Hello, Life? Anissa Mitchell, LCSW

While everyone’s experience in life is different, we are alike. We go about our lives and suddenly something puts a roadblock in our path and it changes our plans or course. That roadblock could be a job loss, a death, an unexpected pregnancy, an injury… or a diagnosis of Parkinson’s disease. We all experience interruptions in the program of our lives and sometimes it’s for a long-term and serious reason. How we deal with it is our own unique experience. We have all likely heard about the five stages of grief and that everyone processes these in different ways and in a different time-frame. But, eventually we all have to move out of denial, anger and take ourselves out of “park” and start life as it is now, accepting where we are, what we are faced with and decide how we proceed from here.

In 2013, I had a speaker at our annual Parkinson’s conference, The Brain and Beyond, by the name of John Bauman. John is an attorney who had a very lucrative practice and was diagnosed in his 40s with Parkinson’s. Because of this “roadblock” John was faced with the need to change how he was doing life. It wasn’t easy, but John states that he is healthier now with Parkinson’s then he was before the diagnosis. John made a decision about his life where it was at that moment and he not only decided on success in living, but wrote about it (check out his book “Decide Success” in the Parkinson’s library). While he is not working the same type of job, he has become an inspirational speaker traveling around the country and sharing his story about how he handled the sudden new direction his life has taken him and capitalized on it.

Gandhi said, “Live as if you were to die tomorrow”, meaning make the most of the moments you have today because none of us are guaranteed the next. But, when we are faced with life-changing circumstances, we often feel overwhelmed and immobilized. Most of us like direction, solutions, and bullet-point lists of tasks to help us deal with life’s difficulties. We are looking for the “what can we do” answers. There are many helpful things that can be done to make life better living with Parkinson’s. You already know these: exercise, eat well, stay active socially, manage stress, take your meds on time, etc. But have you really thought of the other side of your life? The how do I live; the “being part? What purpose does my life have and how do I live it meaningfully now that I have Parkinson’s or I’m caring for someone who does?

These questions offer an opportunity to reset priorities, reframe your expectations and focus on those things that have the most significance in your life. One of the benefits of having to stop and slow down (literally), is that you have more time to experience fully the moment. Time to actually hear what people are saying, see what others are missing as they quickly pass by, and spend time with people you really cherish. I have heard people say that getting Parkinson’s was a gift of sorts because they now have more time to do the things that really matter at the end of life—whether that is tomorrow or twenty years from now. There is a saying that “At the end of life, what really matters is not what we bought but what we built; not what we got but what we shared; not our competence but our character; and not our success, but our significance. Live a life that matters. Live a life of love…” Author Unknown

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Check out: Johnbaum.com
We all want a meaningful life, but many get stuck in a rut of anger, depression, apathy and confusion. Making the choice to engage in life can actually be challenging when you are tired, sad or just don’t care anymore. Parkinson’s can also change relationship dynamics making it difficult to interact with loved ones the way it was before the disease. If you are struggling with moving forward then maybe talking with someone is the work you do to choose living over just existing. Maybe you force yourself to join a group, start a new hobby, try out a new restaurant, play with kids or grandkids, or learn a new skill. Say hi to a stranger, hold hands watching a sunset with your favorite person. Find moments with meaning. Just. Find. Something… to help yourself move forward and embrace this life you have. It is still there, but only you can determine how it will be meaningful and still enjoyable.

“I break tradition, sometimes my tries, are outside the lines.
We've been conditioned to not make mistakes, but I can't live that way.
Staring at the blank page before you
Open up the dirty window
Let the sun illuminate the words (or life) that you could not find.

Reaching for something in the distance
So close you can almost taste it
Release your inhibitions
Feel the rain on your skin
No one else can feel it for you
Only you can let it in
No one else, no one else
Can speak the words on your lips
Drench yourself in words unspoken
Live your life with arms wide open
Today is where your book begins
The rest is still unwritten”.
“Unwritten” Natasha Bedingfield
*(or life) added, not part of original song.

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Visual Disturbances in Parkinson’s Disease

Parkinson’s disease (PD) is a complex neurological disorder due to deficiency of dopamine. Dopamine pathways are located in multiple areas in the brain including the basal ganglia and brainstem. Both areas project to parts of the brain that control our mobility, mood, thinking process and vision. As result of these anatomical connections patients living with PD may suffer changes in vision. This article will help you to identify and understand some of these disturbances.

Blurry vision could be the result of impaired movement of the eye muscles, and the inability of an eyeball to move at the same time and degree that the fellow eye moves. Low dopamine levels could be the cause of this. The good news is that just like your other motor symptoms, this may improve with the medications you already take for PD.

Dry eyes is another common visual complaint patients with PD may have. PD causes a decrease in the frequency of blinking. This limits the distribution of the tears, and may cause itching and burning sensation. Trihexyphenidyl is an example of a drug used for treatment of PD that could alter visual acuity and moisture. Selegiline, pramipexole, ropinirole, levodopa/carbidopa are examples of other medications commonly used for PD that could cause visual side effects.

Poor visual acuity could be the result of both blurry vision and dry eyes. Because the retina also has dopaminergic cells, the loss of these cells may cause poor vision, and limited color perception.

There are other visual disturbances seen as result of PD, but they are the result of changes in the visual cortex in the brain (not in the eyes). Depth perception, visual-spatial orientation, face recognition and visual hallucinations are some of them.

Apraxia of eyelid opening and blepharospasms are two disorders of the eyelids that can affect the vision. Apraxia of eyelid opening causes inability to voluntarily open the eyes. The eyes close involuntarily for several seconds or minutes and resolves spontaneously. Blepharospasm is a disorder in which both eye blinks forcefully multiple times per minute. Both conditions can impair the vision and quality of life if not treated.

Many visual changes patients living with PD could be secondary to the disease process or the use of drugs to control PD symptoms. Having a thorough eye examination by an ophthalmologist or neuro-ophthalmologist (subspecialty that combines Neurology and Ophthalmology) is recommended to identify and treat correctly problems with the vision.

Dr. Sheila Baez-Torres is a fellowship trained movement disorder specialist with Florida Hospital Medical Group. To schedule an appointment with her, contact 407-303-6729

Algorithm encompassing clinical and genetic factors predicts PD

Researchers have devised a model that distinguishes patients with Parkinson’s disease (PD) from those without the condition without relying on motor features. The algorithm can be administered remotely and “at a fraction of the cost” of dopamine transporter scanning, say researcher Andrew Singleton (National Institutes of Health, Bethesda, Maryland, USA) and colleagues. The researchers developed their algorithm in the Parkinson’s Progression Marker Initiative (PPMI) case-control study, which involved 367 patients with recently diagnosed PD verified by dopamine transporter imaging and 165 neurologically healthy individuals. Using stepwise logistic regression they removed uninformative variables from a constellation of non-motor features and known PD risk factors. The resulting model included olfactory discrimination according to the University of Pennsylvania Smell Identification Score (UPSIT), family history of PD, age, gender and a composite genetic risk score based on 30 genetic variants. At its optimum cutoff threshold (receiver operating curve of 0.655), the model correctly identified 83% of patients with PD, at a specificity of 90%. “These data show that the integrative model might be most useful to identify Parkinson’s disease in high-risk populations”, say researchers. An exciting area of research that would benefit from more testing using prospective designs that longitudinally follow people classified at baseline as high risk to determine how many develop PD.

Source: news-medical.net
Repurposing FDA Approved Drugs for Parkinson’s

Recently, the exciting potential has emerged that we could identify and use already FDA approved drugs to modify disease progression and to treat Parkinson’s disease. Drugs used for diabetes and anti-malaria treatment have been suggested as disease modifiers in Parkinson’s and perhaps even candidates to improve disease related symptoms. Pioglitazone is a pill that has been used for diabetes and was recently repurposed as a potential Parkinson’s disease therapy. A multicenter study of early Parkinson’s disease therapy has been recently conducted to assess Pioglitazone as a potential neuroprotective treatment. Preliminary data presented recently at the International Movement Disorders Society suggested that the diabetes drug was not effective in Parkinson’s disease. However, despite the findings, it is very inspiring to think that diabetes and other drugs that are already FDA approved for other diseases could be repurposed for Parkinson’s disease.

Another recent approach led to the suggestion that anti-malarial compounds may be useful therapeutic approaches for Parkinson’s disease. A combined research team from Nanyang Technological University (NTU) in Singapore and from McLean Hospital and Harvard Medical School focused on a brain protein called Nurr1. The protein is important in development and maintenance of brain dopamine cells and it may protect the cells from inflammation and from dying. Previous to this research study there were not any drugs known to bind Nurr1. The team screened approximately 1000 already approved FDA compounds and discovered that two anti-malaria drugs (chloroquine and amodiaquine) act at Nurr1 (3). The team has tested the compounds successfully in rats and will soon be pursuing human trials. This collaboration is a great example of using technology to repurpose already existing drugs. Scientists will need to identify potential brain targets and then test for compounds that act on those targets. The hope is that this approach will lead to more rationale and more meaningful therapies, but perhaps more importantly, that these therapies will reach Parkinson’s disease patients at an accelerated pace. Source: Parkinson.org

Inosine Trial Secures Phase III Funding to Study Effect on Slowing Parkinson’s

The Michael J. Fox Foundation’s largest grant to a single investigator thus far awarded $5.6M in 2008 to Michael Schwarzschild, PhD, of Massachusetts General Hospital for a Phase II trial of inosine, a precursor to the antioxidant of urate. Observational studies had shown people with higher levels of urate had lower risk of Parkinson’s disease (PD) and, if diagnosed with PD, slower disease progression. Today Dr. Schwarzschild and his Parkinson Study Group colleagues announced funding from the National Institutes of Health (NIH) to conduct an inosine Phase III trial at 60 U.S. clinical sites with 270 people with early-stage Parkinson’s. Enrollment is expected to begin early next year. The MJFF-funded Phase II study showed that inosine is safe, tolerable and does raise urate levels in people with early-stage PD. The Foundation also funded early preclinical work investigating the mechanism of urate in neuroprotection. MJFF will continue to support this project by funding two small studies — one clinical, one pre-clinical — to assess interactions between inosine and common foods and other medications taken by people with Parkinson’s. “Patients’ greatest unmet need is a therapy to stop or slow Parkinson’s disease,” said Todd Sherer, PhD, MJFF CEO. “There is a large body of evidence to show that using inosine to raise urate levels could impact Parkinson’s progression. We’re glad that The Michael J. Fox Foundation could support this important work at a critical stage and that the NIH is funding this trial to move inosine closer to patient relevance.” The investigators report that urate stimulates brain cells called astrocytes, the first step in a chain reaction releasing another antioxidant and activating a protein pathway. Both may protect brain cells from degeneration. “This new evidence of a more nuanced molecular mechanism for urate-induced neuroprotection boosts our enthusiasm that this will be a truly novel strategy and not ‘just another direct antioxidant’ that will fail to protect the brain cells that degenerate in Parkinson’s,” said Dr. Schwarzschild.

** Inosine is available commercially as a dietary supplement, but patients should act with caution. Inosine has not been proven as a therapy for Parkinson’s, and, in the absence of medical supervision, it can cause serious side effects such as gout, kidney stones and possibly high blood pressure. It is critical to discuss any medications or natural supplements with your physician before taking them. Source: Michaeljfox.org
Get Involved with Parkinson’s Research

At Compass Research we are dedicated to increasing awareness and education about Parkinson’s disease research advancements. Dr. Ira Goodman has made it a priority to stay on the forefront of new and exciting research that can help those touched by Parkinson’s disease. Our studies explore disease modifying treatments, possible prevention of dyskinesias and rapid delivery systems of Parkinson’s medications. All study-related care is provided to you at no cost. If you or a loved one are living with Parkinson’s disease, we encourage you to volunteer. To learn more about our Parkinson’s research studies, please contact us at 407-734-7866 or visit CompassResearch.com

Google Reveals Gigantic Ambitions to Fight Cancer, Diabetes, Parkinson’s, Heart Problems

Google is pumping vast amounts of cash into its cutting-edge life sciences plans, turning a secretive unit based on smart contact lenses into a high powered, expert company. The newly announced business will be entirely focused on the billions of dollars of annual revenues on offer from helping patients with a range of major health issues, from diabetes, Parkinson’s, cancer and heart disease to the general quest to increase comfortable life span. At the head of the new health unit is Andy Conrad, who has an extensive nanotechnology and molecular biology background, and who was head of life sciences at the former Google X research division. Google co-founder Sergey Brin, never one to miss out on a big business opportunity, is determined for the company to position itself at the forefront of the immensely lucrative health tech market in several key areas.

Some 387 million people globally live with diabetes and 10 million live with Parkinson’s. Around 14 million new cancer cases are diagnosed each year, and over 17 million people die annually from heart disease. Supplying the technology to help patients in these areas is seen as both important for society and as a big potential market. The move into healthcare will be aimed at eventual market leadership. It’s also personal for Brin, who is particularly interested in treating Parkinson’s after his mother developed the condition.

Google will work with companies ranging from research and development startups to advanced clinical firms similar to Novartis. Google is developing a cardiac and activity monitor, and making progress on its ‘Baseline Study’ genomic efforts to map a healthy human body and predict illness before it takes hold. And one year ago it acquired Lift Labs, a fast growing Parkinson’s startup. The work, Brin admits, is a “huge undertaking”. But Google is known for relentlessly pushing its vision. The results over the next few decades are likely to have an equally resounding impact, of course, on both public health and Google’s own financial position.

Source: nwpf.org

What Does Research Say About Exercise?

NPF’s Parkinson’s Outcomes Project team studied the effects of exercise on a large cohort of 3,000 patients. Interestingly, exercising and exercising earlier in the disease revealed improvements in quality of life. They found that the sooner you start exercising, the greater the quality of life benefit. It didn’t matter what exercise patients were doing, the essential finding was, start now! Despite some conflicting findings on exercise, the last point is paramount: it matters less what you do and more that you do it. Engaging in exercise for at least 2.5 hours per week is the most important thing. Talk with your doctor and check out what the POC offers to help you get started!

Source: Parkinson.org

Source: nwpf.org
Florida Hospital Parkinson Outreach Programs

Longwood/Altamonte Support Day Programs-2nd and 4th Tuesday each month 10:00 am to 12:45 pm St Stephen’s Church Parish Hall, 2140 W State Rd 434, Longwood, FL 32779. FREE

Orlando Support Day Programs-2nd and 4th Thursday each month 10:00 am to 12:45 pm Florida Hospital Church, 2800 N Orange Ave, Orlando, FL 32804 FREE

Lake County Support Group-2nd Monday each month 1:00pm to 2:30 pm, Florida Hospital Waterman, 1000 Waterman Way, Tavares, FL-FREE

Movement as Medicine-1st and 3rd Tuesday of each month 2:00-3:15 pm Florida Hospital Church 2800 N Orange Ave, Orlando, FL 32804 FREE

COPE-Care Optimally Parkinson Education for Caregivers-Offered quarterly in several locations/times. For caregiver’s only. FREE Call the POC for details 407-303-5295.

YOPD meetings-Offered monthly to those 50 and under. For days and times, call the POC office 407-303-5295. FREE

PWR! Parkinson Wellness Recovery Exercise Classes Offered in four locations:
Florida Hospital Sports Medicine &Rehab locations:
Altamonte Springs: 711 E Altamonte Dr. Ste 200, Altamonte Sprs. 407-303-5465
Apopka: 201 North Park Ave., Ste 105, Apopka. 407-889-1039
Orlando: 5165 Adanson St, Orlando; 407-303-8041

The Parkinson Outreach Center is now on Facebook! Like us and keep updated on what’s going on!

Want to Give Back?
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