

# LIFESPARK NEWSLETTER

# PESACH: FESTIVAL OF COMPASSION

The common interpretation of the word is to 'pass over,' hence the standard (English) label of our Yom Tov, 'Passover.' Nonetheless, that understanding is presented in Chazal merely as an alternative definition, while the essential translation of TDD is to have 'compassion.' (See (שמות יב, יג): 'ופסחתי עליכם - וחמלתי...(Rashi.) ואני אומר, כל פסיחה לשון דילוג וקפיצה'.



Given that the Torah labels the opening act of מציאת מצרים as one of compassion, it seems that the core of our redemption and the root of our development as a nation is one of deep empathy and care rather than merely an act of plain salvation.

The Navi (יחזקאל פרק מז) describes יציאת מצרים as an act of 'birthing,' wherein הקב"ה miraculously removed us from the womb of מצרים, causing us to be born into our own identity. As in all things primal, our birth must also have an element of חוסד וחמלה, kindness and compassion. If we were to strip the world of its myriad layers of pain, confusion, and suffering, we would find only Divine goodness and compassion. At the core of all creation, we discover only תוסד יבנה חוסד with which Hashem created the world was יוטר with which Hashem created the world was.

Pesach is when it all begins. The month of Nissan also contains elements of ראש השנה (see משנה ריש מס' ראש השנה (see משנה ריש מס' ראש השנה), and according to one opinion, it is when the world was created. In times like these, there is always a heightened sense of Divine compassion, and Hashem's primal חטד וחמלה is displayed.

Our work is cut out for us now as well. As we live by the creed of מה הוא אף אחהי, mirroring the traits of Hashem, we must also strive to discover and act with increased compassion during these times. Even more so, as we strive to be as 'Pesachdik' as possible, living up to its profound meaning and depth, we mustn't forget that at its core, Pesach is a Yom Tov of kindness and compassion, requiring us to act accordingly.

שנזכה לחוג חג הפסח בחמלה,

חג כשר ושמח. Rabbi Tzviki Fener

### SUPPORTING COGNITIVE SKILLS IN PARKINSON

#### **Practical Strategies for Patients and Caregivers:**

Have you ever wondered how Parkinson's disease affects not just the body but also the mind? Beyond tremors and stiffness, cognitive impairment can affect memory, decision-making, and other cognitive skills, adding a hidden layer of complexity to this disease. Many people with Parkinson's experience changes in attention, memory, problem-solving, and the ability to process information quickly. While these challenges can be frustrating, there are many ways to support cognitive function and maintain independence.

#### Parkinson's can impact several areas of thinking and memory:

• Attention difficulties - It may become harder to shift focus from one task to another (alternating attention) or to concentrate on multiple tasks at once (divided attention). Filtering out background noise or distractions, also known as selective attention, can be challenging.

Miri Schmookler, MA CCC-SLP



#### **Memory and Organization Strategies:**

#### **Establish daily routines Minimize distractions** Utilize visual reminder such as dry-erase boards or wall Reduce background noise. Review the schedule each morning. calendars. Focus on key points Highlight or underline Reinforce memory Prioritize main ideas over details. **Emphasize** important Repeat important details information while reading. Allow extra time **Maintain focus** Use tools Don't rush between Visual reminders, like planners, calen-Stick to one topic at a time during activities. conversations. dars, dry-erase boards, or smartphone

#### **Boosting Brain Power:**

- Exercise daily.
- Read articles or books that interest you and discuss them with others.
- Stay socially engaged regular conversations and activities with friends and family can help keep the brain active.
- Look through old photos and create a memory book featuring important people and events.

#### **Caregiver Tips for Reducing Stress:**

Supporting a loved one with PD can be rewarding but also demanding. These strategies can help caregivers manage stress and provide the best possible support:

- Keep a consistent schedule for meals, medications, and rest, to reduce fatigue and confusion.
- Avoid over-scheduling allow time for breaks between activities.
- Prepare the person with PD for any changes in routine by providing advance reminders.
- Make time for self-care, even if it's just a few minutes of deep breathing, stretching, or a short walk. You cannot be present for others if you don't take care of yourself. Try to establish a support system and develop a self-care routine.
- Celebrate special moments in ways that work for both you & your loved one, even if traditions need to be modified.

Cognitive changes in Parkinson's disease can be challenging, but the right strategies and professional support can make a meaningful difference. By working together, people with Parkinson's and their caregivers can establish routines and habits that enhance memory, organization, and overall well-being. If your loved one is experiencing cognitive changes, consider consulting a qualified speech-language pathologist to assess their needs and provide tailored support for an improved quality of life.

Miri Schmookler, M.A CCC-SLP, is a speech-language pathologist whose mission is to improve the lives of individuals living with Parkinson's and other neurodegenerative diseases. Miri can be contacted by calling 718-419-0604 or emailing mirimunk18@gmail.com.



## CAREGIVING AND THE HOLIDAYS

Gloria Lebeaux, LCSW

Every year, as Pesach approaches, caregivers begin to wonder whether they will be able to get through this time, juggling responsibilities, hosting meals, handling shopping, traveling to children, and maintaining all the routines that their loved ones depend on. Although it feels wonderful to be around loved ones, enjoy time together, and celebrate family traditions, navigating the holidays can also be incredibly stressful and overwhelming. For caregivers, the holidays can feel like a mismatch between the season's joy and their daily hardships. There can be unpleasant family members, grief for those who have passed, and an overwhelming to-do list. Maybe your loved one's symptoms have changed since the last time you saw the grandchildren - how do you explain it? How do you maintain your loved one's medication



routines when there is so much chaos and interruption? Traveling can be exhausting and physically taxing for both the person with Parkinson's and the caregiver. How do you maintain your loved one's exercise regimen or your self-care when there is so much to do or when you are in a different environment? How do you balance your feelings with your loved ones?

Are there times when you, as a caregiver, feel you can't handle any of this? Are you experiencing fatigue, headaches, changes in appetite or sleep? Are you irritable, anxious, or feeling helpless? Are you more forgetful and scattered or snapping at your loved one? These are all classic symptoms of Caregiver Stress. First and foremost, recognize that these feelings are all human reactions to your responsibilities. There are even biological reasons, as your cortisol levels increase which can lead to weakened immunity and an increased risk of chronic conditions. It is essential to recognize and validate your own emotions. Then, reflect on the fact that the Seder, which is the central tradition of Pesach, means 'order' in Hebrew. As it suggests, take each thing you need to do, one step at a time, one moment at a time, one task at a time. Choose only one thing to focus on which you feel you can handle. Then recognize that while there is so much we have no control over, there are ways we can still influence some changes: We have the power to ask for help, the power to study and learn new things that can help us, the power to get instructions for engaging in new challenging things, the power to learn each day from our own experience and others, the power to say yes, and most importantly, the power to say no. We possess spiritual, physical, emotional, intellectual, and social powers.

#### Here are some practical strategies to relieve caregiver stress during the holidays:

Make time for yourself: Set aside some time to sit quietly, relax, and recharge.

Know your priorities: What is most important to you? Take the time to consider what brings you the most meaning and fulfillment without overexerting yourself. Cooking and baking can be exhausting, so consider looking for shortcuts, serving store-bought

desserts, or asking your guests or other family members to bring their favorite dishes.



Enlist Friends and Relatives: Never hesitate to ask for help. It can come from anyone, including family members, neighbors, and friends. Identify individuals who can offer support and possess the strengths you need. Arranging meals or providing companionship can make a significant difference. Be specific about your needs and communicate them clearly to those who are willing to pitch in.

Take care of yourself during complex family interactions: If people are criticizing your caregiving, don't help out, or are unsupportive or unkind, limit contact, stay neutral, and remain civil. The Pesach table is not the time to vent

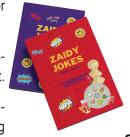
frustrations or hash out more significant issues.

Find reasons to laugh: Humor is an excellent stress reducer and an effective way to cope with challenging situations.

Take a few moments for deep breathing, meditation, or music: Try simple breathing exercises, do a quick workout, or stretch your body to help relax and release tension.

Set realistic expectations: Recognize that you cannot do everything perfectly, and it's okay to make mistakes. Don't hesitate to ask for help or to delegate complex tasks. Learn to let go of perfectionism and embrace a more flexible mindset.

Set boundaries: Learn to say no when necessary and establish clear limits on what you can do. Time-block your schedule with non-negotiable periods for self-care. Learn to recognize when you are reaching your limits before becoming



completely depleted.

Handle caregiver guilt: Identify guilt triggers and challenge unrealistic expectations. Practice self-compassion statements, such as, "I am doing my best with what I have."

Maintain your own identity beyond caregiving: Schedule 'no caregiving zones'- times when you and your loved one connect as a family, rather than caregiver and care recipient. Schedule personal activities that nurture passions beyond caregiving. Connect with friends, support network members, and other family members for fun or meaningful activities outside of giving care. Even brief interactions with others can help boost your morale.

Caregiving is challenging, especially around the holidays, but is also beautiful. It's a delicate balance, but with focus and determination, it can bring you joy. Try to remember that systematic self-preservation is necessary and not selfish. It will enable you to continue providing kind and meaningful care, while also protecting their own physical and emotional well-being. Remember to be kind to yourself, take breaks as needed, and prioritize your own mental and physical health. This will allow you to truly enjoy the holiday with your family and friends, giving you the freedom that Pesach embodies and leaving the bondage of worry and anxiety behind.

Gloria Lebeaux, LCSW Psychotherapist-Eldercare Specialist lebeauxgloria@gmail.com 516-582-5313

# MIND GYM

#### SPOT THE ODD ONE QUT - ULTIMATE CHALLENGE

How to Play: Below are lists of words. In each list, one word doesn't belong. Your task is to figure out which word is the "odd one out" and explain why.

#### Level 1: Easy (Beginner)

Apple, Banana, Carrot, Grape

Dog, Cat, Elephant, Fish

Circle, Square, Triangle, Rectangle

#### **Level 2: Medium (Intermediate)**

Piano, Guitar, Violin, Drum

Red, Blue, Green, Banana

Tuesday, Wednesday, Thursday, Sunday

Football, Baseball, Tennis, Swimming

#### Level 3: Hard (Advanced)

Shakespeare, Dickens, Austen, Picasso

Mars, Venus, Earth, Sun

Tree, Flower, Leaf, Cloud

Oxygen, Nitrogen, Hydrogen, Gold

#### Level 4: Expert (Challenge)

Albert Einstein, Nikola Tesla, Leonardo da Vinci, Julius Caesar

New York, Paris, Tokyo, Hawaii

Mercury, Venus, Earth, Pluto

Piano, Trumpet, Flute, ViOlin

Shark, Dolphin, Whale, Squid

#### **Bonus:**

For an added twist, try to come up with your own!



By Dr. Sheng-Han Kuo

### TREMORS & BEYOND

### LATEST CLINICAL INSIGHTS INTO PARKINSON'S,

#### **PARKINSONISM & ESSENTIAL TREMORS**

Dr. Sheng-Han Kuo is a Movement Disorder Specialist and associate professor of Neurology at Columbia University Hospital. He is a physician-scientist whose research is funded by the NIH, has published articles and books extensively, serves as the vice-chair and advisor of the movement disorder section of the American Neurological Association, and has received numerous rewards. On February 16th, he shared his wisdom, insight, and experience regarding tremors. He began by discussing what causes PD tremors, how they differ from Essential Tremors, and some novel therapies used to treat them.



A typical PD Tremor would be a resting tremor, which is not as pronounced during an action. However, there still might be a slight tremor in a different area of the body at the time of the

action, such as a tremor in the hand while walking. An Essential Tremor is a tremor during an action, which can be subdivided into three types – while trying to touch a target (intention), while writing (kinetic), or while using a spoon (postural). Sometimes the tremors overlap, so to diagnose Parkinson's, doctors would also look for other PD symptoms such as shuffling, slowness, or stiffness in gait. By the numbers, there are 1 million people in the US with PD tremors; by comparison, there are 7 million with Essential Tremors.

Two small studies have shown that for those who got Essential Tremors earlier on, there is 4-5 times higher risk factor of getting PD than the general population. They will also have the tremor as the predominant symptom of Parkinson's. Although that sounds disheartening, tremor-dominant PD has a better prognosis than other types, and the disease typically progresses slower.

Approximately 80% of PD patients will have tremors, and in early-stage PD, tremors are the 2nd to most bothersome symptom. Rest tremors are caused by the loss of dopamine, which causes difficulty initiating movement, but a very complex process in the brain leads to tremors. The more we learn about the on/off circuit in the brain that causes tremors, the easier it will be for researchers to work on new therapies that will help. Typically, PD rest tremors get worse over time, more so in a postural tremor than a kinetic tremor. Stress definitely exacerbates tremors. For those on Levodopa (or Rytary, which is a slow-release form of Levodopa), 20-40% will have no tremor improvement, 20-40% will have a partial improvement, and the remaining 20-40% will have full improvement. This translates into about two-thirds of the PD population needing other therapies to help them with their tremors.

What can be done to help tremors? Listed here are the options the doctor gave.

Propranolol, a beta blocker usually used for high blood pressure or anxiety, can sometimes reduce tremors at rest & when stressed.

Pharmacologic solutions are limited, but dopamine agonists and anticholinergics might work.

DBS can suppress tremors in real-time, but it is an invasive treatment.

Recently, the FDA approved focused ultrasound-mediated sub-thalamotomy, which can be done during an MRI. This is a minimally invasive procedure where focused ultrasound technology uses MRI guidance to burn a specific, targeted brain area to help minimize tremors.

In conclusion, although tremors are a considerable factor in Parkinson's, as the science and medical world understand their causes better, more options will be available to help treat the tremors. We look forward to that soon!

As always, the full Zoom event was recorded and posted on our website at www.lifesparkpd.com/education



#### A Comeback Story for people with Parkinson's

Our first annual Volleyball Tournament, held at The Dome at Adventure Crossing in Jackson, NJ, on February 27th, was a resounding success! It far exceeded expectations and impressed all those who attended. The sense of camaraderie was palpable, and participants felt honored and excited to come together and support such a worthy cause.

Twenty-eight teams of players gathered together, each playing with a sense of spirit and fun, while maintaining a competitive edge that did not lose sight of playfulness. There was an abundance of food and drink, and opportunities to meet many professionals in the medical field were plentiful. Also, massage tables were available to soothe players' muscles, and much more to keep everyone entertained for hours.

The competition drew to a close as we approached midnight, and all players left as winners, having done their part in such an extensive and successful campaign.

Amazing
Organization
LIFESPARK





#### 1000s

Dollars Raised to help those with Parkinsons

#### 1700+

People Helped make this Event Happen!

A huge thank you to all the sponsors that participated – we couldn't have done it without you! Thank you to all donors, big and small – we appreciate you all! And thank you to some dear friends for coming out to show your support.

Among those in Attendance:

Erika Adelman, Lcsw, SIFI, Neurology Social Work Manager at Columbia University Medical Center

Dana Dolce, APN, Neuromodulation Program Manager at Hackensack Meridian Health

The Michael J. Fox Foundation for Parkinson's Research

**American Parkinson's Disease Association** 

Alisha Poplawski, DBS Therapy Representative at Medtronic

What people are saying:

"'Twas a gem of an event!" "This is incredible!"

"What a fantastic event for such a meaningful cause!

"It's so inspiring to see the impact it's making!"

"Thanks for letting us be a part of this great event!"



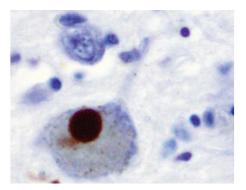
# MEDICAL MOVEMENT

### RESEARCH SUGGESTS WE MAY ALREADY HAVE AN FDA-APPROVED DRUG WITH POTENTIAL FOR TREATMENT OF PARKINSON'S

Parkinson's affects more than 8.5 million people globally, making it the second most common neurodegenerative disease after Alzheimer's. As a progressive movement disorder, it is usually only diagnosed when symptoms appear, which include tremors, stiffness, balance problems, speech difficulties, and disturbed sleep patterns. Parkinson's symptoms mainly result from the death or impairment of dopamine-producing neurons in the brain's substantia nigra, a region involved in fine motor control.

Within the substantia nigra, there is a protein called alpha-synuclein which produces dopamine and typically manages communication between neurons. Problems arise when alpha-synuclein becomes misfolded and insoluble, causing abnormal clumps of protein known as Lewy bodies.

Two cell surface proteins called Aplp1 and Lag3 have been implicated in the pathologic transmission of alpha-synuclein in the brain, leading to Parkinson's disease. Each protein, on its own, can independently help brain cells absorb harmful alpha-synuclein, but together they significantly enhance transmission. Researchers have been studying how these two proteins interact to help harmful alpha-synuclein protein clumps enter brain cells, thereby further understanding how alpha-synuclein contributes to the progression of Parkinson's disease. Their findings suggest that targeting the interaction between Aplp1 and Lag3 with drugs can significantly slow



Alpha-synclein shown by positive staining (brown) in a Lewy body in the substantia nigra of a patient with Parkinson's disease (Marvin 101/CC BY-SA 3.0/Wikimedia Commons)

the progression of PD and possibly other neurodegenerative diseases as well. Notably, an FDA-approved cancer drug that targets Lag3 has been shown to block the transmission of alpha-synuclein in mice, suggesting that a potential therapy may already exist. Researchers administered the drug Nivolumab/Relatlimab, a melanoma medication that targets Lag3, to normal mice and found that it also inhibited the interaction between Aplp1 and Lag3, nearly completely blocking the formation of harmful, disease-causing alpha-synuclein clumps in neurons. While this is exciting, the next step will be to test this drug on mouse models with Parkinson's, and only then can trials be initiated in humans.

Our tefillah to the Rofeh chol basar is to give the wisdom needed to the scientists and doctors to bring refuos and yeshuos to all Yidden b'karov!



Julius Caesar – He was a Roman emperor, while the others were scientists/
artists.
Hawaii – It's a U.S. state, while the others are international cities.
Pluto – It's no longer classified as a planet, while the others are.
Trumpet – It's a brass instrument, while the others are string instruments.
Squid – It's a cephalopod, while the others are mammals.

Level 3: Picasso – He was a painter, while the others were novelists. Sun – It's a star, while the others are planets. Cloud – It's not a living organism, while the others are. Gold – It's a metal, while the others are gases. Level 2:

Swimming – It's a percussion instrument, while the others are string instruments.

Sunday – It's a weekend day, while the others are weekdays.

Swimming – It's not a team sport, while the others are.

Level 1: Carrot – It's a vegetable, while the others are fruits. Elephant – It's a land animal, while the others are typically pets. Circle – It has no corners, while the others do.

Answer Key:



1200 River Ave. Unit 9d Lakewood, NJ 08701 WhatsApp732.534.6388 Call/Text 732.806.1133 info@lifesparkpd.com

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#### **Quotes from The Rally:**

Blown away. This was a once-in-a-lifetime event.

A.Y. Gruskin is a straight-up legend.

I am deeply touched by your father's courage and determination. New respect!!!

So inspired by what you pulled off! I am grateful and honored to have taken a small part in it.

#### SUPPORT GROUPS

Our support groups serve as a dedicated space for individuals with Parkinson's and/or their caregivers to come together, share, and gain understanding in dealing with and coping with PD. They are not in person; they are conducted via zoom or telephone.

Ladies' Caregiver Support Group Sunday mornings 10:30-11:45 AM Moderater Mrs. Tehila Weisberg, LCSW Ladies' Patient Support Group Monday evenings 7:00 PM Moderater Gloria Lebeaux, LCSW Men's Patient Support Group Tuesday evenings 7:00 PM Moderater Rabbi Dr. Fishel Mael

For more information or if you are interested in joining any of these groups, please reach out to nivka at rivka@lifesparkpd.com or 732.806.1133 ext. 302