means that you should be at your ideal weight, exercise regularly, consume a healthy diet, abstain from smoking or excessive alcohol consumption, and employ good sleep habits. Numerous studies have shown the benefit of exercise for people with PD, whether that's walking or even running on a treadmill, using a NordicTrack, or doing yoga or Tai Chi. Taking control of those aspects of your PD over which you have control will help you to feel as if you, instead of the disease, is in charge of your life.



### ***Coping Skills***

Do you have healthy or unhealthy coping strategies when you encounter a bump in the road of life? Faced with a diagnosis of PD or a worsening of the condition, you are likely to respond with coping strategies that you've used at other times when you've faced adversity.

Do you withdraw and become isolated or self-medicate with prescription or street drugs or alcohol? Or, do you participate in activities that make you feel good about yourself, surrounding yourself with positive upbeat people, exercising, and listening to music? People who were the most independent before developing a chronic illness are often

the most likely to become isolated and withdrawn because it's difficult for them to understand that reaching out and asking for help is not a sign of weakness or failure. Choosing healthy coping strategies or seeking help to overcome ineffective and negative coping strategies are essential to developing positive skills to manage your health and health care.



## ***Problem-solving Skills***

Just when you thought that you had everything under control, a new symptom associated with PD appears. When you have a chronic illness like PD, you are constantly facing new issues, new challenges. Perhaps the problem is a side effect from a new medication that you're taking. Perhaps you realize that you have recently developed difficulty balancing your checkbook or following a recipe. When encountering a new problem or considering how to handle an existing problem, be creative in identifying what you want to have happen, and then dedicate your creative energy to finding solutions to the problem. Having good problem-solving skills means that you are able to

- Think about or define the problem
- Identify your options
- Evaluate your options
- Choose a course of action



Let's take the example of the side effect from your new medication.

- *Define the problem*
  - ✓ You began taking a new medication and now you're so nauseous that you can't function.
- *Identify your options*
  - ✓ Read the package insert or call your pharmacist to see if the new medication could be causing the nausea
  - ✓ Nibble on candied ginger or sip on chamomile tea to help relieve the nausea
  - ✓ Read the package insert or call your pharmacist to see if you can take the new medicine with meals to help decrease the nausea
  - ✓ Stop taking the medicine and see if the nausea stops
  - ✓ Call your doctor and see if she can switch you to another medicine
- *Evaluate your options*
  - ✓ All of these seem like reasonable options, except stopping the medicine. Reading the package insert and calling the pharmacist, as well as taking some comfort measures to relieve the nausea are reasonable first steps. If none of them work, calling the doctor makes sense.
- *Choose your course of action*
  - ✓ Decide on the best course of action and takes steps to relieve your nausea.



For you to be most effective in solving problems, researchers have found that it's essential that you have as much information about PD and how it affects you. Seeking accurate information from a reliable source puts you clearly on the path to self-management of your PD.

## ***How is PD Diagnosed?***

PD is a clinical diagnosis, meaning that doctors make the diagnosis of PD based on the symptoms that you tell them you are experiencing, your medical and medication history, and the signs that your doctor sees. These signs and symptoms include the cardinal symptoms ([Table 1](#)). However, difficulties with balance are not usually seen in early PD. You have to have two of the remaining three cardinal symptoms for the doctor to diagnose PD.



When doctors make a diagnosis of PD, they do so not only by reviewing the signs and symptoms that you do have, but also being aware of what symptoms you don't have. For example, you may have a tremor, but all tremor is not PD. Essential tremor is often misdiagnosed as PD. However, by evaluating the type of tremor that you have, how it is relieved, and your family history, your doctor will be able to sort out these two diagnoses. Some other forms of parkinsonism—that is, disorders that have symptoms similar to those of PD but that are actually not PD—can be easily misdiagnosed as PD, and vice versa. Some signs that the disorder is not actually PD include early falls, dementia, and hallucinations and abnormal eye movements.

There are no specific tests that prove the diagnosis of PD. No laboratory tests and no x-rays or other imaging studies can confirm the diagnosis of PD.

## ***What Are the Symptoms of PD?***

Over the past decade, physicians and scientists have come to realize that the symptoms (what you can feel) and the signs (what others can see) of PD are far more widespread than the cardinal signs of the disorder ([Table 1](#)).

Other signs and symptoms that affect your motor (called this because they involve movement of your body and not because they have anything to do with the engine that runs your car) and nonmotor (those that affect your body but are not related to movement) systems have become increasingly recognized as aspects of PD that may have a major impact on your quality of life—your ability to participate in and enjoy everyday activities ([Table 2](#)). Research has shown that some of these signs and symptoms may actually begin before the cardinal signs are obvious.



Dopamine is a specific type of chemical, called a neurotransmitter, that is produced and stored in specialized nerve cells in a part of the brain called the substantia nigra.



***What’s Happening in my Brain and Body?***

The cardinal signs of PD occur because of a lack of dopamine-producing and -storing cells in a part of your brain called the substantia nigra. In the past decade, scientists have come to understand that other chemicals in areas of the brain outside of the substantia nigra can compensate for the lack of dopamine until about 70% to 80% of the dopamine-producing cells are gone. Subtle changes in your mood, behavior, thinking ability, posture, and sense of smell may take place before the cardinal signs occur. In addition, a sleep disorder called REM sleep behavior disorder, in which people act out their dreams, occurs in many people who go on to develop PD.



Doctors have linked the amount of the loss of the dopamine-producing and -storing cells to various signs and symptoms of the disorder.

Substantia nigra means literally black substance. This area of the brain contains pigmented dopamine-containing cells. People with PD have fewer of these cells, so the area is not as dark as in people without PD.

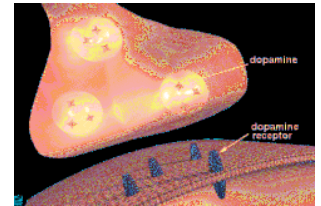


Once the threshold is crossed in the loss of dopamine-producing and -storing cells, you may begin to exhibit the classic signs of PD. When you and your doctor decide that the time is right, you may begin taking medication to help restore the levels of dopamine or that balance out other chemicals in your brain. These medications are often life changing, allowing you to resume activities that you may have thought were no longer possible. In addition, further advances in the treatment of PD are on the horizon as scientists actively search for new medications and treatments that will continue to help you deal with the effects of PD.

At some point, you may find that your dose of levodopa, a medication that you may be taking to replace the dopamine in your brain, no longer seems to be working as well or is leading to what are called motor fluctuations and dyskinesias. Motor fluctuations are manifest as a shorter-than-normal effect of medication, that is, the medication doesn’t seem to last as long as it did previously. Motor fluctuations may also involve an on-off phenomenon, in which the medication suddenly stops working for no apparent reason. You may find yourself frozen in place, with your feet literally glued to the floor. Dyskinesias are movements that you can’t control—they’re not the tremor that you usually experience, but, instead, are more of the writhing, twisting, or flinging movement of your arms, head, or legs. You may also experience dystonia in your legs or feet—a severe cramping-type feeling that moves your limbs in one direction—which is common upon first awakening in the morning. When these issues develop, your healthcare professional may recommend that you keep track of your symptoms using a [Motor Diary](#). This self-assessment tool can provide a basis for you and your healthcare professional to make decisions together on how to best manage these troublesome side effects.

The motor fluctuations and dyskinesias occur because the number of dopamine-producing and dopamine-storing cells continue to decrease. The levodopa that you take by mouth and that is converted in your brain into dopamine no longer has a place to be

stored, so the medication effects occur in a peak, resulting in the dyskinesias and shortened benefit of action. In addition, in a brain without PD, the dopamine receptors receive a steady state of stimulation because dopamine is released in a steady manner from the dopamine-producing and -storing cells. However, as those cells disappear and dopamine can no longer be stored and steadily released, the dopamine that your brain converts from the levodopa that you take stimulates the receptors in bursts or pulses, resulting in hypersensitivity and, ultimately, the motor fluctuations and dyskinesias.



The reason to share these symptoms with you is not to frighten you about what you may be facing if you have early PD. Instead, the reason is to help you to learn the language of PD and to understand what is happening in your body. Being conversant in this language may help you to feel as if you are on more of an equal footing with the other members of your healthcare team—you will be able to speak more knowledgeably and understand what your team is saying.

### ***Who Are These Team Members Who Can Help Me Manage my Symptoms?***

Research has shown that one of the best ways to manage the symptoms of PD is through a multidisciplinary team approach. With you and your caregivers at the center of team, healthcare professionals work with you to optimize your care ([Table 3](#)). To be most effective as a member of the healthcare team, you need to be armed with skills, knowledge, and motivation.



Regrettably, not everyone with PD is fortunate enough to be able to receive their care as part of a multidisciplinary team. Health plans may dictate where you receive your care or you may live somewhere that you don't have access to care provided by a multidisciplinary team. These teams are most readily available at major medical centers and teaching hospitals. If you don't have access to a multidisciplinary team for your care, it becomes incumbent upon you to devise your own team and to coordinate your care. WE MOVE has put together a list of items that are commonly included in a [Care Notebook](#) to assist you in organizing pertinent information regarding your health care, which you may then wish to share with members of your team.

### ***I Have Information, Am I Ready to Make Some Changes in Managing my PD?***

By participating in this webinar, you have taken a vital step in gathering information to become an effective and engaged member of your healthcare team—that is, to become *activated*. But how do you know if you're ready to make some changes? Dr. Hibbard has outlined a four-stage process that people go through to become fully competent in managing their health ([Table 4](#)). She and her coworkers have also developed a means

to assess people's readiness to accept responsibility for or self-management of their chronic health conditions (their *activation* level). Called the [\*Patient Activation Measure\*<sup>TM</sup>](#), this tool assesses your skill, knowledge, and confidence to manage a chronic health condition, such as PD.

### ***How Do I Make Changes?***

If you decide that you want to take more responsibility for managing your health and your PD, that is, to move up from one stage to the next on the path to competent self-



management of your health, take a moment to look the list of competencies that people who have PD can meet to achieve self-management of their disease ([Table 5](#)). Are there any areas in which you feel that you could make a few changes to become more competent?

If so, you can use a [Goal-setting Chart](#) to help get started. The chart can help you to lay out any changes you might want to make or goals you wish to set, examine why you want to make these changes or achieve these goals, identify any obstacles that may stand in your way of making the changes or achieving your goals, and sketch out your plans to make the change or achieve the goal, with a target date for implementing your plan. We've inserted a few items on a sample [Goal-setting Chart](#) to give you an idea of what we mean. Feel free to print copies of the blank [Goal-setting Chart](#) provided in the appendix and use them to help you set your goals.

Start with small changes or goals. For example, if you haven't been exercising at all, it makes sense to set a goal of walking to the end of the driveway every morning to pick up the newspaper and not one of running a marathon. Once you've been able to pick up the newspaper every day for two weeks, go back to the Goal-setting Chart, and create a new goal, perhaps one of walking to the corner and back or even around the block, depending upon how you feel.

Enlist the support of others to help you to make changes. If you want to start exercising, talk with your doctor or physical therapist. They may be able to help you to find an exercise plan that fits your needs, and the physical therapist may be able to supervise you as you begin to implement your exercise program. If you feel a little unsteady, ask your physical therapist or occupational therapist to help you find adaptive tools, such as a cane or walker, to provide support. If you have companions, family members, or neighbors who are willing to help you achieve your goals, ask them if they will accompany you on your walk. If you've had to give up your exercise program because of your symptoms of PD, find new ways of exercising. Perhaps there's a Tai Chi or water aerobics group in your community just for people with PD.



By setting small, realistic, and attainable goals and then achieving your goals, you will gain confidence that you are capable of making change. And remember that it takes time to make changes. You can't go from sedentary to elite runner in six months, even if you don't have PD. Be patient with yourself. Keep in mind that when you are faced with a chronic illness like PD, your dreams don't have to change, but you will likely have to go about realizing your dreams in different ways.

### ***Consider Helping WE MOVE to Help Others***

As a not-for-profit organization, WE MOVE depends heavily on private donors—individuals like you who benefit from the services WE MOVE provides. Please consider making a donation today. Your contribution will help ensure that WE MOVE can continue to serve the millions of individuals who continue to dream, but who may have to realize their dreams in a new way.

## ***Care Notebook***

A *Care Notebook* serves as a central place to organize all of your healthcare information. Using a *Care Notebook* will make it easier for you to find and share important information with people who are part of your healthcare team. You can use your *Care Notebook* to

- Prepare for appointments
- Keep track of changes in your medications or treatments
- File lab or x-ray results or other test reports
- List contact information for key people on your healthcare team
- Compile information that you download from Internet searches, brochures, and other sources of information and support
- Record your immunizations
- Note any allergies or adverse reactions to medications or foods
- Share information with family members and all members of your healthcare team

The following tips may make it easier for you to create and use your new *Care Notebook*

- Most people find it easiest to use a three-ring binder to create their *Care Notebooks*. You may also want to buy a three-hole punch that slips into the rings of the binder. By keeping the punch handy, you can avoid the hassle of dealing with loose material. When you receive a report or other information, simply punch the holes on the spot and slip the new material into the notebook. You may wish to include a few plastic sheets in which to insert information that can't be punched. Other people prefer to store their material in an accordion file, so use whatever method works best for you.
- Use dividers to separate the material in your *Care Notebook*. You can create the dividers in any way that is helpful to you.
- When you first put together your *Care Notebook*, you will likely want to spend some time creating a medical history. Make note of any operations or hospitalizations as well as other helpful information on your current medical conditions.
- Include blank pages in a special section of your *Notebook* where you can jot down questions for upcoming appointments. Make sure to leave space so that you or your advocate can write down the doctor's responses to those questions.
- Keep your *Care Notebook* in an easily accessible spot. Make sure that a family member or other caregiver can locate your *Notebook* in an emergency and knows to bring it to the clinic or hospital
- Bring your *Care Notebook* to all medical appointments.

You will want to create a *Care Notebook* that is specific to you and your medical conditions. Insert the pages that are most important to you. Here is a list of our suggestions for pages to start you off.

- Contact information for
  - You and other family members
  - Caregivers
  - Emergency contacts
  - Hospital
  - Healthcare providers
  - Therapists
  - Pharmacy
  - Insurance company or even a copy of your insurance card
  - Special transportation
  - Equipment providers
  
- Diary pages to track
  - Medication effects
  - Sleep
  - Activities
  
- An appointment log that includes
  - Who the appointment is with
  - The reason for the appointment
  - The results of the appointment
  - Any follow-up action that you need to take
  
- A medication log that includes
  - Name of the medication, including any brand or generic names
  - Date the medication was first prescribed
  - Who prescribed the medication
  - The dose
  - How often or when you take it
  - The way you take it
    - With or without food
    - By mouth, injected, or some other route
    - Date the medication was stopped and why
  
- Highlight pages for
  - Treatment results
  - Hospitalizations
  - Questions for upcoming appointments
  - Test results
  - Calendar

## **Table 1—Cardinal signs of PD**

Tremor

Slowness of movement (bradykinesia)

Stiffness (rigidity)

Balance (postural instability)

## Table 2—Motor and Nonmotor Signs and Symptoms Associated with PD

Anxiety	Bland or masked facial expression
Bladder problems	Decreased sense of smell
Constipation	Depression
Difficulty starting or keeping moving	Difficulty maintaining an erection
Difficulty breathing	Drooling
Heavy sweating	Lack of arm swing when walking
Lightheadedness or dizziness when standing	Pain (e.g., shoulder pain)
Skin problems (e.g., seborrhea)	Sleepiness during the day
Sleep problems	Small handwriting
Small quick steps when walking	Soft or garbled voice
Stooped or bent posture	Tiredness or fatigue
Trouble thinking or remembering	Trouble swallowing

**Table 3—Healthcare Professionals and Their Role on the Multidisciplinary PD Team**

<b>Healthcare Professional</b>	<b>Role</b>
<b>Dentists or dental hygienists</b>	Provide recommendations for oral hygiene, particularly as it relates to dry mouth or excessive production of saliva.
<b>Dieticians</b>	Determine your dietary intake and dietary needs, make recommendations for modifications in diet as the disease progresses and dietary needs change, and offer advice regarding protein intake and timing for people who take levodopa.
<b>Nurses</b>	Provide information about PD, including information about the symptoms of PD, managing day-to-day issues, clarifying your medication regimen, what to expect as the disease progresses, and how to find and participate in research studies.
<b>Occupational therapists</b>	Assess you and your environment, recommend the use of adaptive or assistive devices, and support you in maintaining independent living.
<b>Physical therapists</b>	Evaluate your balance and strength, recommend the use of adaptive or assistive devices, provide and supervise exercise plans, and assist you in maintaining strength, agility, and balance.
<b>Physicians and Advance Practice Nurses</b>	Manage your symptoms of PD through medication, injection therapy, or surgery.
<b>Psychologists</b>	Provide support and counseling for you and your caregivers, including information regarding living with a chronic degenerative disease and coping or adjustment strategies
<b>Social workers</b>	Supply information regarding financial assistance and nursing home placement, recommend networks for social support, and provide counseling for you and your caregivers.
<b>Speech therapists</b>	Assess your speech and swallowing, provide training to increase the volume and clarity of your speech, recommend dietary and feeding modifications, and offer exercises to improve swallowing.

**Table 4—The Path to Competent Self-Management of Health**

<b>Stage</b>	<b>Definition</b>
1	I am a passive recipient of care—I don't yet grasp that I must play a role in my own health.
2	I don't yet have the basic facts about PD and my health.
3	I have the key facts that I need to understand PD and my health and am beginning to take action, but I'm not yet confident about my ability to make changes or adopt new behaviors.
4	I have adopted new behaviors but I may have trouble maintaining these behaviors when I'm faced with stressful situations or health crises.

## Table 5—Core Competencies in Managing Parkinson Disease

### Knowledge of Parkinson disease

Understand the signs and symptoms of Parkinson disease, including nonmotor symptoms

Know which symptoms should trigger a call to my doctor

Keep a motor diary, if my doctor has requested that I do so

### Medications

Understand the reasons why my doctor has prescribed each of the medications I'm taking

Know the side effects of the medications and when to call the doctor about side effects

Take each of my medications in the right amount, at the right time, and in the right way

### Management of Health Care

Have a *Care Notebook* to organize my medical information

Know when I should schedule my next appointment with the doctor

Be aware of the results of my laboratory or imaging studies

### Lifestyle factors

Exercise regularly

Practice good sleep hygiene

Eat a healthy diet

Refrain from excessive alcohol or caffeine consumption

Stop smoking if I currently smoke

## ***Patient Activation Measure™***

Please read each statement below and then fill in the circle that matches the answer that best fits how you feel.

<b>Statement</b>	<b>Response</b>			
	Strongly disagree	Disagree	Agree	Strongly agree
When all is said and done, I am the person who is responsible for managing my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking an active role in my own health care is the most important thing that affects my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I can help prevent or reduce problems associated with my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know what each of my prescribed medications do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I can tell a doctor my concerns, even when he or she does not ask.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I can follow through on medical treatments I may need to do at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understand my health problems and what causes them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know what treatments are available for my health problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how to prevent problems with my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident I can figure out solutions when new situations or problems arise with my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I can maintain lifestyle changes, like eating right and exercise, even during times of stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

©2003 University of Oregon, Judith H. Hibbard, DrPH

***Goal-setting Chart***

<b>My goal</b>	<b>My reasons for setting this goal</b>	<b>Barriers to achieving this goal</b>	<b>Solutions for overcoming the barriers</b>	<b>Date I plan to implement this goal</b>

### Example of a Completed Goal-setting Chart

My goal	Reasons for setting this goal	Barriers to achieving this goal	Solutions for overcoming the barriers	Date I plan to implement this goal
Begin an exercise program	I want to have more energy and feel better about myself. My doctor told me that exercise might help me to deal with my PD symptoms.	I don't have anyone to walk with me. I'm afraid I'll fall. I'm too tired.	Join a PD exercise group. Cut back on TV and go to bed earlier at night.	March 17, 2009
Learn more about PD	My doctor told me last month that I have PD. I was thrown for such a loop, that I've just buried my head in the sand.	I really don't want to deal with this. It seems so overwhelming. I don't where to turn for accurate up-to-date information on PD. I don't want to burden my family with the diagnosis.	Recognize that what I'm feeling is perfectly normal. Find a support group in town and go to a meeting. Log on to wemove.org and read the information on PD. Join the online discussion forum and ask other people to help me. Dig up the literature that my doctor gave me and read it. Share it with my family members.	March 8, 2009

Take my medication on time

My doctor told me that it's important to take my medicine the same way and at the same time every day so that I can keep a constant level in my bloodstream and avoid the peaks and valleys.

I take several different medications throughout the day. Sometimes I forget if I've taken the next dose. My memory just doesn't seem to be as good as it used to be. The schedule just seems so complicated.

Ask my doctor if there is a medicine that I can take that combines two or more of my medications. Use a pillbox. Ask my daughter when she comes on Sundays if she can help me to set up the box for the week. Ask my doctor if there are any sustained-release forms of my medicines that I can take less often. Set up automatic refills at my pharmacy so that I don't run out of any of my medicines.

During my next doctor's visit and next Sunday when Julie comes over.

## ***MOTOR DIARY***

One way that doctors have developed to help decrease your OFF time and ON time with dyskinesias is to have you or your caregiver record symptoms in a motor diary. During an office visit, your doctor can then review the diary and see how your symptoms change throughout a usual day. Doctors have developed a standard way for patients to record their symptoms in a motor diary. This is so that every patient records information the same way, making the results easier for the doctor to interpret.

A motor diary is used to keep track of ON time, OFF time, and ON time with dyskinesias during the time that you are awake for an entire week. Upon awakening in the morning, you record which of the three phases you're in. Every half hour after that, you will again record what phase you are in. During the night, you will also mark down any times that you are awake and make note of the phase at that time as well.

It is very important to record every 30 minutes from the time you wake up until the time you go to sleep. You will also record when you take your medication and any other thoughts that you have about how you are feeling at that time.

Once you've kept the diary for at least a week and shared it with your doctor, the two of you can decide how often each day you should keep recording. Some people cycle between the three phases of ON, OFF, and ON with dyskinesias quickly, so it will be important for them to keep recording in their diaries every 30 minutes. Other people cycle more slowly.

The sample diary on the following page is divided into 30-minute periods, 12:00 AM is midnight, and 12:00 PM is noon. For each 30-minute period, please mark an X in the box that corresponds to your ability to move during that period. Remember to mark only one box in each period. If your ability to move varied throughout a 30-minute period, please mark the one box that is valid for MOST of that period.

Please keep in mind the following definitions when rating your ability to move. Please remember to record any times that you wake up during your sleep period, and note your ability to move at that time. In the right-hand column, please record any medication and the amount of medication that you take during the 30-minute periods.

<b>Term</b>	<b>Definition</b>
ON	You are able to move normally or almost normally.
ON with troubling dyskinesias (TD)	You are able to move but are troubled by twisting or turning movements that you can't control. These movements are not the same as the tremor, or back and forth movement, that is part of PD.
OFF	You are very stiff and either have great difficulty moving or are unable to move at all.
Asleep	You are sleeping.

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Day of the week:

\_\_\_ Sunday \_\_\_ Monday \_\_\_ Tuesday \_\_\_ Wednesday \_\_\_ Thursday \_\_\_ Friday \_\_\_ Saturday

Time	ON	ON with TD	OFF	Asleep	Medication or comment
Midnight – 12:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12:30 AM – 1:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:00 AM – 1:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:30 AM – 2:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:00 AM – 2:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:30 AM – 3:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:00 AM – 3:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:30 AM – 4:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:00 AM – 4:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:30 AM – 5:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:00 AM – 5:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:30 AM – 6:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:00 AM – 6:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:30 AM – 7:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:00 AM – 7:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:30 AM – 8:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:00 AM – 8:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:30 AM – 9:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:00 AM – 9:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:30 AM – 10:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:00 AM – 10:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:30 AM – 11:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:00 AM – 11:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:30 AM - Noon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Time	ON	ON with TD	OFF	Asleep	Medication or comment
Noon – 12:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12:30 PM – 1:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:00 PM – 1:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:30 pm – 2:00 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:00 PM – 2:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:30 PM – 3:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:00 PM – 3:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:30 PM – 4:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:00 PM – 4:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:30 PM – 5:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:00 PM – 5:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:30 PM – 6:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:00 PM – 6:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:30 PM – 7:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:00 PM – 7:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:30 PM – 8:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:00 PM – 8:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:30 PM – 9:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:00 PM – 9:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:30 PM – 10:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:00 PM – 10:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:30 PM – 11:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:00 PM – 11:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:30 PM – Midnight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	