

# LIVING WELL CHALLENGE: Q&A WITH THE EXPERTS

On June 15, 2011, the *Living Well Challenge* webinar was broadcast live online. People were invited to submit their questions to the panel. Here, Monique Giroux, MD, Medical Director at the Northwest Parkinson's Association and Terry Ellis, PhD, PT from Boston University and Sierra Farris, PA-C, MPAS share their responses.

## ***Monique L. Giroux, M.D.***

Dr. Monique Giroux is a national leader in comprehensive patient-centered care for Parkinson's and related movement disorders. Dr. Giroux complements her expertise in disease management with an added focus in self care management, wellness, lifestyle and personal healing to promote living best with chronic neurologic conditions. Dr. Giroux completed her Neurology residency at Yale followed by a 2 year fellowship in Movement Disorders at Emory University in Atlanta. She has also studied holistic health as a clinical fellow in Integrative Medicine at the University of AZ. She is board certified in Neurology. Dr. Giroux has developed comprehensive care programs for people with Parkinson's including the Booth Gardner Parkinson's Care Center in Kirkland, WA and the Cleveland Clinic Foundation. In addition to her clinical care, Dr. Giroux is advancing quality care and wellness for Parkinson's in her positions as medical director of the Northwest Parkinson's Foundation in Seattle and medical director for the National Parkinson's Foundation's Allied Team Training Program and national care consortium project. She is the director of a unique Parkinson's virtual wellness center [www.nwpf.org/wellness/](http://www.nwpf.org/wellness/). Giroux has developed specialized Neurorehabilitation programs for patients with Parkinson's and movement disorders, Deep brain stimulation patients, Botulinum toxin therapies, spasticity, and gait and balance problems.

## ***Terry Ellis, PhD, PT, NCS***

Dr. Ellis is a Clinical Associate Professor at Boston University, College of Health & Rehabilitation Sciences: Sargent College in the Department of Physical Therapy & Athletic Training. Dr. Ellis is also the Co-Director of the Center for Neurorehabilitation at Boston University where she conducts research, provides clinical consultations and education to healthcare professionals and to persons with neurological disorders. She teaches examination and treatment of patients with neurological disorders within the Doctor of Physical Therapy Program. In addition, Dr. Ellis directs the APDA National Rehabilitation Resource Center housed at Boston University. Dr. Ellis has a Ph.D. in Behavioral Neurosciences from Boston University School of Medicine. In addition, she is a board

certified specialist in Neurologic Physical Therapy. Her research focuses on investigating the impact of exercise and rehabilitation on the progression of disability in individuals with Parkinson disease. She is the recipient of a K12 Boston University Building Interdisciplinary Research in Women's Health (BIRCWH) career development award where she is investigating the natural history of change in quality of life and physical function in women with Parkinson Disease. As part of the Research Career Development Core in the Pepper Center at Boston University, she is investigating the effects of an exercise program in reducing fall risk and fall rate in people with Parkinson Disease.

### ***Sierra Farris, PA-C, MPAS***

Sierra Farris is a certified neurological physician assistant and an accomplished clinician in the treatment of Parkinson's disease with over a decade of expertise in deep brain stimulation programming and education. She has programmed more than 1000 neurostimulators with special interest in troubleshooting DBS complications. Sierra has worked primarily in an intradisciplinary patient centered care setting to include neuro-rehabilitation and neurosurgery. Sierra is a clinical exercise specialist certified by the American College of Sports Medicine with primary exercise interests as a treatment for Parkinson's disease and other neurological conditions. Sierra just recently completed a Master's degree in Bioethics and plans to continue promoting patient advocacy.

# EXERCISE

## **Q: Which types of exercise are best for people with Parkinson's disease and how much exercise should people with Parkinson's disease be doing?**

Dr. Ellis: First, it may be helpful to describe what a physical therapist can offer people with Parkinson's disease. Physical therapists can help with the following:

1. Promotion of physical activity and adherence to an exercise program
2. Teach strategies to move easier (e.g., walk, rise from a chair, get in and out of bed)
3. Develop an exercise program to improve fitness level, strength and flexibility
4. Improve balance and reduce fall risk

The research reveals that people with Parkinson's can improve quality of life, walking, general mobility, fitness level, strength and flexibility with participation in exercise. The key is to make exercise a part of your life over the long-term in order to experience the greatest benefit.

Below is a general set of exercise recommendations for people with Parkinson's disease. However, each person must consult with their physician to ensure that it is safe for them to exercise. ***In addition, exercise programs should be individualized to meet the needs of each person in order to experience the greatest benefits.*** Therefore, I recommend that people with Parkinson's disease consult with a physical therapist to develop an exercise program to best meet their needs.

### ***Recommended Exercise:***

#### **CARDIOVASCULAR TRAINING**

Cardiovascular exercise or aerobic exercise is exercise that involves oxygen consumption by the body and uses large muscle groups. Depending on your fitness level, cardiovascular exercise can include walking at a fast pace, jogging, swimming, biking, hiking, dancing or others.

Studies reveal that people with Parkinson's disease benefit from cardiovascular training. Improvements have been observed in oxygen consumption, economy of movement, walking distance and speed and overall function. No one form of cardiovascular training has been shown to be superior to another.

We don't know the most optimal dose of cardiovascular exercise for people with Parkinson's disease; however, the American College of Sports Medicine (ACSM) has published guidelines for the general population that we can use as a guide. The ACSM recommends doing moderately intense cardiovascular exercise 30 minutes a day, 5 days per week or vigorously intense cardiovascular exercise 20 minutes a day, 3 days per week.

## **STRENGTH TRAINING**

Strength training involves contracting muscles while they are loaded. Muscles can be loaded by using free weights, elastic bands, and machines or by simply using body weight.

Studies reveal that strength training has resulted in improved strength, muscle volume, walking and stair climbing in people with Parkinson's disease.

In general, people with Parkinson's disease should target the large muscle groups – particularly the extensor muscles in the legs (hip extensors, knee extensors) and the back (postural extensors). The ACSM recommends performing 8-10 strengthening exercises, 8-12 repetitions each, twice per week.

## **STRETCHING**

Stretching involved holding a muscle in a lengthened position to increase its flexibility.

Studies reveal that people with Parkinson's disease benefit from stretching. Improvements in muscle flexibility, balance and walking have been demonstrated.

In general, people with Parkinson's disease should perform exercises to increase the flexibility of the hamstrings, hip flexors, chest muscles and calf muscles. Mobility exercises to help improve extension and rotation of the trunk may also be helpful.

Stretching exercises should be performed 3 times per week. Each stretch should be carried out 2-3 times while holding each stretch for about 30 seconds.

In summary, it is beneficial to include exercise into your daily routine. It is important that you keep up the exercise over the long-term so choose exercises that you enjoy and then you'll be more likely to stick to it. Consider exercising as part of a group or with friends or family as social interactions can make exercising more fun.

**Q: How important is high intensity exercise, and what do you mean by “intense exercise”?**

Dr. Ellis: These are great questions and more difficult to answer than you would think. *Intense* can actually mean different things to different people. Intense exercise might mean that the exercise is challenging, makes you work hard or work over a long duration. Intense exercise is actually different for each individual. What is intense for one person may not be intense for another. It seems that for any type of exercise to be effective, it must be challenge the individual beyond their current capabilities. For example, moderately intense physical activity is defined by the ACSM as working hard enough to raise your heart rate and break a sweat yet still be able to carry on a conversation. So for some people, walking may be moderately intense and for others biking may be moderately intense. In strength training, you should work hard enough so your last few repetitions are difficult. For some people, this may be 5 pounds or for others it may be 10 pounds for a particular muscle group. So when we say exercise should be intense, it seems it needs to be somewhat challenging but not so difficult that you risk injury or are unable to complete the exercises.

**Q: I play and love tennis. Is it a good, bad or indifferent exercise?**

Dr. Ellis: Tennis is typically a great exercise for people with Parkinson’s disease. People with Parkinson’s generally experience stiffness in the trunk area and swinging the tennis racquet helps promote rotation leading to improved trunk flexibility (necessary for turning, moving in bed). Tennis can also help with moving quickly, changing directions and is a great cardiovascular workout. For people that are unable to play in a game of tennis effectively or safely, simply hitting balls from a tennis ball machine can be fun and allows continued participation in the sport.

**Q: Because of balance concerns, I fear riding a bicycle anymore; but it sounds like any form of exercise is good.**

Dr. Ellis: The research reveals benefits of cardiovascular exercise for people with Parkinson’s disease. However, no one specific type of cardiovascular exercise is known to be better than any other type. Therefore, participating in any form of cardiovascular exercise, such as riding a bicycle, walking, dancing or swimming can be beneficial.

**Q: My Question has to do with exercise intensity. Dr. Alberts' study on forced exercise facilitated through tandem stationary cycling indicated that high intensity training is effective in combating the symptoms of Parkinson's. In contrast, Dr. Shulman at the Maryland School of Medicine recently presented the results of a study she conducted which included treadmill walking and Parkinson's that indicated that low intensity training was more effective than high intensity training for people with Parkinson's who want to improve their gait. In interviews on the study, she seemed to indicate that low intensity training of all kinds, not just treadmill walking, is generally the most effective for all people with PD. Could one of the panelists compare and contrast these two studies and the seemingly contradictory messages?**

Dr. Ellis: This is a great question! During the past decade, we have seen a growing number of studies that show the benefits of exercise for people with Parkinson's disease. However, what we don't have is enough information on the type of exercise and the *amount* (or the dose) of exercise that is most beneficial for people with Parkinson's disease. Many of the exercise studies in humans and in animal models seems to suggest that high intensity exercise leads to better outcomes compared to low intensity.

Dr. Shulman's study suggests that low intensity exercise may be more beneficial. This gets back to the issue of how we define intensity. Dr. Shulman's high intensity group walked on a treadmill at faster speeds but for only 30 minutes at a time; whereas the low intensity group walked at slower speeds but for 50 minutes at a time. Perhaps longer *durations* of exercise led to better outcomes – some define longer duration as "higher intensity". Your point is an important one and is an issue we will be studying in greater depth in the upcoming months and years.

**Q: I have just had spinal surgery. I get very tired when walking any distance. My spinal surgery turned out very good. I had severe pain for three years, and now that pain is gone. I was diagnosed with Parkinson's in Sept. My neurologist stated that I was in advanced stages. I find it very hard to exercise. Will slow walking help?**

Dr. Ellis: Some exercise is better than no exercise. Exercise that you can do safely and effectively is likely to be helpful. Walking has been shown to be beneficial for people with Parkinson's disease and is a great choice of exercise. The pace of walking needs to be adjusted for each individual depending on their capabilities, and slow walking can still be valuable.

**Q: Does Exercise Slow the Progression of Parkinson’s disease? How can intense and strenuous exercise helps PD patients with motor control and balance?**

Dr. Ellis: Exercise studies in Parkinson’s animal models suggest that exercise may be *neuroprotective*, or slow the progression of Parkinson’s disease. Animals that participated in vigorous exercise had improved Parkinson’s symptoms, which were associated with changes in the brain. It seems that the exercise reduced the vulnerability of dopamine neurons so that they were more likely to remain viable. This effect may be explained by an increase in a *glial-cell line derived neurotrophic factor* (GDNF) protein in the striatum of the brain. Some studies in animal models reveal an increase in the release of dopamine. Other studies reveal that exercise may suppress the expression of the dopamine transporter – therefore increasing the available of dopamine for use by the motor system.

The results of these exercise studies in Parkinson’s animal models are quite exciting and hold much promise. However, we don’t know if these results apply to humans. It is difficult to study the possible neuroprotective effects of exercise in humans with Parkinson’s disease because we don’t have sensitive enough tests to measure the changes that may occur in the brain of living human beings. There is a great deal of research that is focused on identifying sensitive tests to better measure disease progression. These tests will help us answer important questions in future studies.

**Q: For years, I was a road cyclist. Is there a way to know that my balance is still good enough to ride my road bike, or am I limited to recumbent tadpole trikes?**

Dr. Ellis: The recumbent tadpole trike is a great alternative to a road bike, but it’s not a foregone conclusion for everyone. Some people with Parkinson’s disease are able to ride a road bike, and others are not. This is not something you want to try alone. I would recommend getting a consult with a physical therapist that could conduct a thorough assessment of your balance and recommend the most optimal biking option for you.

**Q: Is there research or the possibility that exercise will help slow progression in a person living with PD who has been diagnosed for a number of years versus newly diagnosed?**

Dr. Ellis: Given that we don’t have enough information about whether exercise is neuroprotective in humans with Parkinson’s disease, we don’t know whether any neuroprotective effects would apply to early versus late stages of the disease.

**Q: How much exercise is required to slow or stop the progression of the disease, and what is the level of exercise that must take place to be neuro-protective?**

Dr. Ellis: Given our limited understanding of the neuroprotective effects of exercise in humans, we don't know how much exercise is needed. However, the research reveals many other benefits of exercise, which suggests that there are many reasons why people with Parkinson's disease should engage in exercise!

**Q: Can one induce what is called forced exercise by riding a stationary on their own at >80 rpm for 40 min. Is it the speed or movement that is important? How long is the positive effect of the exercise likely to last after one stops an exercise session?**

Dr. Ellis: It is generally difficult for people with Parkinson's disease to sustain riding a bike for long periods with a cadence of 80 rpm or more. This is because repetitive movements often become slower and smaller. In the absence of a trainer or a mechanical bike that would allow this, using a metronome as an external cue can help people with Parkinson's disease sustain a set rate (to prevent slowing down). Turn the metronome on, set the cadence to 80 rpm, and give it a try.

In the study by Dr. Alberts, he demonstrated that the effects of an 8-week biking program (three times per week) lasted for four weeks after the program had ended – although the effects at four weeks were less than the effects right after the program had ceased. Typically the effects of exercise taper off if the exercise is stopped. This is why it is so important to keep exercising over the long-term.

**Q: I purchased the Theracycle motorized bike and do notice an improvement in symptoms.**

Dr. Ellis: The Theracycle provides a mechanism for people with Parkinson's disease to participate in biking. It makes it easier to pedal while still reaping the benefits of exercise.

**Q: I had DBS (both sides) in 2008. For about the past nine months, I have walked around a lake (7 miles) 107 times. Is it affecting my brain's dopamine production?**

Dr. Ellis: Wow! This is a lot of walking! There is evidence in Parkinson's animal models that suggests the exercise increases the release of dopamine making more dopamine available for the brain to use. Hopefully, you are experience the positive effects of exercise!

Seems to me that Davis's aggressive exercise may very well have forestalled his PD. Epidemiological studies have demonstrated that adults who participated in vigorous exercise had a significantly reduced risk of developing Parkinson's disease. It is unknown

whether people with Parkinson's disease who have exercised vigorously as adults have a slower progression of the disease. This is certainly an intriguing area of study that has important implications.

**Q: Can a person, especially a PD patient, exercise too much?**

Dr. Ellis: There is some research in Parkinson's animal models that suggest a detrimental effect of too much exercise. However, the amount of exercise necessary to have detrimental effects is excessive, and it is unknown if humans could experience these effects. It is recommended that people gradually increase the amount of exercise they are doing over time. This allows you to assess the effects of exercise on your function as you systematically increase it. It is important to be aware of your response to exercise so that you can increase it if it is too easy or decrease it if it feels too hard.

**Q: I have always enjoyed exercise—running, all sports, and weight lifting. Often when I leave the gym I'm really dragging my butt. Is that bad?**

Dr. Ellis: It can be normal to feel a bit tired or a bit sore after exercising. However, these effects should be relatively short in duration, and it should not be difficult for you to participate in activities throughout the remainder of the day. If you are experiencing a significant amount of fatigue, the exercise may be too much. You could try doing less and see if that makes you feel less tired.

**Q: I overdid it on the bike. My goal was to ride at a setting of 4. One day, I set the resistance to 8 and developed a sore quadriceps. I've been working with a P.T. to figure out how much resistance to use; less seems to be better for me.**

Dr. Ellis: Increasing the resistance from 4 to 8 may be too much of an increase, too quickly. This can result in muscle soreness. Any increase in intensity of exercise should be made gradually to optimize the benefits and reduce risk of injury. Finding the exercise level that is somewhat challenging, but not too challenging, is likely to be most beneficial.

**Q: I believe in the value of exercise. One of the programs I have found most beneficial is a private Pilates class. This is expensive. My doctor actually wrote me a prescription. The question is, how can I claim this on my taxes?**

Dr. Ellis: I am not an expert on taxes, but I am aware that it may be possible to qualify for a tax deduction for medical expenses, if these expenses exceed a particular amount. I would encourage you to ask your accountant or tax attorney about this.

**Q: How do you measure exercise as improving quality of life?**

Dr. Ellis: People with Parkinson's disease may be asked to fill out a questionnaire, or they may be interviewed and asked to respond to a series of questions that are designed to assess quality of life. For example, the questions may ask about overall wellbeing, mobility, communication, emotional status and ability to participate in community activities. People may be asked to respond to these questions before and after participating in an exercise program, with the goal of evaluating changes in quality of life that may be related to participating in exercise. Even without this type of formal assessment, the same questions apply to self-assessment.

**Q: Given that physical education is no longer presented to high school students, isn't that counterproductive for the prevention of the more serious PD experience?**

Dr. Ellis: Eliminating or reducing physical education may have negative consequences for the prevention of many diseases. The benefits of physical activity are well known, and it seems that we need to figure out better ways to get people in our society moving!

**Q: Is there any exercise that affects tremor?**

Dr. Ellis: Exercise will not eliminate tremor, but it may reduce the tremor – at least over the short-term. Exercise seems to increase the availability of dopamine, and this may contribute to a reduction in symptoms. Other ways to reduce tremor include moving the limb with the tremor – because tremors in Parkinson disease occur at rest – any type of movement usually leads to a reduction in tremor. Putting weight on the extremity (leaning an arm on the table or standing with weight on the leg) may reduce the tremor, as well.

# MEDICAL AND SURGICAL THERAPIES

**Q: I take time-released carbidopa/levodopa (50/200 mg) five times per day. I have been told to try to only eat protein either one hour before or after a meal. Does it matter, since the drugs are always in my system? I have some “wearing off” symptoms. What do you advise?**

Dr. Giroux: Protein competes with the absorption of levodopa into the bloodstream and, for some people, can delay the onset of medicine effectiveness. This is especially important if you are experiencing end of dose wearing off or find that some doses do not take effect. Talk to your healthcare provider about your wearing off symptoms, diet and medication regimen.

**Q: How do dairy products respond or interact with Parkinson’s symptoms and medication? It seems like when I eat or drink dairy products, it delays the positive effects of my Sinemet.**

Dr. Giroux: Dairy products contain protein. Protein can delay the absorption of the Parkinson’s medicine levodopa (active ingredient in carbidopa/ldopa or Sinemet) into the bloodstream and brain. The effects of this are more noticeable in people that experience motor fluctuations or wearing off effect prior to the next dose of levodopa. Drinking milk one hour before or after a medication dose may reduce this effect.

**Q: What is the best medication for severe restless leg syndrome?**

Dr. Giroux: There are multiple medicines used for the treatment of restless leg syndrome, and treatment response varies. The dopaminergic medicines, ropinirole and pramipexole are FDA approved for RLS. The anti-seizure medicine gabapentin and narcotics are sometimes used. Be sure to review all your medicines and treatment with your doctor as many medicines can also worsen RLS.

**Q: For those taking a statin for lipid control (elevated cholesterol), is there any reason for those with PD to switch to simvastatin?**

Dr. Giroux: In one study, people treated with cholesterol-lowering statin medicines had a lower risk of developing Parkinson’s disease when followed over five years. The authors cautioned that this does not prove that the drugs prevent the disease. There is not enough evidence to recommend statin therapy for Parkinson’s or PD prevention. Only your doctor can decide if simvastatin is the best drug for your cholesterol control.

Does ropinirole cause pupil dilation? Although not commonly noted or studied, it is possible that ropinirole can cause pupil dilation (a similar dopamine agonist, pramipexole was found to be associated with this phenomenon.)

**Q: What is the correlation between drug half-life and drug effectiveness?**

Dr. Giroux: Half-life is the time it takes for a drug to be reduced by half in body tissue, such as blood. This may not always correlate with the duration of effect for that drug. For instance, levodopa has a half-life of 90 minutes (time for it to be reduced by half in the bloodstream.) However, its effect can last much longer. This is due to the fact that the drug is transported into the brain, taken up by dopamine nerve cells and converted to dopamine, stored and used as needed.

**Q: I never learned to tolerate my CPAP machine. Are there better masks now?**

Dr. Giroux: There are significant improvements in CPAP machines and other sleep apnea devices. Re-evaluation by a sleep specialist can determine if a different device will help.

**Q: Is there any correlation between Parkinson's and the need for a laminectomy?**

Dr. Giroux: Laminectomy is a surgical procedure designed to correct arthritic or other degenerative changes of the spine or vertebral disc. These conditions are distinct from Parkinson's disease. However, the postural changes, involuntary movements and lack of activity experienced by some people with PD can further complicate bony changes from arthritis/degeneration or associated pain.

**Q: My DBS gave me a new lease on life. How long can it help?**

Ms. Farris: Deep Brain Stimulation (DBS) will continue to be helpful in managing motor symptoms for many years, and we have research studies that confirm that the effectiveness of DBS continues at least for the time we have been able to assess the long-term effects (about a decade). DBS has only been available since the late 1990s, so our experience is still rather limited. The benefit of DBS varies as much as Parkinson's varies among individuals. We do know, however, that the motor symptoms of stiffness, slowness, tremor wearing off and dyskinesia are known to be responsive to stimulation for at least a decade. As our experience with DBS grows, so does our understanding of what to expect in the long-term. The motor symptoms that we know will naturally progress in spite of DBS include posture changes, speech and balance problems, gait difficulty and gait freezing. The wearing off phenomenon greatly improves, but it becomes more unpredictable after DBS, due to the complex involvement of the non-motor symptoms. Stress seems to reduce the effectiveness of DBS, so developing good coping skills in times of stress is a very important complementary therapeutic strategy.

**Q: If I have had a stroke at some time in the past, what are my chances of a successful DBS surgery?**

Ms. Farris: The location of the stroke and whether any areas affected by the stroke could impact motor control are questions to consider before having DBS. Typically, if the stroke is in a remote area and not impacting your motor abilities, it is possible to obtain the expected benefit from DBS. Discussion with a surgeon that performs DBS is the best person to review any concerns related to a past stroke. The type of stroke should also be discussed thoroughly before DBS to inform you about any increased risks for brain surgery.

**Q: I'm aware of some of the benefits with having DBS surgery. How long has this procedure been used, and what are the long-term side effects that I can expect?**

Ms. Farris: The first published report about DBS was in 1993; however, DBS has been performed since the 1980s. The FDA approved the use of DBS for Parkinson's disease in 2002. Although initially performed in academic centers, DBS is now available in most metropolitan areas. The long-term side effects are minimal with proper electrode placement and stimulation settings; however, even with appropriate therapy, weight gain and eyelid opening difficulty are the more commonly experienced long-term effects. The other considerations for the long-term include DBS battery replacements, scar tissue around the incisions or wire tracts, and the added risk over the years of living with implanted hardware in the body. The hardware can also break so any abrupt change in symptoms must include an assessment of the hardware. Long-term expectations for DBS in the setting of a progressive condition can also be challenging psychologically as there is only so much DBS can accomplish and maintain when some aspects of the PD continue to worsen that are not responsive to stimulation.

**Q: I spoke with my doctor about DBS and asked if he thought I'd be a good candidate for the procedure. He said not at this time...what are criteria the doctor uses to determine candidacy?**

Ms. Farris: DBS is considered an elective procedure, which in layman terms means that if the procedure will benefit your symptoms and the risks are acceptable when considering the impact of the disease, an individual may pursue a treatment. DBS is now considered standard care for any person with Parkinson's that has any or all the following: intolerable tremor, wearing off, dyskinesia or intolerable medication side effects. Basically, if the PD medication has historically improved motor symptoms but the disease has progressed to the point the medication cannot keep the symptoms under control, a doctor may consider DBS. The person with Parkinson's may be thinking about DBS sooner than the doctor, since they experience the "Parkinson's rollercoaster" on a daily basis, while the doctor might only see the person every 3-6 months.

The impact of disability caused by the disease can only be judged by the person who has it, and the right time for DBS is, therefore, a personal decision.

Centers with DBS expertise go through a process to determine if a person will benefit from DBS. The process typically includes an examination on and off medications to both verify the diagnosis and to assess the benefit that can be expected from stimulation. It is very important to remember that stimulation improves symptoms that are also improved by medication. This information is very helpful to the person who programs the device. Then there is a neuropsychological evaluation and a discussion with both a neurologist and neurosurgeon to review the results of the evaluations. People with bleeding problems are at a high risk for bleeding in the brain during or after the procedure, so the risk must be deemed acceptable by the medical team in order to proceed. Other factors that may disqualify a person include dementia, depression, psychosis, severe impulse control disorder, or active medical condition that may increase surgical risks such as HIV infection or untreated thyroid problems. Living in remote areas that have no DBS expertise available may be a factor in determining if a person can safely manage with DBS.

**Q: I've read about known benefits for the "standard" DBS in the STN. How far have we progressed on DBS in the Global Pallidus for other symptoms?**

We have many studies that show that the subthalamic nucleus (STN) and the globus pallidus (GPi) are both very effective in improving the motor symptoms of Parkinson's. There are individual characteristics that may lean the DBS team toward one target over the other. The bottom line is that each person is considered as a unique case when determining which brain target represents the best option. DBS centers that have expert teams typically determine the brain target after the evaluation has been completed. Since there are a multitude of possible individual characteristics and circumstances, it would be impractical to indicate one brain target as superior based on some sort of general rule.

**Q: I'm a PD patient and have recently been diagnosed with Alzheimer's Disease, which certainly feels like a death sentence. I have been considering Deep Brain Stimulation, but don't know if I would be a candidate for it now [with this new diagnosis]. My neurologist would not answer my question: can you tell me if I could still have the DBS procedure?**

Deep brain stimulation is typically not recommended if significant cognitive problems or signs of dementia are present. However, there are treatments for Alzheimer's disease. Neuropsychological testing can help identify changes in cognitive abilities. The information derived from these tests can be helpful to you and can aid your healthcare team in developing a treatment plan. Ask your doctor if neuropsychological testing would be helpful in your treatment.

**Q: Is Botox helpful in Parkinson’s disease, and can it help with muscle weakness?**

Dr. Ellis: Botulinum toxin (Botox) injections are considered an alternative treatment for *focal dystonias* (abnormal involuntary muscle contractions). Botox is not a treatment for weak muscles; in fact, weakness is one of the main side effects of Botox. Strengthening exercises may help with weak muscles. I would recommend consulting with a physical therapist that could assess the weakness and the implications on physical function. The physical therapist can develop a program to address the specific issues you face.

**Q: Have you heard of Gyro-Kinetics?**

Dr. Giroux: Gyro-Kinetics is a physical treatment in development combining functional movement and massage. Whether this therapy has additional benefits over similar treatments as performed by physical therapist and other exercise specialists is not known.

# SLEEP AND FATIGUE

**Q: You talked about lack of sleep, but did not mention sleeping too much. Can you elaborate?**

Dr. Giroux: Sleepiness, or *hypersomnolence*, can be a problem, especially as disease advances. Some PD medicines, such as the dopaminergic agonists, ropinirole and pramipexole, can also worsen daytime sleepiness. It is important to remember that there are many causes of this symptom, including other medicines and medical conditions, so be sure you're you discuss this with your healthcare provider.

**Q: Davis talks about getting out of the house and participating in life and connecting with people. I have always been active in my community and been a "goer." One of the most frustrating aspects of my PD is that I suffer from extreme fatigue and am not able to do and go to the things I enjoy so much. Some days, I am so fatigued that I can't cook for my family.**

Dr. Giroux: Fatigue, like sleepiness, can be a problem during the day. Talk to your healthcare provider about this problem, as other medical problems and medicines can also contribute to this problem. Review the timing of your medicines and the time of the day that your fatigue is worse to help optimize your medicine regimen. For instance, some people have more trouble in the morning due to the fact that they have been off medication for a significant portion of the night. Treatment of fatigue often requires a multidisciplinary approach. Nutrition, exercise and daily planning can reduce fatigue. A referral to a dietitian, physical therapist and occupational therapist can help in these areas. In addition, the more fit you are the more energy you will have at your best times of the day. Lack of adequate nutrition and hydration will also greatly increase fatigue.

**Q: Please discuss talking in one's sleep: is it a symptom of delusion? Is it OK to ignore it? Is it progressive?**

Dr. Giroux: Talking in sleep may be a symptom of REM Sleep Disorder, a condition commonly seen in Parkinson's. In this condition, people act out their dreams by talking, punching, hitting, etc. This can be a sign of other problems, be worsened by certain medicines, affect sleep quality, and be a safety concern for you or your bed partner. For this reason, it is important to review this problem with your healthcare provider as there are treatments that may be helpful.

**Q: Can people with PD take sleeping pills?**

Dr. Giroux: Most sleeping pills are sedatives and are associated with side effects such as daytime drowsiness, thinking problems, dizziness and walking problems, weakness, depression, tolerance and addiction. There are non-medicine recommendations to help sleep. Ask your doctor for these sleep hygiene tips. Only your doctor or healthcare provider can tell you if they are right for you.

**Q: Do medications affect sleep?**

Dr. Giroux: Medications can affect sleep in many ways. The dopaminergic medicines, especially dopaminergic agonists, can cause sleepiness. Medication-induced *dyskinesia*, or involuntary movements, can also affect sleep. Other medicines used to treat conditions associated with Parkinson's such as depression, muscle spasm, bladder control, and hallucinations can all impact sleep. Because there are many causes of sleep difficulty, be sure to talk to your doctor about your sleep problems.

**Q: Can melatonin help sleeplessness?**

Dr. Giroux: Melatonin is a natural hormone that helps regulate sleep and is also available as a supplement. Research suggests that melatonin is helpful for some sleep-related problems, although its effect in Parkinson's and sleep-related problems is not clear.

**Q: Do dopamine drugs cause vivid dreams and/or night terrors?**

Dr. Giroux: Dopamine medicines can sometimes worsen vivid dreams. It is recommended that you review this problem with your healthcare provider to examine this and other causes.

**Q: I have difficulty sleeping, even with sleeping pills. I have had Parkinsons for nine years. I am 63 and female.**

Dr. Giroux: Sleeping difficulty is a highly reported symptom of PD and a cause of daytime fatigue, mental fogginess and sleepiness. A consultation with a sleep specialist will help eliminate aggravating factors for insomnia, such as sleep apnea.

# NUTRITION

**Q: Are fava beans helpful to replace carbo/levo medication? If so, where can I get them?**

Dr. Giroux: Fava beans, otherwise known as *Vicia faba*, is a green, flat been known to contain levodopa. Both the seed and the pod can be eaten. It can be purchased at specialty groceries in dried, fresh and canned forms. Fava beans contain the chemical levodopa used to treat Parkinson's motor symptoms. The amount of levodopa in fava beans varies tremendously depending on the part of the bean eaten, age of the bean at harvest and growing conditions. Younger, green fava beans and pods have more levodopa than older or dried beans. It is difficult to treat motor symptoms with fava beans because of this variability in amount of levodopa present.

**Q: On the nutrition worksheet it suggests "300mg CoQ10 with 200 IU vitamin E four times a day." Does that mean 300mg CoQ10 four times a day or just the Vitamin four times a day? What is the status of CoQ10 research?**

Dr. Giroux: New results have become available since the printing of this worksheet. Research results announced in Spring 2011 did not show a benefit of CoEnzyme Q10 in Parkinson's disease. Talk to your healthcare provider about this and any other supplements you may be taking.

Editor's note: The Nutrition Worksheet has been updated as of July 5, 2011 to reflect the latest recommendations, which do not include CoQ10.

**Q: A recent article I read suggested that older people in general (without Parkinson's) need more protein and to spread out that protein more evenly throughout the day, rather than loading up primarily at the evening meal. However, people who take frequent doses of levadopa sometimes have difficulty timing their protein intake so that it doesn't interfere with the medication. Does the general recommendation apply for people with Parkinson's? Also, would creatine supplements help increase muscle strength? So many people feel a sense of fatigue that they relate to weakness. Perhaps the muscles are not getting the quantity and timing of protein needed for maintaining muscle strength. Is there any research on these points specific to PD, and could you comment?**

Dr. Giroux: Protein is needed for many reasons, including muscle development, cell growth, immune function and energy metabolism. Older people usually have less total body muscle, and therefore, fewer protein stores in their body. This may be one explanation for an increased protein need in the elderly. "Spreading out" the intake of

food improves the absorption and utilization nutrients; however, this may be difficult for a person with Parkinson's disease who is experiencing motor fluctuations or "off" times. This is due to the fact that protein can delay the absorption of levodopa, a medicine commonly used to treat movement problems. Since there is tremendous variability in dietary needs from one person to the next, a nutritionist can help sort out the timing and daily protein needs for an individual.

*Creatine* is produced by our bodies and also is available as a nutritional supplement. Creatine plays an important role in muscle and nerve cell energy production. A multicenter research study is investigating the effect of creatine on Parkinson's disease progression, possibly through its impact on mitochondria health and its antioxidant effects. The direct effect of creatine on muscle mass and strength in Parkinson's is not clear; therefore, more research is needed before this supplement can be recommended. Creatine does have side effects, so it is important to talk to your healthcare provider about this and any other supplement you are taking.

**Q: If you want to take a fish oil supplement, what dosage do you recommend as a daily dietary supplement?**

Dr. Giroux: The active ingredients are fish oil is DHA and EPA. Some experts recommend 1000 to 2000 mg total DHA and EPA per day. However, the full benefits and side effects of fish oil are not yet certain, so be sure to talk to your doctor before taking this or any other supplement.

# SYMPTOMS

**Q: I have two major problems with Parkinson's: the first is dystonia (like a charlie horse in various parts of my body, including back, diaphragm, arm pit and ribs); the second is hypersensitivity to environmental factors like wind, temperature extremes, crowds, noise. I walked normally into a long, full house musical production and had to be wheeled out in a wheelchair! I had to have water poured on my head to cool me down!**

Dr. Giroux: Each person experiences symptoms differently. *Dystonia* is an involuntary contraction of muscle that often leads to twisting, bending and painful muscle spasm. Dystonia and sensory symptoms can be experienced in the "off" state when the effect of medication is wearing off. These symptoms can also occur at other times, and there is significant variability in symptoms and treatment from one person to the next.

**Q: I'm having more trouble walking. I have had PD for eight years; will this keep getting worse?**

Dr. Giroux: It is important to remember that there are many causes of walking problems as Parkinson's advances. Other medical conditions and deconditioning can also cause walking problems. Work with your doctor to be sure that all possible causes of walking difficulties are identified. Let your doctor know if your walking worsens before your next dose of medicine is due, at the end of the day when you are tired, or if walking is always a problem. This can help your doctor review your medicines to be sure they are optimized. It is very helpful to see a physical therapist to work on walking and balance issues. An occupational therapist can also help keep you safe by reducing your fall risk.

**Q: I am starting to have balance issues. Sometimes standing still, I will start to fall backwards or maybe sideways. At a recent visit with my neurologist, I mentioned it and he had me close my eyes and stand still, and I did not fine. He said I was "chasing my center of gravity." What should I be doing to be aware of keeping my center of gravity? I have an interest in Tai Chi, but am concerned that I would fall on my face.**

Dr. Ellis: It is common for people with Parkinson's disease to experience problems with balance. This is an important issue to address, as a decrease in balance can lead to falling. There are some things you can do to improve balance. Some strengthening exercises and balance training may help to improve balance. In addition, learning strategies to help avoid falling could be beneficial. I would recommend that you consult with a physical therapist in your area that has expertise in working with people with

Parkinson's disease. The physical therapist can teach you the exercises and strategies to help improve your balance. He/she can also tell you whether Tai Chi is appropriate for you or not, given the specific types of problems you are experiencing.

**Q: What is the best way to manage my elevated weight given I am menopausal and post DBS?**

Ms. Farris: With many causes of weight gain, eliminating those factors that contribute to the extra weight is a practical approach that typically works better than fad diets or fickle exercise plans. A well-rounded diet that is high in soluble fiber and variety, combined with long-duration or frequent, shorter bouts of physical exercise that includes strengthening will help you to shed pounds as you burn more calories than you consume. Your meals should be colorful and antioxidant- and nutrient-rich. Getting enough protein is a challenge that most people with Parkinson's experience, so a visit with a dietician may be helpful. Eliminate simple sugars and as many processed foods as possible, as this will reduce overall empty calories. Monitor your calorie consumption of fats and carbohydrates; seek out complex carbohydrates to help keep energy levels high while moderating blood sugar fluctuations. This all sounds so easy, but it takes time to see meaningful weight loss and to experience fully the rewards of a healthy weight management routine. Eventually, these lifestyle changes will become a habit that positively impacts your health and the way you feel.

**Q: My husband does not seem to be able to make up his mind on what to do, i.e. completing a project takes him a long time because he cannot decide on the method, color, etc. Is this a side effect of the medication, a symptom of Parkinson's or both?**

Dr. Giroux: Projects can take longer for many reasons, including difficulty with movement and dexterity and trouble with the cognitive or thinking requirements of the task, such as the ability to multitask and follow complex instructions or steps. Medications can also cause these difficulties, so talk to your healthcare provider about your concerns.

**Q: I'm having much pain in my abdomen by grabbing or trunk flexion. Is this common? It's difficult to exercise with the pain and cramping.**

Dr. Giroux: Dystonic pain is common in PD and can occur in various muscles in the body. Abdominal pain in a person with Parkinson's disease has many causes one of which can be truncal dystonia. This is a sometimes painful contraction of the abdominal surface muscles. Dystonia often worsens with activity. Changes in Parkinson's medicine, change in dosing or botulinum toxin injections can sometimes help if abdominal muscle dystonia is determined. Review with your doctor as other gastrointestinal problems can also cause abdominal pain with activity.

Dr. Ellis: I recommend discussing these symptoms with your Parkinson's doctor. You may be experiencing dystonias (abnormal involuntary muscle contractions) in the trunk muscles which can be uncomfortable. Many of the medicines used to treat Parkinson's disease are effective in improving dystonias and may help reduce the cramping and discomfort. Botox is sometimes considered to treat dystonias when they are limited to a particular muscle group. You should discuss your symptoms and all the treatment options with your Parkinson's doctor to decide which is best for you.

**Q: Can lightheadedness and dizziness be a PD symptom?**

Dr. Giroux: Lightheadedness and dizziness can be signs of orthostatic hypotension, or low blood pressure when standing. In this condition, blood pressure decreases with change in posture such as sitting to standing due to change in gravity and loss of your autonomic nervous system's ability to protect against these changes. Other causes of lightheadedness include, but are not limited to, cardiac problems, medicines, dehydration, imbalance, and inner ear problems. Discuss this problem with your healthcare provider as these problems can lead to walking problems, falls, and fatigue.

**Q: I am 67 I was diagnosed 4-1/2 years ago. My toes curl inward only for about an hour each morning when I wake up. I can't walk during that time. Anything I should or can do about this?**

Dr. Giroux: Early morning foot *dystonia* is a condition described a painful muscle cramping associated with toe curling or "pulling on the foot muscles." This is sometimes experienced as an "off"-related symptom, that is, a re-emergence of symptoms at times when medication levels are low such as first thing in the morning. Talk to your doctor about this symptom, your medication regimen and timing.

**Q: I have developed apraxia of my eyelids. Is it unusual for people with Parkinson's to develop this, and is there a treatment?**

Dr. Giroux: Eye opening apraxia is one of two problems with eye closure seen in Parkinson's disease. *Eye opening apraxia* is a difficulty in opening eyelids after closure. It is more common in forms of atypical parkinsonism, such as Progressive Nuclear Palsy and less commonly seen in Parkinson's disease. STN DSB stimulation can sometimes cause eye opening apraxia. *Blepharospasm* is more commonly seen in PD and is a closure of eyelids due to involuntary contraction of the eyelid and adjacent muscles. Botulinum toxin injection into the eyelid muscles is sometimes helpful for these conditions.

# EMOTIONAL SUPPORT

**Q: I have found that people are receptive initially, but as you and your Parkinson's progress, they really get "tired" of the PD. Do other people have this experience? What can you do?**

Dr. Giroux: First, set goals for yourself. Think about something you really want to do, but find challenging. When you reach your goals, you have something very positive to focus on and to share with those around you. Unfortunately, PD has many ups and downs, and it is easy to focus on what you *can't* do. Setting positive goals and working toward them will refocus the attention on what you *can* do, versus what you can't. Then celebrate! Everyone enjoys celebrating accomplishments.

**Q: Most people I encounter are extremely supportive and encouraging about PD, but there are people whom I encounter on a regular basis that do not believe I have been diagnosed properly (suggest I have Lupus, Lyme's Disease, etc.) and express their feelings outwardly that I should see another doctor. Fortunately for me, I have had PD for 12 years and am not progressing rapidly. However my symptoms are progressing gradually, as is the amount of medication I take daily. These doubters do not see me attempting to roll over in bed, or trying to get up from a soft couch or walking across the room when I am half an hour late taking my medication. I wish I were quicker with a humorous response. Instead I am overwhelmed and do not respond at all. Do you have any suggestions?**

Dr. Giroux: A counselor can help you work through these and other concerns you may have. It is often difficult to talk to people about symptoms and describe how you are feeling with Parkinson's. Let them know that you appreciate their concern, but are confident in the care and treatment you are receiving from your healthcare provider. You may find it helpful to use this as an opportunity to educate by discussing the symptoms of PD, the variability between one patient and the next and the fact that your symptoms also vary from one time of day to the next. Talking to other people with PD to explore how they have handled similar situations can also help.

**Q: Is it common for young-onset Parkinson's patients to want to try to go it alone on doctor visits? I've wondered if [the person with Parkinson's] is trying to stay as autonomous as possible and is excluding me as a part of his [effort to maintain] control.**

Dr. Giroux: Seek out a Parkinson's specialist in your region. Almost all major cities have specialists. This may require traveling a couple times a year for treatment updates, but may be worth it in the long run if you are not having success with your current physician.

**Q: I am struggling with the decision of when to tell those outside of my immediate family, my close circle of friends and a few of my co-workers about my PD. My concern is that once I "out" myself, others will look upon me differently and pity me, which is the last thing I want. Yet, hiding my symptoms can be difficult and creates unnecessary anxiety/stress. Any advice on how opening up about my condition can be made easier would be appreciated.**

Dr. Giroux: Many people with Parkinson's disease struggle with this situation, and it is impossible to know what others are thinking unless you open up the discussion. Many times, just talking about something is a great relief, and you may find that those close to you may already suspect something is affecting you. Every person's situation is different, so it is difficult to give specific advice. It may be helpful to talk with a professional such as your doctor, a counselor or social worker. Begin by asking for a referral from your doctor or healthcare provider. Talking with other people with Parkinson's can also help, because they can share their own experiences.

# RESEARCH AND CAUSES OF PARKINSON'S

**Q: Is one type of research better to engage in than another, i.e. pharmaceutical vs. university or NIH-driven?**

Dr. Giroux: Both types of research are important to the care and understanding of Parkinson's disease. Pharmaceutical trials are necessary to gain FDA approval for drugs and bring safe and effective treatments to the market. NIH and other funded trials help bring treatments to the market, but also focus on the science and biology that leads to a better understanding of the disease, its cause, and avenues of exploration for treatment. One size does not fit all, and the type of research you explore may depend on how accessible the location is or on requirements such as frequency of research visits.

**Q: What is the probability of winning the overall fight with Parkinson's and rolling the clock back to restore some of the pre-Parkinson's abilities of the body? Or, are we doomed to a life that doesn't get any better—or any worse?**

Dr. Giroux: Parkinson's disease is a progressive disorder, meaning that it does worsen over time. However, the rate at which it changes varies from one person to the another. In addition, how you feel with PD is often a combination of the disease, your emotional well-being, your physical fitness level and your general health. Therefore, attention to preventative medicine, lifestyle choices such as a healthy diet, exercise and stress management can improve how you feel and reduce the effects of symptoms on your body. In addition, research is exploring treatments that are *neuroprotective*, that is, treatments that slow disease progression by protecting vulnerable nerve cells from future damage or cell death. Studies involving the neuroprotective effect of medications, exercise, and gene therapy are some examples of the types of trials that are currently underway.

**Q: What role does genetics play in Parkinson's disease? I have two half-brothers on my father's side, and both of them have developed PD. My father died at an early age (50) back in 1955 before there was much talk about the disease, and I do not think he had any of the symptoms. I have tremors in both hands at times and wonder if I might be at risk of getting this disease, too.**

Dr. Giroux: Parkinson's disease appears to be caused by multiple factors, including genetics and exposure to environmental toxins. The risk of developing Parkinson's disease is estimated to be 2.5 to 3.7 times greater in first-degree relatives (sibling, parent, child) of a person with PD. However, this is not the case for half-siblings, because a set of genes are inherited from both parents (one of which you do not share). It is important to be evaluated by a neurologist, as there are many causes of tremor.

**Q: What do you think about the clinical trials involving cycling at a cadence of 90 rpms and the resulting decrease in symptoms? I purchased the Theracycle motorized bike and do notice an improvement in symptoms.**

Dr. Giroux: Exercise is beneficial for your general health, fitness levels, stamina, balance, and emotional wellbeing. Research is also investigating the possible neuroprotective effects of exercise (can exercise protect vulnerable nerve cells from future cell death). One of the problems of analyzing the effect of exercise on symptoms is that it is difficult to know how you would be feeling or managing if you did not exercise since Parkinson's progresses differently for different people. Although the cycling research is promising, it is important to note that other forms of exercise may also be helpful and we need further study to make specific recommendations. Tennis can help your balance, agility, and as a sport can be fun, socially engaging and challenging.

Bottom line, exercise can help stamina, mood, confidence, energy, cardiovascular health, diabetes and weight management, balance and agility, flexibility, pain control and maybe even Parkinson's progression. It is important to choose an exercise or activity that is safe, accessible, enjoyable, challenging and that you will do over time. Ask your doctor about a physical therapy evaluation to optimize your results and minimize injury.

**Q: What does the latest research show regarding the benefits of tandem cycling for PD?**

Research done by Dr. Jay Alberts has shown that cycling at high rpm (80-90) and keeping your heart rate within 60-80% of your maximum heart rate for an hour, three days a week for eight weeks results in a 35% reduction in PD symptoms. I have nearly eliminated my symptoms and reduced my medication in half through this cycling program. Would you please comment?

Dr. Ellis: People with Parkinson's disease often produce slow and small amplitude movements that can limit their ability to exercise at high rates. Dr. Alberts studied the effects of augmenting voluntary exercise by using a tandem bike where a trainer on the front of the bike set the pace and the person with Parkinson's disease on the back of the bike was "forced" to keep pace, resulting in faster movements. His study revealed significant improvements in motor function in those participants with Parkinson's disease who rode the tandem bike with the trainer (forced exercise) compared to participants who rode a stationary bike without a trainer (voluntary exercise). Dr. Alberts speculated that the improvement might be associated with altered patterns of neuronal activity in the brain or possibly an increase in neurotrophic factors. He is conducting additional studies in larger groups of people with Parkinson disease to investigate these findings further.

**Q: What do you think about the clinical trials involving cycling at 90 rpm and the resulting decrease in symptoms?**

Dr. Ellis: I think that the results from Dr. Alberts' study are exciting, and I am looking forward to more studies in this area. This is a great way to take what we have learned from exercise studies in Parkinson's animal models and apply it to humans.

**Q: After listening to Holly Shill, I wondered if there has been any work done regarding TMJ manipulation to alleviate Parkinson's systems. I have been following Jo Rosen (Parkinson's Research Organization) who thinks that this is a very viable treatment. It just seems to make sense.**

Dr. Giroux: TMJ therapy is helpful in relieving pain and discomfort that can accompany disorders of the jaw and TMJ joint. However claims as to the benefit of TMJ manipulation on Parkinson's symptoms need further study using placebo control blinded studies. Talk with your neurologist about current treatments and research.

**Q: I would like to know if there is any evidence that Parkinson's disease is infectious. Is it possible for for a person with PD to give the disease to his wife and children?**

Dr. Giroux: Parkinson's is not contagious and cannot be transmitted to other people. Parkinson's disease is likely caused by many factors, including genetics and exposure to environmental toxins. The majority of people have sporadic Parkinson's disease and do not have the genes known to be associated with Parkinson's disease.

**Q: I have PD, but also take cortisone shots in lumbar #4 every three months. What kind of exercise can I do without one hurting the other?**

Dr. Giroux: A physical therapy evaluation is recommended to tailor an exercise program to your needs and reduce risk of injury, given the fact that you have Parkinson's disease and spine disease. Your healthcare provider can give you a referral to get you started.

**Q: As an occupational therapist and head of a group trying to form an interdisciplinary team for people with Parkinson's, we would like to be involved in research from the very start. Where do we start? Are there any specific questions you are looking at addressing? We have physical, occupational, neurologic music, speech, nutrition therapist and social work as well as a rehab nurse/counselor and a support group and at least a twice a month exercise group. Thanks for ANY advice!**

Dr. Giroux: Contact your local university and start networking with the departments that interest your team. Also contact any local foundations to review the needs of your own community.

**Q: Is it common for the PD patient to crave sugary foods? My husband's appetite has diminished considerably, but he craves candy, cakes, ice cream, etc.**

Dr. Giroux: Many people with Parkinson's describe a craving for sweets. The cause of this is not clear, but include change in sense of taste, impulsivity control problems such as seen with binge eating, greater accessibility, and even potential mood altering effects such as seen with chocolate (one study did show people with PD ate more chocolate). It is important to get a balance of nutrients, and this is especially important when a person's appetite is decreased. Your healthcare provider or nutritionist can be a source of guidance.

**Q: Is dementia inevitable with PD? How can it be managed?**

Dr. Giroux: Cognitive problems range from difficulties with executive function, slowness in thinking, altered visuospatial skills, and word finding problems. Dementia is an advanced form of cognitive difficulty that has a significant impact on daily function. Accurate estimates are not available but research suggests that 20-30% of people with Parkinson's experience dementia. Neuropsychological testing can help define the degree of cognitive problems and diagnose dementia and related cognitive difficulties. Medication, depression and other medical conditions can worsen thinking problems so be sure to talk with your healthcare provider about this concern. There are specific medicines used to treat cognitive difficulties in dementia. Non-medical therapies that can help reduce the impact or progression of cognitive change as we age include exercise, staying socially engaged and intellectually challenged. Dementia risk increases as we age, with or without PD.

# SAFETY

## **Q: How does one make the house safe for a person with Parkinson disease?**

Dr. Ellis: Some of the ways to make the house safe for someone with Parkinson's disease include reducing the number of obstacles and minimizing clutter. People with Parkinson disease generally have less difficulty with walking in clear, open spaces. Using chairs with arm rests often helps with getting out of chairs. People with Parkinson's disease tend to have difficulty multi-tasking or doing several tasks at a time – this can compromise mobility. Minimizing doing other tasks while walking can help increase safety. You can ask your doctor to write a referral for a physical therapist to come to your home to assess safety. The physical therapist can make specific suggestions to help you optimize safety in your home. Optimizing safety may include changes to the home environment but will also include strategies to optimize mobility (walking, getting out of bed, turning to change directions, going up and down stairs etc.).