Living with PD

For people with Parkinson’s disease (PD), managing the disease often comes down to a daily balance of dopamine — the neurotransmitter that is lost in PD. The challenge is to work with dopamine replacement therapies to find the right levels of dopamine. Dopamine medications have improved life for millions of people, but researchers believe that some people with PD on these medications can develop impulse control disorders (ICDs) — unhealthy levels of gambling, shopping, eating and sexual activity.

What are Impulse Control Disorders?

An impulse control disorder is the inability to stop doing something that is harmful, or could become harmful, to yourself or others. Performing the harmful activity is believed to relieve anxiety and tension.

How Common are Impulse Control Disorders?

Scientists have known for over a decade that dopamine-related drugs for Parkinson’s could be linked to ICDs in some patients. However, it was not until 2004 that people living with Parkinson’s began to learn that ICDs could be a rare side effect of dopamine agonists. Today, we know that one in six people taking dopamine agonists will experience impulse control disorders.

How Serious are Impulse Control Disorders?

For some people, ICDs may be mild, or just a minor nuisance (for example, increased focus on eating sweets). For others, the impact may be more severe. People who experience compulsive gambling and compulsive shopping may lose large sums of money, even to the point of bankruptcy. Those who binge eat may experience significant weight gain, causing discomfort and embarrassment and possibly increasing vascular disease risk factors. Some of those who experience compulsive sexual behaviors may begin engaging in unprotected sex or sex outside of an established relationship, placing themselves and others at risk physically and emotionally. ICDs typically impact not only the person living with PD, but loved ones as well.

What should I do if I suspect I have an ICD?

- Keep a drug diary and record changes in your mood or behavior, as well as physical responses.
- If you find yourself starting to engage in any of the behaviors listed above or doing things that you feel guilty doing, talk to someone about it. A support group member, your doctor or someone from your place of worship are potential resources.
- Let your family know what is happening, because the problem affects them too. ICDs could be a significant stressor on a marriage.

If the doctor determines that you have a medication-induced ICD and the medications in question are dopamine agonists or monoamine oxidase (MAO) inhibitors (ex. Pramipaxole, Ropinirole, Rasagiline, Rotigotine patch), the doctor can work with you to reduce your dosage or switch to another medication.

ICDs usually subside for people who clearly did not experience the ICD previous to that time and developed it in the context of taking a dopamine replacement therapy for Parkinson’s. There is a much smaller subset of people for whom ICDs persist despite the discontinuation
of medications. There is another subset of individuals for whom going off a medication is not an option. Perhaps their Parkinson’s symptoms are too severe, or they are receiving psychological benefit from the medication. These individuals have other options. People who have significant motor fluctuations and have lived with PD for several years may be candidates for deep brain stimulation (DBS) surgery. Since a person can typically decrease his or her medications after DBS, this often will ease his or her ICD. A few other strategies have been explored, such as use of antidepressants, but there is little evidence at this point of their efficacy. Scientists are also investigating novel treatments to resolve ICDs but the evidence on these strategies is limited at this point.

**Should people with Parkinson’s be concerned about their risk of developing ICDs?**

It is now confirmed that dopamine agonists are associated with impulse control disorders. Data from the U.S. Food and Drug Administration and many other sources support this association. The large incidence (1:6) of impulse control disorders has been strongly associated with the use of dopamine agonists and should prompt practitioners to warn patients and family members about these issues. Remember, an impulse control disorder may be pleasurable, and therefore patients may hide the issue from friends and family. A prospective monitoring plan should be initiated along with the dopamine agonist therapy. The safest plans involve spouses, caregivers and friends who can provide feedback on any change in behavior directly to the prescribing physician. Remember, a person with Parkinson’s must consent to a prospective monitoring plan is necessary before implementation.

Call our Helpline for more information at 1-800-4PD-INFO (473-4636).