# **TAKE CHARGE**

# An Action Plan for Managing Your Parkinson's



**Partners Parkinson and Movement Disorders Center** 







U.S. News and World Report consistently names Massachusetts General Hospital among the best hospitals in the country, and its neurology and neurosurgery services are among the top ten in the nation.



A National Parkinson Foundation Center of Excellence



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#### **Disclaimer**

This booklet was written by a team of physicians, nurse, therapists, and social worker at Partners Parkinson Center at the Massachusetts General Hospital in Boston to provide health-related information to you so that you may be better informed.

Some material may reflect the opinion of the authors and not necessarily that of your doctor or the Massachusetts General Hospital.

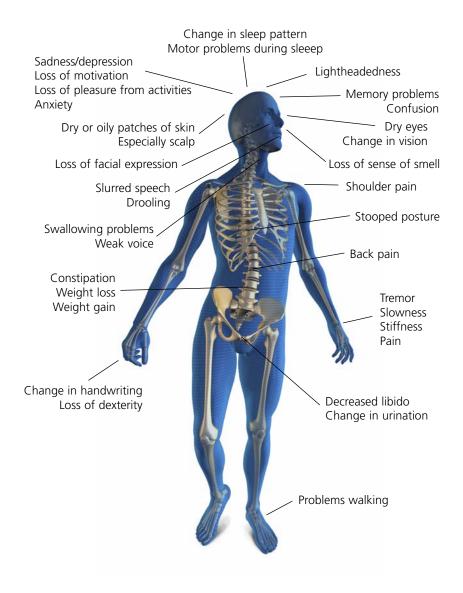
If you want medical advice, diagnosis, or treatment, you should consult your doctor.

# **TAKE CHARGE**

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#### **Common Problems in Parkinsonism**



# TAKE CHARGE

Welcome to the Partners Parkinson's Center at Massachusetts General Hospital, a nationallydesignated Center of Excellence offering comprehensive Parkinson's care.

Now that you have been diagnosed with Parkinson's, you probably have a lot of questions.

Can I continue to do my job, parent my children, be a husband or wife?

How will my life change?

Can I continue to pursue my hobbies?

Travel?

Live safely in my house?

What can I do to maximize my ability to keep on doing the things I need and want to do?

This brochure is intended to provide answers to some of your questions, to present resources to help you manage your Parkinson's, and to empower you to take charge of your health and well-being.

Parkinson's is a chronic condition that primarily affects movement. It is caused by the breakdown of brain cells that create a substance called dopamine. Dopamine acts as a chemical messenger to the parts of the brain that control movement. Lack of sufficient dopamine causes the typical Parkinson's symptoms of tremor, slow movement, stiffness, and problems with balance and walking.

Today there is more reason than ever before for you to be optimistic about your prognosis. A full spectrum of evidence-based therapies, including medications and surgery, is available to manage your symptoms, and a robust research effort is underway, working to uncover the causes of and identify better treatments for Parkinson's. As a patient of the Partners Parkinson Center at Massachusetts General Hospital, you have access to all proven therapies, as well as an opportunity to participate in clinical trials of new treatments that may benefit you.

Your care team includes your neurologist and nurse practitioner, as well as other specialists in physiatry, psychiatry, urology, physical therapy, occupational therapy, speech therapy, nutrition, psychology, and social work. The team works together to design the best management strategies to suit your individual needs and preferences. All team members can be valuable resources for you, and you should not hesitate to contact any of us for information and to help you address any concerns about your symptoms or your care.

But it is important not to overlook the most important member of your care team – you. There is much you can do to manage your symptoms, and we encourage you to adopt a proactive approach and focus on things that you can start doing today to enhance your health and well-being. In this brochure you will find information on exercise, nutrition, and self-care that you can incorporate into your daily life. Please take a few moments to look it over and make note of any questions for your care team.

As time goes on, you and your family will certainly have more questions about living with Parkinson's, and you may choose to consult Internet sources. While much of the information available on the Internet is reliable, some is not, and some may not be applicable to you. Remember that you can always call on the members of your care team to answer your questions, direct you to responsible websites and useful published information, and help you interpret what the information means for you. In addition, you will find a list of reliable and helpful resources at the back of this brochure.

Your Parkinson's diagnosis is one of many challenges that you have faced and will face throughout your life. Please use this brochure to help you take heart, take charge, and live a full, meaningful, and joyful life with Parkinson's.

#### Rx: Keep Moving

Exercise improves overall health and well-being for everyone, but it has special benefits for people with Parkinson's. A regular program of moderate exercise can help control your symptoms, help you continue to enjoy your daily activities, and enhance your comfort, mobility, and quality of life.

Exercise has been shown to reduce rates of coronary artery disease, stroke, and adult onset diabetes. It can lower high blood pressure, help manage weight, enhance bone health, elevate mood, and improve sleep. Exercise also increases oxygen to the brain and other vital organs.

Exercise confers several benefits of special interest for people with Parkinson's. Scientific studies show that exercise programs improve strength, balance, walking speed, overall physical functioning, and quality of life. Further, there is evidence suggesting that when exercise is introduced early, disease progression can be slowed. Some of the benefit is probably related to increased oxygenation and promotes "neuroplasticity" or brain cell regeneration and repair. In addition, physical activity stimulates the creation of dopamine and reduces Parkinson's symptoms.

So how can you incorporate exercise into your daily routine? If you already have an exercise program, good for you! You probably know what your body can handle, and you can continue with your current program. If you do not currently engage in regular exercise, please consult your care team to ensure that you do not have cardiovascular, orthopedic, or other problems that would affect your ability to participate in physical activity and to help identify an exercise program that is appropriate for your medical history, age, and fitness level.

Whether you are a novice or an experienced exerciser, your exercise prescription should include activities to promote aerobic conditioning, strength, and flexibility. Aerobic exercise improves cardiovascular capacity, or your heart's ability to pump blood and provide oxygen to your brain and muscles.

Strengthening exercise, often called resistance training, is particularly important in managing Parkinson's symptoms. Alone or within a broader fitness routine, resistance training can improve balance, bone health, and muscle strength, all of which can minimize or delay the appearance of typical Parkinson's symptoms.

Flexibility exercises help keep joints mobile, protect against muscle strain, ease muscle tension, and promote good posture, which can help you maintain your strength, balance, and mobility.

# Here are some helpful hints that can make starting an exercise routine more manageable and more fun.

- Wear comfortable clothing that does not limit your movement.
- Choose comfortable, supportive footwear.
- Choose exercise that is manageable, affordable, and fun.
- Start slowly. If you're new to exercise, try a few exercises and choose two or three that make you feel good. Add new exercises weekly. If you're experienced, gradually add exercises, increase repetitions, and increase resistance to raise your fitness level.
- Some exercises combine arm and leg movements.
   You can begin by doing only the arm or the leg portion and combining them as you become more fit.
- Strengthening and flexibility exercises should be performed slowly. Rapid movements can push muscles and joints beyond safe limits and result in injury.
- Exercise should not be painful. If an exercise hurts, don't do it. Consult a physical therapist to ensure that you're doing the exercise correctly. You may simply need to build up your fitness level.
- Feel good about what you can do and don't worry about exercises you can't do. Everything you do will promote your overall fitness and well-being.

#### What types of exercise are best?

The kind of exercise you can commit to and enjoy is best! Be sure to include aerobic, strength, and flexibility exercises in your program. Many people participate in Pilates, yoga, tai chi, or other group classes because they enjoy the social interaction as well as the physical activity. You can choose the activities that are most attractive to you and individualize your program to suit your own preferences.

#### The big three

There are three major categories of exercise that you should be sure to include in your exercise program right from the very start.



Here we present specific examples as well as ideas to help incorporate them into your daily routine to increase your chances of success. Remember, these are examples designed to help you get started. You can build and vary your program as your fitness level increases and according to your own preferences.

#### Aerobic Exercise

An aerobic workout should include 5 to 10 minutes of warm-up, at least 20 minutes of moderate-intensity activity, and 5 to 10 minutes of cool-down. Walking, running, swimming, dancing, rowing, skating, biking, and hiking are good aerobic activities.

Recommendations vary for how many times a week and for how long you should exercise. Begin slowly, working up to a minimum of three times per week.

#### Strengthening Exercise

Strengthening your muscles typically involves weights or resistance bands (resistance training).

Strengthening can also be accomplished by moving a particular body part into a position and holding it for a period of time.

Resistance training should be performed three times per week, spaced evenly throughout the week. Use weight or resistance sufficient to tire you after 10 to 12 repetitions. When holding a position, it is helpful to count to five out loud to avoid holding your breath. Once you are able to perform 10 to 12 repetitions without difficulty, it's time to increase your resistance. Any muscle soreness occurring after exercise should be gone in a day or two.

#### Flexibility Exercise

Exercises designed to improve flexibility involve moving your trunk, arms or legs to a position where you begin to feel slight tension or pulling. This pull is the soft tissues (muscles, tendons, ligaments and joint structures) telling you they've reached the limit of their comfort zone.

When performing flexibility exercises, hold the initial position for 20 to 30 seconds. When the tension eases, stretch a little farther. Repeat 3 to 5 times.

Following are ten basic strength and flexibility exercises you can do at home.

#### **Trunk twists**

## Flexibility

- 1. Lie on back with knees bent
- 2. Drop your knees to one side, arms and head to the other side.
- 3. Gently stretch your neck and spine.

#### **Modified trunk twist**

- 1. Sit comfortably at edge of chair.
- 2. Moving from the waist, gently twist upper body to one side, then to the other.







#### **Hip lifts**

#### Strength

- 1. Lie on back with knees bent.
- 2. With your feet flat on floor (or bed), lift your buttocks. Hold, slowly lower down.
- 3. To advance this exercise, support yourself on one leg and lift the other as shown.





## Arm and leg lifts

# Strength Flexibility

- 1. Lie on stomach with hips over flat pillow.
- 2. Lift arm and opposite leg and hold.
- 3. Return to starting position.
- 4. Repeat using other arm and leg.



#### **Hip twists**

#### Flexibility

- 1. Sit comfortably at the edge of a chair.
- 2. Touch foot to the side, then to the front, then lift heel to opposite knee.
- 3. Repeat with other leg.



Caution: If you have had a hip replacement surgery do not perform this exercise without consulting your doctor





## Leg stretch

# Flexibility

- 1. Sit at the edge of a chair with heel on a stool.
- Leaning forward from hips, slide hands toward foot, keeping back and knee straight. Hold this position.
- 3. Repeat with other leg.

You can do the same stretch sitting at your desk chair.





#### Lunges

Strength

Flexibility

#### **Forward**

- 1. Stand with hands on hips, feet shoulder-width apart.
- 2. Take a comfortable step forward, transferring weight to front leg and bending front knee.
- 3. Return to starting position.
- 4. Repeat with other leg.

#### Side

- 1. Stand with hands on hips, feet shoulder-width apart.
- 2. Take a comfortable step to the side, transferring weight and bending knee.
- 3. Return to starting position.
- 4. Repeat with other leg.







# **Upper back squeeze**

Strength

Flexibility

- 1. Extend hands in front of you, palms down.
- 2. Pull hands back toward ears. Hold this position.
- 3. To advance this exercise, use a resistance band as shown.











Incorporate this activity into your daily routine while brushing your hair.

### Leg extension



- 1. Stand next to chair for support.
- 2. Lift knee across your body
- 3. Extend leg at a 45 degree angle behind you, toes pointed.
- 4. Return to starting position.
- 5. Repeat with other leg.
- To advance this exercise, add resistance band. Hold band in hand holding chair and wrap other end around working leg at the ankle.





### Leg and arm extension

Flexibility

Strength

- 1. Stand beside a chair and hold for support.
- 2. Bring free hand across to other shoulder and lift opposite leg and hold.
- 3. Lift arm over your head and to the side, while extending opposite leg behind you at 45 degrees, as shown.
- 4. Repeat using other arm and leg.
- 5. This exercise can be performed without resistance band.



Incorporate this extension into your daily routine when reaching for objects on high shelves.





#### **Heel lifts**

## Strength

- 1. Stand with hands on chair or counter for support.
- 2. Rise on toes as high as you can, keeping knees straight.
- 3. Lower heels slowly.
- 4. To advance this exercise, rise and lower on one leg, repeat with other leg.





#### **Staying active**

Many activities that you do for fun and recreation also confer exercise benefits. For example

**Gardening** builds arm strength.

**Swimming** is a great form of exercise that increases aerobic capacity, strength, and flexibility.

Bowling builds arm and leg strength.

**Dancing**, like swimming, provides the benefits of aerobic, strengthening, and flexibility training.

**Games/crafts** increase strength and flexibility in the hands and fingers.

Including some of these recreational activities along with a basic exercise program will help you build and maintain your fitness level and keep it fun.









# Rx: Eat Healthy

Maintaining a healthy diet contributes to your overall health and well-being and also can be very helpful in managing the constipation that commonly affects people with Parkinson. Degeneration of intestinal nerves, certain medications, and reduced fluid intake can all contribute to Parkinson-related constipation. Ignoring constipation can lead hemorrhoids, bowel impaction, and considerable discomfort.

To reduce your risk of constipation and its resulting complications, it is important to get enough fiber and fluid each day. Fiber comes from plant sources such as fruit, vegetables, nuts, grains and beans. It helps the bowels move regularly and easily; it also helps to keep the intestinal muscles strong and working properly. Get your fiber from food, as fiber-rich foods also contain many other vitamins and minerals your body needs to function properly.

Consuming enough fiber also can help keep your heart healthy and may reduce your risk of developing colon cancer. In addition, getting enough fiber each day can reduce your risk of having to rely on laxative medications, which can damage the intestines over time. Fluid is also important when increasing fiber intake, because it helps to keep stools soft and easy to pass.

Read on for tips on how to assess your current fiber intake and add more food sources to your diet, as needed. There is also a section to help you keep track of your fluid consumption each day.

### Consume enough fiber

Your goal is to consume 25 to 35 grams of fiber, or at least 8 servings of fiber-rich foods per day. If you need to increase your fiber intake, do it slowly, adding 5 grams each week, to help prevent bloating.

How many servings of fiber do you get per day? \_\_\_\_

All of the serving sizes below have about 3 grams of fiber per serving.

### **Fruit and Vegetables**

1/2 cup fresh fruit, 1/2 cup cooked vegetables, or 1 cup raw vegetables

How many servings of fruit and vegetables do you eat per day? \_\_\_

Quick tip: Leave edible skins on fruit and vegetables even when recipes call for peeled produce.

#### **Beans**

1/4 cup black beans, kidney beans, chickpeas, lentils, etc., or 3 tablespoons of hummus

How many servings of beans and lentils do you eat per day? \_\_\_

Quick tip: Add beans to soups and salads and use hummus as a spread for sandwiches.

### Whole grains

1 slice whole wheat bread, 1 cup whole wheat pasta, 1 cup oatmeal, 1 cup brown rice

How many servings of whole grains do you eat per day? \_\_\_

Quick tip: Choose whole wheat pasta and brown rice.

#### Nuts

1/4 cup of nuts or 2 tablespoons of peanut butter

How many servings of nuts do you eat per day? \_\_\_\_

Quick tip: Nuts are heart-healthy and make a great snack. Try making your own trail mix.

You can use food labels to help figure your fiber intake. First, look at the nutrition facts.

**Look at the suggested serving size.** For the example below, the serving size is one cup.

Look at the dietary fiber. That is the amount of fiber in one serving of the product. In the example below, there are 3 grams of dietary fiber in a one-cup serving.

Assess the fiber content of the product. 3 grams of fiber means the product is a good source of fiber. A product containing 3g of fiber or more per serving is a good source of fiber.

Next, read the ingredients list. A fiber-rich wholegrain product will list one of the following whole grains as the first ingredient on the food label:

Whole wheat flour
Whole [type of grain]
Stoneground [type of grain]
Oats
Brown rice

Don't be fooled by words like "multigrain" or "enriched." These words do not mean the product is a good source of fiber.

| Calories 90 Calories from | irai 30   |
|---------------------------|-----------|
| % Dai                     | ly Value* |
| Total Fat 3g              | 5%        |
| Saturated Fat 0g          | 0%        |
| Cholesterol 0mg           | 0%        |
| Sodium 300mg              | 13%       |
| Total Carbohydrate 13g    | 4%        |
| Dietary Fiber 3g          | 12%       |
| Sugars 3g                 |           |
| Protein 3g                | E TOTAL   |

## Get plenty of fluid

When your body does not get enough fluid, your colon has to remove water from the stools to deliver it to other organs that need fluid to function. This can cause constipation. Many Parkinson's medications can also contribute to dehydration and constipation.

Use the guide below to help you keep track of how much fluid you consume a day. Aim for 8 glasses of fluid per day, unless your doctor has put you on a fluid restriction.



Although the majority of your fluid intake should come from water, some can come from other sources. One cup of broth, fruit juice, ice cream, yogurt, herbal tea, or gelatin may be substituted for one cup of water. Four popsicles can also equal one cup of fluid. While foods like ice cream and popsicles can count as a source of fluid, you should limit your consumption of sugary drinks and foods.

## Set goals for yourself

A registered dietitian on your care team can help you design a healthy eating plan and establish goals to get you there. Use the goal sheet below to help get you started.

| My nutrition goals are: |  |
|-------------------------|--|
| 1                       |  |
|                         |  |
| 2                       |  |
|                         |  |
| 3                       |  |
|                         |  |
| 4                       |  |
|                         |  |
| 5                       |  |
|                         |  |
| 6                       |  |
|                         |  |

### Examples:

- 1. I will switch from white bread to whole wheat bread.
- 2. I will leave the skin on potatoes when making mashed potatoes.
- 3. I will increase my fluid intake.

# Rx: Mind Your Health and Safety

Besides maintaining an effective exercise program and good nutrition, there a number of steps you can take to care for yourself so you can continue with your work, family responsibilities, recreation, and other activities you enjoy.

**Neurological concerns.** Schedule a regular check-up with your neurologist. If possible, choose a provider with experience and expertise in treating Parkinson's. They can offer the latest therapies, as well as access to trials of new medications and procedures that may benefit you.

**General health.** Continue to see your primary care physician for your regular check-ups and screenings. Be sure to stay current with the vaccines that your primary care doctor recommends.

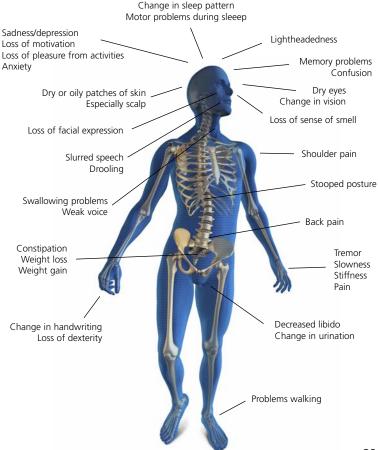
You may notice non-typical Parkinson's symptoms including depression, constipation, urinary incontinence, and sexual potency. Report these and any other new symptoms to your primary care provider. Whether or not these manifestations are associated with Parkinson's, they can be treated. You may wish to circle the symptom on the drawing below as a reminder to talk to your physician.

**Safety.** You may want to make some simple changes to your home to make you feel safer and more independent. If you experience difficulty with walking, consider adding support bars in your bathroom and railings in stairs and hallways.

Make an honest evaluation of your ability to drive a car. Parkinson's can slow reflexes and Parkinson's medications can cause excessive daytime sleepiness, both of which may affect your ability to drive safely.

If you believe your driving skills have diminished, take advantage of programs to test your driving skills available at many motor vehicle offices. Please take the initiative to assess your ability to drive and take steps to prevent injury to yourself and others.

### Common Problems in Parkinsonism



# Rx: Take Charge

A diagnosis of Parkinson's is never welcome and always changes people's lives. We hope the following stories, shared by people who have Parkinson's, will encourage and inspire you to find your own ways to manage Parkinson's and to take charge of your health, well-being, and joy.

### **Bob's Story**

My name is Bob Porter. I am 72 years old, and I have had Parkinson's for 25 years. When my symptoms first appeared, I denied them. I was training for a marathon and my shoulder became stiff. I went to a local neurologist who told me to wait three months and see. Six months later, I went to Massachusetts General Hospital and they made the diagnosis of Parkinson's. Having lived with it for 25 years, I think of it as "Porter's," not Parkinson's.

I never dreamed I would feel so good after all this time. I have very little tremor and almost no difficulty with movement. I have continued to exercise, and I play chess every day, which has improved my concentration. I am not depressed, and this fact is my single most important asset in combating Parkinson's. I think this is in large part due to my positive attitude and determination to keep active.

There are many mysteries associated with Parkinson symptoms. For example, I can struggle to stand up from a chair and then surprise everyone in the room when seconds later I am dancing to jazz music without a trace of Parkinson's

I am a scientist who writes non-scientific books and essays. I cannot write legibly, so I dictate most of my work. I have published eight books over the last ten years.



I work about 30 hours a week.

I run three companies but do not manage any of them on a day-by-day basis. My memory is not as good as it once was, but it does not interfere with my social or business life. My eyes are extremely light sensitive, sometimes closing involuntarily. This makes it appear that I have fallen asleep, and sometimes I actually do. This is embarrassing in business meetings.

I travel, sometimes alone, but I have my appointments scheduled carefully to allow for rest. I use a wheelchair in the airports. I usually have some help in getting dressed, and I fall more easily than the average person.

I remain awed by humans' ability to think, to have bursts of thoughts, to extract labels from the subconscious, each one with its attached story. I am awed by my mind's ability to amplify fear and depression so that seconds seem like years and then how quickly I can have full recovery with everything back in calm, orderly perspective.

Further, when this incredible organ, my brain, is juxtaposed to the power of my mind consciously or subconsciously, to mediate between conflicting genetically transferred survival instincts, and information acquired through experience, I can only shake my head in appreciation of a higher order in nature than I will ever understand.

Robert Porter

## The Sullivan's Story

My wife Margaret was diagnosed with Parkinson's in the early 1990s when she was 42 years old. Of course, the news of her diagnosis came as a shock and a surprise to our family and close friends. The physical symptoms were subtle in the early years, which gave us a chance to become acclimated to the effect her illness would have on our marriage and on our two sons, then ages 8 and 10. A Parkinson's diagnosis is one that is shared by and has a major impact on all of the patient's immediate family members.

Following her diagnosis, Margaret spent time coming to grips with what it would mean to have this disturbance in her life. As a nurse she knew the importance of getting involved in the local and national organizations that make it their mission to fight Parkinson's and Parkinson-related disorders. For a number of years, we participated in and raised funds for the Parkinson's Unity Walks in New York City. That was an important way for us to make a contribution and get involved. We also have worked to support the important research being done at the MassGeneral Institute for Neurodegenerative Disease.

One of the issues we faced as a relatively young family was how to help our children understand and deal with their mother's Parkinson's. Each child responds differently. It is important for the children of Parkinson's patients to learn that they can openly discuss their feelings about their parent's condition, and in our case, it was helpful to get a family therapist involved to help promote these discussions.

It also is important to let children know that their parent's condition is not something that must be hidden from their community of friends, but rather is a challenge that can and must be addressed. We hope they learned from the example we tried to set.



Both of our sons have become particularly devoted to their mother and have come to see themselves as important members of her support team. I am sure the dialogue we developed with them in the early years was a major factor in their reaching a good comfort level with the changes Parkinson's has brought to our family and in allowing them, as young adults, to find their own ways of being part of the solution.

We treat Parkinson's as an uninvited guest in our home. We always know it is present, but we work together to live our lives in ways that will reduce its impact. The best advice that we can give a newly diagnosed Parkinson's patient is to keep living your life, stay active, and continue to enjoy the presence of the people in your life who love you.

Ralph C Sullivan

# **Resource Library**

#### **Books**

Ahlskog, J. E. (2005). The Parkinson's Disease Treatment Book: Partnering with your doctor to get the most from your medications. New York: Oxford University Press.

Ali, R. (2005). I'll Hold Your Hand So You Won't Fall: A child's guide to Parkinson's disease. Florida: Merit Publishing.

Argue, J. (2000). *Parkinson's Disease and the Art of Moving*. California: New Harbinger Publications.

Carley, G. (2007). Surviving Adversity: Living with Parkinson's disease. Canada: Surviving Adversity.

Christensen, J. (2005). The First Year Parkinson's Disease: An essential guide for the newly diagnosed. New York: Marlowe and Company.

Le Verrier, R. (2009) Yoga for Movement Disorders: Rebuilding Strength, Flexibility and Balance for Parkinson's and Dystonia. Jupiter, FL; Surrey, England: Merit Publishing International.

Rosenstein, A. (2002). Water Exercises for Parkinson's: Maintaining balance, strength, endurance and flexibility. Washington: Idyll Arbor.

Sharma, N. & Richman, E. (2005). *Parkinson's Disease and the Family.* Massachusetts: Harvard University Press.

Tagliati, M., Guten, G., & Horne, J. (2007). *Parkinson's Disease For Dummies*. New Jersey: Wiley Publishing.

#### **Brochures**

Coltrera, F. (2004). Strength and Power Training: A guide for adults of all ages (W. Frontera & J. Bean, Eds.). Massachusetts: Harvard Medical School.

National Parkinson Foundation (2006). *Parkinson's Disease: Fitness counts* (3rd ed.) Florida: H. Cianci.

National Parkinson Foundation (2007). Parkinson's Disease: Nutrition matters. Florida: K. Holden.

National Parkinson Foundation (2005) *Looking Forward Moving Ahead* Support Group Leader's Manual

Slon, S. & Saunders, C. (2004). *Parkinson's Disease: A New Hope* (J. Growdon, Ed.). Massachusetts: Harvard Medical School.

#### Additional information:

American Parkinson Disease Association (www.apdama.org)
European Parkinson's Disease Association
(www.epda.eu.com)
National Institute of Neurological Disorders and Stroke
(www.ninds.nih.gov)
National Parkinson Foundation (www.parkinson.org)
Nutrition Analysis Tool (www.nat.uiuc.edu)
Nutrition You Can Live With

(www.nutritionucanlivewith.com)
Michael J. Fox Foundation for Parkinson's Research
(www.michaeljfox.org)

American Dietetic Association (www.eatright.org)