Rescue Therapies for Parkinson’s Disease Update

By Dr Jen Nagao, MBBS, FRACP, Movement Disorders Fellow, Henry Ford Health System

Motor fluctuations affect 40% of people with Parkinson’s disease (PD) after 4-6 years of PD-specific therapy. “Wearing off” is the most common phenomenon, characterised by a noticeable deterioration in symptoms prior to the next scheduled dose of medication. Whilst this can be managed by measures such as bringing medication doses closer together, when the wearing off becomes unpredictable, treatment becomes more difficult. Other disabling features of fluctuations include unpredictable dose failures or a prolonged delay to medication effect. Motor fluctuations can have a profound impact on day to day function, mobility, sense of well-being and quality of life. For the remainder of the article, I will refer to “on” as the state when medications are working and symptoms are controlled and “off” as the state when medications are not working and symptoms are problematic. Until now, subcutaneous apomorphine injections (Apokyn) have been the only marketed option to use as a “rescue” therapy in situations where people with PD unpredictably switched “off” or the medication failed to take effect. Whilst oral, rapidly dissolving forms of levodopa such as Madopar Rapid (benserazide-levodopa), are used outside of the USA, they are inconsistent and have a delayed onset of action compared to subcutaneous apomorphine. Promisingly, recent research developments have introduced alternative rescue options that will hopefully become available on the market in the near future.

Subcutaneous apomorphine hydrochloride

An FDA-approved formulation available as 30mg/3ml and Apomorphine, despite its name, is not a narcotic. It contains a structure that is similar to dopamine (the neurochemical deficient in the PD brain), and in this way, can bind to dopamine receptors. Previous barriers to widespread use of apomorphine were its rapid metabolism by the liver and its potential to cause severe nausea. When apomorphine is injected subcutaneously, it bypasses the liver and is rapidly absorbed into the bloodstream. As a result, it reaches its peak concentration in the blood much faster than standard oral levodopa. Concurrent treatment in the initial few weeks with trimethobenzamide or domperidone (available in Canada) adequately manages the nausea and is usually not required long-term. The common side effects are sleepiness, dizziness, yawning, nausea, low blood pressure and nasal discharge. Injection site reactions, skin nodules and local pain are also not uncommon. (continued on page 2)
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Of the proposed rescue therapies, subcutaneous apomorphine has the most research data available, including long-term experience. The average optimal dose in blinded studies was 5.4mg and was very effective, aborting an “off” episode in 95% of patients. The range of doses used were 1.5 to 10mg. The benefit was noticed as early as 7.5 minutes after injection, with a similar degree of benefit to standard levodopa achieved at 20 minutes. In addition, total daily “off” time reduced by 2 hours. Follow-up studies showed that the effect of subcutaneous apomorphine was maintained, even after 1 year of use as rescue therapy, with no adjustment in dose required.

### Sublingual apomorphine – an experimental formulation under development

Sublingual apomorphine is an alternative preparation of apomorphine that also bypasses the liver but avoids the unpleasantness of injections. It is an oral strip that is placed under the tongue for 2 minutes. In reported studies to date, the apomorphine rapidly diffuses and is absorbed by the oral mucosa. Initial studies have shown that almost 80% of patients achieve a full “on” state. All responders felt a benefit within 30 minutes, and in almost half the responders the onset of effect took less than 15 minutes. The average time for peak effect was 24 minutes, and the average duration of effect was 50 minutes (90 minutes or more in 60% of patients). Common side effects were dizziness, sleepiness and nausea but most side effects were not severe enough to stop therapy. More than two-thirds of patients had a blood pressure drop on standing at some point during the study, but did not necessarily have symptoms reflective of this. 80% of patients only required 20mg or less, with the most common effective doses being 15mg or 20mg.

### Inhaled levodopa - an experimental formulation under development

Inhaled levodopa is an inhaled powder, administered by a breath-actuated device using a single, deep, comfortable breath followed by breath holding for approximately 5 seconds. Studies have shown that the device is able to be used even in “off” states of low dexterity. Plasma levodopa levels rise more rapidly and more predictably than standard oral levodopa. Both 35mg and 50mg fine particle dosing have shown efficacy. In a 4 week randomized study, 79% of patients taking inhaled levodopa achieved an “on” state compared to only 45% of the placebo group. In both dosage groups, onset of medication benefit began at 10 minutes, peaked at 30 minutes and was sustained for at least 60 minutes following administration. Common adverse effects are dizziness, nausea and cough. The cough is usually short-lived and mild. It has no detrimental effect on lung function.

In summary, there are exciting new research developments in the area of rescue therapies for PD. Subcutaneous apomorphine remains an effective option, but there will be alternatives for people who prefer a non-injectable medication that provides a comparable benefit. While all options have side effects, most were mild to moderate in most studies and were tolerated well. No head-to-head studies have been completed between the rescue therapies to date.
Clinical Research Update

By Peter A. LeWitt, M.D.
Chairman, Professional Advisory Board Michigan Parkinson Foundation
Professor of Neurology, Wayne State University School of Medicine
Director, Parkinson’s Disease and Movement Disorders Program Henry Ford Hospital - West Bloomfield

As 2018 rolls to a close, PD research rolls on! Here in Michigan, there are several out-patient studies underway, including a clinical trial in which two currently-marketed medications (rasagiline and pramipexole) are combined to determine if this can achieve a better outcome in symptom control. Another study is investigating the effectiveness of droxidopa as a treatment for hard-to-manage symptoms of low blood pressure. Soon to begin is a clinical research trial of a promising neuroprotective strategy targeting inflammatory cells in the brain – one of the current hypotheses as to how PD might be initiated. This drug in this study is similar to nilotinib, another experimental anti-inflammatory drug that also is undergoing testing around the U.S. for slowing the progression of PD.

Two studies investigating subcutaneous infusion of levodopa and apomorphine have finished their enrollment, as is a study of a monoclonal antibody against alpha-synuclein. We should hear reports as to study results in the next year. Testing of another longer-acting carbidopa-levodopa product (the Accordion pill) is also awaiting study completion. In the near future, there are plans for investigation of another longer-acting carbidopa-levodopa formulation and for a novel means of suppressing involuntary movement (dyskinesias). An exciting development is a first-of-its-kind clinical trial of a potential neuroprotective treatment for a hereditary form of PD (LRRK2). This study will begin shorty; genetic testing for the LRRK2 mutation will be part of the screening process for this trial.

Another project for which we welcome the participation of any person with PD not currently taking carbidopa-levodopa is a biomarker project studying metabolism of caffeine and amino acids. Each of these is provided as a tablet in this study, which then samples a blood specimen and 24-hour urine collection to learn if such a test could help in PD diagnosis. Participants receive $50 and our appreciation for their participation in this promising biomarker research.

Other therapies under development are wrist-worn anti-tremor devices that might prove to be alternatives to medications in control of tremor. For more information on these and other promising research directions for PD, contact the Parkinson Disease and Movement Disorders Program at Henry Ford Hospital (248-661-6540; parkinsons@hfhs.org).

For more information on clinical trials, visit these sites:
- ClinicalTrials.gov.
- https://clinicaltrials.info.nih.gov/
- www.centerwatch.com
- www.parkinson-study-group.org

The following organizations are currently recruiting patients for clinical trials: University of Michigan has a number of research studies in progress. You can register at their website for more information at U of M Health Research and University of Michigan Udall Center of Excellence for Parkinson’s Disease Research

Henry Ford Hospital, West Bloomfield is looking for participants in several Parkinson research studies.

Contact them at 248-325-2452 or e-mail at movementdisorders@hfhs.org

QUEST Research Institute in Farmington Hills is offering several medical research studies for People with Parkinson’s disease.

Call 248-957-8940 or visit www.Questri.com

Michigan Parkinson Foundation • Messenger Late Fall 2018 • (800) 852-9781 • (248) 433-1011 • www.parkinsonsmi.org
**A Parkinson’s Support Group Is...**

A group of people who meet together to learn more about PD and the services available for people affected by this condition. Who knows more about PD than the people who live with it and their partners who help? A group brings together people with a common bond. After attending a meeting, so many people say, “And I thought I was the only one with this problem.” Groups include people with PD, care partners, friends, families and health professionals.

**Dave Bartczak Stepping Down After 27 Years**

Dave’s dad had Parkinson’s disease and passed away in 1993. When his dad was first diagnosed, Dave wanted to educate himself about the treatment and daily management of Parkinson’s. Dave sought answers and found the Michigan Parkinson Foundation. He started attending the Royal Oak Parkinson support group in 1991. He had only gone to a few meetings when the leader decided to retire. Dave graciously stepped in and agreed to facilitate the group. That was 27 years ago. Throughout the years, Dave helped guide hundreds of people through the daily challenges of living with Parkinson’s. When asked about what impressed him the most about the group, he said, ”People with Parkinson’s in our group have a dignity about them, and just press on with their lives. They don’t complain, they just get on with the job of living”. He also said the most common remark he has heard over the years was “If I’d known I was going to live this long, I would have taken better care of my body.” Words to live by for all of us.

In addition to being a support group leader, Dave joined the MPF Board of Directors in 1995 serving continuously since then. Dave also serves on the Metro Detroit Walk committee and has been instrumental in the walk’s growth in size and income.

We thank Dave for his years of service, insight, wisdom and dedication to the people with Parkinson’s and their families.

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**Introducing**

Adam Kuhlman, DO  
**Director, Movement disorders**  
**Department of Neurology**  
**Beaumont Health System, Royal Oak**

Dr. Kuhlman will be speaking on  
**March 8 at 5:00pm at the**  
**Beaumont Macomb Center**  
15979 Hall Rd.  
Macomb, MI 48044

For a complete list of Parkinson Support Groups affiliated with the Michigan Parkinson Foundation please visit:  
https://parkinsonsmi.org/programs-support-groups/support-groups

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**Virtual Support Group via Conference Call**

Statewide, you don’t need to leave your home, just call in and connect with others who are dealing with the same issues you are.

**Upcoming meeting dates:**

<table>
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| December 4, 2018 | January 22, 2019  
| December 18, 2018 | February 5, 2019  
| January 8, 2019 |  

**Meets on selected Tuesday evenings at 7:00 pm**  
Call (888) 387-8686  
Participant code: 274 290 7005
The following groups were either newly formed in 2018 or they had leadership changes, meeting date or location changes.

**Bay County**  
Bay City, MI  
The meeting will be third Friday of each month at 12 Noon.  
Paramount Rehab Center  
2535 22nd Street  
Bay City, MI 48708  
989-891-9800  
Contacts Megan Monroe OTRL mmonroe@prsmichigan.com  
Sunil Malware, PT, OCS, COMT Bob Richard PhD  
rrichard@oldtymeradio.net  
(989) 391-9892

**Berrien County**  
St. Joseph (NEW LOCATION!)  
2nd Thursday, 3:00 pm  
Barbara Ford (269) 429-3675  
CARING CIRCLE  
4025 Health Park Lane  
St. Joseph MI 49085  
(Corner of Hollywood and Glenlord)

**Hillsdale County**  
Hillsdale County Senior Center  
2nd Thursday at 3:30 pm  
Maggi Monroe, RN (New Leader)  
(517) 437-2422 x 127  
Hillsdale County Senior Center  
Lower level  
320 W. Bacon, Hillsdale, MI 49242

**Iosco County**  
Parkinson Support Group  
(Will meet April through October)  
3rd Thursday, 10:00 am  
Rachel Haviland NEW NUMBER FOR RACHEL (989) 984-5292  
Tawas Area Presbyterian Church,  
2095 US-23, East Tawas, MI 48730

**Oakland County**  
Novi/Fox Run  
1st Tuesday, 3:00 pm  
Rhonda Kotzen, MSPT (248) 668-8655  
New Co-leader Ruthann Lapham Ruthann.Lapham@erickson.co (New Leader)  
Fox Run – Derby Room in the Belmont Club House  
41100 W. 13 Mile Road, Novi MI 48377

**Macomb County**  
(Not meeting in January or February)  
2nd Friday, 5:00 pm  
Donna Zimny, RN (248) 964-8786  
Beaumont Macomb Center  
15979 Hall Rd.  
Macomb, MI 48044

**Washtenaw County**  
Ann Arbor Care Partners Split Group  
4th Thursday, 1:30 pm  
Facilitator contact: Diana45@comcast.net  
St. Joseph Hospital, Ellen Thompson  
Women’s Health Center  
Classroom 1, 2nd Floor  
5320 Elliott Drive, Ypsilanti MI 48197  
Sept through June

**Chippewa County**  
Sault Ste. Marie  
3rd Wednesday, 1:00 pm  
Rene Shimmon (313) 357-3407  
Bayliss Library  
541 Library Dr.  
Sault Sainte Marie, MI 49783

Steve McMahon from Birmingham, MI will assume the role of support group leader for the Royal Oak group. Steve has Parkinson’s and has been volunteering in the MPF office for the past two years. Steve is extremely knowledgeable about Parkinson’s and will be a real asset to the group. We thank Steve for his willingness to take on this new role. The group will continue to meet at the same time and day of the month.
The 9th Annual Lansing Walk Event was held on Saturday, September 15, 2018, for the second year on Michigan State University Campus. The event raised just under $53,000! The 300+ participants loved the walk along the Red Cedar River, with just a hint of fall colors beginning to appear. A special thank you to Dana Whyte from WLNS for taking time from her busy schedule to Emcee the event, to the MSU Marching Band and, of course, SPARTY! Wendy Koerner, the 2018 Lansing Honoree, instilled the importance of EXERCISE, EXERCISE and MORE EXERCISE to slow down the progression of Parkinson’s.

A BIG shout out to the Hubbert Family – Volunteers from beginning to end!

Thank you, Jim Galloway!
Jim announced that he will be resigning as Chairman of the Lansing Walk Committee this year. Michigan Parkinson Foundation is grateful for his hard work and dedication to the event for the past 8 years. THANK YOU, JIM and we look forward to seeing you at next year’s event as a participant (you can take it easy from now on)!!

Top Fundraising Teams (raised $1,000 or more):

Amy Wilson and Team Michiana Walks for Hannah raised $6,811 (pictured above)

Wendy Koerner and Wendy’s Walking Warriors raised $3,866 (pictured above)

Dorothy Scherer and Scherer Madness raised $2,405 in loving memory of Vincent Scherer

Wayne & Elaine Thelen and Thelen Acres raised $1,560

Tim Gleeson and Team OMG Walk with Me raised $1,220

Chloe Silm and Papa’s Posse raised $1,155
Our last Walk Event for 2018 was the 5th Annual Southwest Michigan Area Walk Event, held on Saturday, September 22, 2018 at Binder Park Zoo in Battle Creek, a new venue for MPF. Jeff Laethem, Chairman of MPF, joined the 300+ participants to celebrate in honor or memory their loved ones affected by Parkinson’s. The event raised an amazing $52,000. Jeanette Gagnon was the 2018 Honoree and is always a true inspiration to all those living with PD. She was supported again this year by her family as she completed the 3 Mile Route!

The Southwest Michigan Walk Event grew 300% from last year with a special shout out to Jerry Howell, Midwest Business Exchange, who was able to obtain the use of Binder Park Zoo using donated trade dollars, allowing all proceeds to go directly to funding MPF’s programs and services. In fact, MPF is able to increase the In-Home Respite Program due to the great success of our walk events. Jerry Howell is our Hero!

Day of event set-up is always a task at our walk events, and lots of volunteers are needed. Anne Clark with Senior Health Partners, Battle Creek (pictured left) secured volunteers from the Michigan Youth Challenge Academy to help with all aspects of the event, from set up to tear down.

THANK YOU to all of our wonderful and hardworking volunteers!

Top Fundraising Teams (raised $1,000 or more):

Alyson Fransted and Team Fransted raised $4,082 (pictured above)

Joanne Shelton and JoJo’s Fighters raised $3,550 (pictured above)

Jean Vargas and Jean V’s Team raised $2,500

Aaron Steinhilb and Steinhilb’s Wolf Pack raised $2,422

Tom Simpson and Tom’s Warp Speed Walkers raised $1,890

Karin Gallagher and Rock Steady Boxing Battle Creek raised $1,820

Doug Logan and Barry County Parkinson’s Support Group raised $1,506

Jane Brady-Ertz and The Brady Bunch raised $1,440

Laura Cameron and The Cameron Clan raised $1,350

Brandy Skelton and Audrey’s Animals raised $1,318

Tammy Gagnon and Phillippians 4:13 raised $1,025

Samantha Baize and Mustache Papa raised $1,021

Jeanette Gagnon and some of Team Phillippians 4:13 - “I can do all things through him who strengthens me.”

Linda Grap (Senior Health Partners), Mary Sue Lanigan (MPF Executive Director), Jerry Howell (Midwest Business Exchange), and Jeff Laethem (MPF Chairman)
SAVE THE DATES for MPF’s 2019 Walk Events.
2019 “I Gave My Sole for Parkinson’s” WALK EVENTS

**Metro Detroit Walk**
Saturday, June 8, 2019
(NEW DATE CHANGE FROM MAY to JUNE)
17th annual in Detroit Area,
3rd year in Birmingham

Seaholm High School – Football Field
2436 West Lincoln
Birmingham, MI 48009

Registration opens at 9:00 am
Opening Ceremony at 10:15 am
Walk Begins at 10:30 am
To Register visit, www.parkinsonsmi.org
or call 248-433-1011

**Southwest Michigan Walk –**
Saturday, September 28, 2019
6th annual event in SW Michigan Area,
2nd year at Binder Park Zoo in Battle Creek

Binder Park Zoo
7400 Division Dr.
Battle Creek, MI 49014

Registration opens at 10:00 am
Opening Ceremony at 11:15 am
Walk Begins at 11:30 am

**Lansing Area Walk –**
Saturday in October,
Date to be announced
(NEW DATE CHANGE FROM SEPTEMBER to OCTOBER)
10th annual event in the Lansing Area,
3rd year on MSU Campus

MSU Campus, The Auditorium Building
542 Auditorium Rd (at Farm Lane)
E. Lansing, MI 48824

Registration opens at 9:00 am
Opening Ceremony at 10:15 am
Walk Begins at 10:30 am

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**SPECIAL MENTION:**

**YOUNGEST HEROES**

from Metro Detroit Walk

What do Cameron Spagna, Logan McGuire, and Isla Yessian all have in common? They have a very special person in their lives that is living with Parkinson's disease, and each found a very special way to honor them.

Cameron is very close to her grandmother, Lorraine Applebaum (“Bubba” to Cameron), who has been living with Parkinson's for many years. In lieu of gifts for her Bat Mitzvah, Cameron asked family and friends to donate to Team Lorraine, which she created for the Metro Detroit Walk. Cameron raised an amazing $4,370.

Logan and Isla attend St. Patrick’s Catholic School in White Lake. Their principal, Mr. Jeremy Clark (diagnosed with Young Onset Parkinson’s at age 35), was captain of Team Clark for the Metro Detroit Walk. Logan created his own Walk Page to raise money for Team Clark. Isla’s birthday party was the same day as the Metro Detroit Walk (May 19). On the invitation to her birthday party, she asked family and friends to donate to Team Clark in lieu of buying her birthday presents. Both Logan and Isla EACH raised over $500 in honor of Mr. Clark.

Well done!

MPF is very proud of these young Heroes, and grateful for their giving spirits!

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**“Never get tired of doing little things for others, sometimes those little things occupy the biggest parts of their hearts.”**

— Unknown

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**Back Row:** Cameron Spagna and Lorraine Applebaum
**Front Row:** Lorraine’s other grandchildren

**Back row:** Nina & Matt Yessian, Mr. Jeremy Clark, and Marci McGuire
**Front Row:** Isla Yessian and Logan McGuire
The Small Steps, Big Strides for Parkinson’s Gala

The Small Steps, Big Strides for Parkinson’s Gala took place on October 19, 2018 at the Henry Ford Museum. Three hundred guests enjoyed cocktails, dinner and dancing in America’s Museum of Innovation. Guests had access to the entire museum for the evening. It was a special night for the foundation and by all measures a big success. While guests had a great time enjoying the ambience of the museum, fabulous food and each other’s company, the event had a purpose; to raise much needed funds for the MPF and to bring awareness to the Parkinson cause. Jeremy Clark, the featured speaker was diagnosed with Young Onset Parkinson’s when he was 35. Jeremy shared his experiences and the day to day challenges of living with Parkinson’s disease. Jeremy did a great job in shedding light on the difficulties people with Parkinson’s face on a daily basis. Thank you Jeremy!

Pictured above is Jeremy Clark, the featured speaker who was diagnosed with Young Onset Parkinson’s when he was 35.
2019 Patient Education Programs

LIVING WITH & UNDERSTANDING PARKINSON’S DISEASE : A Program for People with Parkinson’s and their Families

This 5-week series presented by Michigan Parkinson Foundation will take place in the following communities in 2019.

- Alpena
- Lansing
- Muskegon
- Metro Detroit

The series provides information and discussion on all aspects of living with Parkinson’s disease (PD). This program is of value to the newly diagnosed as well as patients and families dealing with PD for several years. The workshops will be presented by health care professionals who specialize in Parkinson’s disease. Workshops include:

- What is Parkinson’s Disease and Managing Medications
- Non-Motor Symptoms of Parkinson’s
- The Role of Rehab Therapy and Exercise in Managing Parkinson’s
- Speech and Swallowing Issues
- Mental Health Issues: Coping with Depression and Anxiety

MPF staff is finalizing times, dates and venues for the 2019 programs. Once dates are established, printed invitations will be sent to our constituents who live in the counties surrounding the area where the program is being presented. Stay tuned!
Thank you to our corporate sponsors and community foundations who support the Michigan Parkinson Foundation’s education programs and special events in 2018.

### Gold Sponsors
$5,500 to $15,000

- Abbvie Inc.
- Acadia
- Adamas Pharmaceuticals, Inc.
- Ascension Michigan
- Big Boy
- Boston Scientific
- Great Lakes Wine & Spirit
- Henry Ford Health System
- Home Instead Senior Care
- Impax Specialty Pharma
- Joyce Wagner
- Lundbeck
- Magna
- Medtronic
- Michigan Neurology Institute
- Quest Research Institute
- Ray Laethem Motor Village
- Sunovion Pharmaceuticals Inc.
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- William J. Nicholson Foundation
- US World Meds

### Silver Sponsors
$3,000 to $5,000

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- Battle Creek Community Foundation
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- KBC Tools & Machinery
- Kroger
- Ryan Messacar Family
- Michigan Institute for Neurological Disorders
- Ted Lindsay Foundation
- Tonik Media

### Bronze Sponsors
$2,000 to $2,800

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- Michigan Head & Spine Institute
- Recovery Project
- Senior Helpers
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$500 to $1,000

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- Flagstar Bank
- Grant Millman & Johnson
- Human Services Association Workers Compensation Fund
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- Mr. Stadium Coin Laundry
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- Ron Jackson Insurance
- Schena Roofing & Sheet Metal Co
- Senior Health Partners
- Sheila Bass
- Sterling Insurance Group
- Vesco Oil Corporation
- Vintage Wine Company

### Patron Sponsors
$1,500

- All State Fastener
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- Enterprise Holdings
- Rabahy Foundation
- University of Michigan Medical School
- United Jewish Fund
- Wayne State University School of Medicine, Department of Neurology

### A Gift From You Makes A Real Difference In The Life Of Someone Affected By Parkinsons

The act of philanthropy is a spiritual act, an expression of caring for one’s fellow human beings. It is a belief in the future and that the future can be good. It is investing in that future. It is helping to make the dream come true.

- Arthur Frantzreb
Voice Assistants Can Help People with Parkinson’s Disease

People with Parkinson’s often report, “Everything becomes smaller...smaller steps, softer voice, slower speech, smaller handwriting, and slower movement.” The MPF conducts a Virtual Support Group and many of the participants reported that they are using assisted communication devices to help with a variety of everyday tasks. We did some research on the various products and found the most commonly used devices are Amazon Echo (Alexa), Google Home and the Apple HomePod. These devices primarily help users perform everyday tasks.

How do they help?

Devices can be programmed to turn on and off room lights, TV’s, furnaces, air conditioners, ovens and favorite music. It can provide alerts to take medications, encouragement to do an exercise at a certain time, reminders for medical appointments, phone calls to be made or communicating with a care partner in another part of the house. For example, some married couples keep an Echo on each floor of the home, one in the basement, first floor and second floor. The device can be programmed so that if the person with PD is in the basement and gets “stuck or frozen” they can call out to Alexa and say

“Alexa tell my spouse I need help in the basement”.

Many people report “my smart phone can do all that for me”. For those that find the phone is too small or difficult to use, consider trying a communication device. Everything is programmed with your voice. The Amazon device, which leads the market, ranges in price from $40 to $100.

Many medical providers are considering the potential for voice technology to improve the health of aging-in place seniors. One example is Lois Seed, a ninety year old widow who is vision impaired and has difficulty reading or looking for information on the Internet. When her retirement community offered to place an Amazon Echo with Alexa voice technology in her one-bedroom apartment, she decided to give the home speaker a try. Now Seed is hooked and she’s one of a growing number of seniors who are turning to digital voice assistants to make life easier. The 90-year-old widow placed the device next to a comfortable chair, where she listens to audiobooks and to classical music streamed from a radio station in Los Angeles, where she used to live. “If I no longer want to listen, I say, “Alexa, stop”

she says. "I can make it louder or softer."

Seed also installed Alexa-enabled “smart home” plug-ins, which allow her to ask Alexa to turn a light on and off and to change the room temperature up or down. Before, she says, she had trouble reading and manipulating the thermostat.

When it comes to voice assistants, Seed’s advice to seniors is to learn about the numerous functions that voice technology offers. "Ask friends and family to help you," she says. "It can make your life more interesting." Seed was introduced to the Echo last year when she agreed to participate in a six-month pilot study at her continuing-care retirement community. The project began with 12 households and was later expanded to 90 units, with most participants in their eighties. The pilot was conducted by the Front Porch Center for Innovation and Wellbeing, which researches aging-related technology.

Residents attended workshops where they learned about the numerous capabilities (called skills) that Alexa offers. Front Porch technicians helped users customize the skills based on their individual interests, such as connecting Seed to her favorite music station.

In the study’s findings, all participants reported that Alexa made their lives easier. More than 70% noted that the device helped them stay connected to friends, family and the community. And about 75% said they used their smart-home devices daily. “We were really floored by the level of enthusiasm," says Davis Park, the Front Porch Center’s Executive Director.

Simple skills, such as setting a timer for boiling eggs, "resonated" with participants who want to maintain a sense of independence and control. "People are concerned with forgetfulness, and the ease of setting something like a timer with voice was powerful," Park says. Front Porch is expanding the program to other retirement communities.

For many people with Parkinson’s who live in their own home, voice-first technology can prolong independence and reduce social isolation, according to experts. By simply using their voices, older adults can ask their devices to call a relative, read e-mails, find recipes, set medication reminders, order a taxi or food from a favorite restaurant, and add items to a shopping list.

In another study for people with diabetes, patients were more likely to stick to eating and exercise regimens by having a voice assistant in their home. By interacting with Alexa, patients set daily goals, completed daily health assessments and reported health concerns to providers.
Remote Caregivers Stay In Touch

Voice-first technology is also entering the caregiving arena. LifePod (www.lifepod.com), which the company calls a "virtual caregiver," is set for market release at the end of the year. The service "will help make a user's life easier and safer, while providing the caregiver with greater peace of mind," says Stuart Patterson, LifePod's Chief Executive Officer.

With LifePod, remote caregivers, such as a family member or geriatric care manager, could remind a user to take medication, to drink water for hydration or remember that a bridge game is scheduled that afternoon. Caregivers log into a portal on a computer or mobile app to set the messages, which can change daily depending on the older person’s schedule. The messages are relayed through LifePod wall units in a user's home.

The reminders could be programmed to request a response. For instance, LifePod could ask if the senior has taken her medication. If a person says "no," the digital assistant could promise to check in later or to send a text to a caregiver, who would follow up. Or perhaps when it is a half hour until a medical appointment, LifePod could ask whether the user needs a ride; if the answer is "yes," Patterson says, the device will call a preprogrammed driving service.

Remote caregivers can check a daily report on the user's activities, such as requests for music and responses to reminders. The estimated cost for a wall unit will be about $125, with a monthly subscription ranging from $25 to $35, depending on the features.

Ask Marvee (https://askmarvee.com) is another service geared to families with loved ones who live alone. This Alexa skill is named after the late mother of the company's founder and Chief Executive Officer, Heidi Culbertson. "The mission was to reduce social isolation and to help older adults and families interact in a new way," Culbertson says.

Until age 90, Culbertson’s mother was an active senior living alone. Then, macular degeneration left her blind, but she refused to move to assisted living. Culbertson and her siblings bought her an Amazon Echo when it came on the market in 2014, and their mother was able to ask to listen to music, the news and books.

But Marvee was no longer able to send daily e-mails to her six children to let them know she was okay, and the telephone speed dial was difficult for her to manipulate. "She had a big family but she felt disconnected," Culbertson says. Culbertson, who spent much of her career developing mobile technology, asked someone to tweak the device so her mom could send simple messages to her family by talking to Alexa.

The Ask Marvee Alexa Skill was launched last year. Family members manage the app through a mobile device or computer. A family member sends a "morning beacon," which enables the senior to ask Marvee to send an "I'm ok" text or e-mail to designated family members and other contacts. An older person can also ask Marvee to have a loved one make a personal visit or a call, which the user can take by phone or through the Echo. Users can also ask for "family news," which relays messages sent by loved ones.

Sections of this article were originally published in the August 2018 edition of Kiplinger's Retirement report, article by Susan B. Garland.
CBD and THC—Cannabis is the name for a group of plants, the most famous of which is the marijuana plant. These plants contain 60 different chemicals called cannabinoids. That is a lot, but there are only two you need to know: THC and CBD. THC is the cannabinoid responsible for the “high” that comes from smoking marijuana. CBD is the cannabinoid that is thought to provide the medical benefits of cannabis.

The reason we think that cannabinoids like CBD may help certain medical conditions is that they are not just found in plants. The human body makes cannabinoids too, and there are even receptors for cannabinoids in the human brain. That is why some people believe that these chemicals might be useful in epilepsy, multiple sclerosis and Parkinson’s Disease. Studies have been done with smoked marijuana as well as CBD and other compounds. The results have not all been positive, but cannabinoids still hold promise.

The Promise – The hope for cannabinoids in Parkinson’s Disease is that they can reduce bradykinesia (slow movement due to stiffness) and dyskinesias (restless movements) as well as pain. There are individual stories of patients getting these benefits from smoking marijuana and from using something called CBD oil. Small studies have been done, and of course patients have tried both of these interventions on their own. Some have posted their experiences on YouTube. Larry Smith’s video about treating his dyskinesias with CBD oil has gotten 2.3 million views.

The Pitfalls – Cannabinoids can lower blood pressure. Many Parkinson’s patients have problems with low blood pressure already, which causes lightheadedness and even passing out. Those patients should not use cannabinoids, as doing so can make that problem worse. Some Parkinson’s patients have hallucinations. Those patients should not use anything that has the cannabinoid THC in it. Remember, that is the one that produces the “high.” In some studies, using CBD without THC actually reduced hallucinations.

The Science – Scientific studies come in different kinds, and some are more rigorous than others. The most informal (least “scientific”) is a survey, and most cannabis studies have been like that. In the largest such study, 84 Parkinson’s patients smoked marijuana cigarettes and then answered questions about whether they felt their tremor, stiffness and other symptoms improved.

Some things you need to know about legalized recreational marijuana in Michigan

by Mike Thompson, Detroit Free Press

Reflecting the legalization of marijuana for recreational use, the state department that regulates the pot industry is changing its name. The Bureau of Medical Marijuana Regulation is now called the Bureau of Marijuana Regulation. The department is charged with coming up with the rules and regulations that will govern the fledgling recreational marijuana industry. “While many other states have various licensing, regulation, and patient programs spread throughout different departments and agencies, BMR will keep marijuana-related services in one place in order to best enhance consumer protections and make regulations more efficient for business customers,” said Shelly Edgerton, director of the state’s Department of Licensing and Regulatory Affairs.

The state has also launched a new website – michigan.gov/marijuana – with resources for both the medical and recreational marijuana communities. The department is calling the new industry the “adult use” marijuana market to better reflect that the new legalization only applies to people 21 or older.
Many of them said they felt better. That is where most of the positive news about cannabis comes from. The problem is that asking someone if they feel better after smoking pot is not groundbreaking science. And we don’t know how much of what chemical was in each cigarette, which would have to be standardized if we are going to recommend something as a treatment. The most rigorous kind of study is the randomized, double-blind, placebo-controlled trial. In that kind of study, half the patients get the medicine, and half get the placebo (the fake medicine). It is “randomized” because patients are assigned to either group randomly. It is “double blind” because neither patients nor the doctors evaluating them know who is getting the real drug and who is getting the fake. They only find out later. That way, there can be no bias in looking at the results. To date, there have been four such trials looking at cannabinoids in Parkinson’s Disease. None showed significant benefits from cannabinoids.

Does that mean that cannabinoids don’t help Parkinson’s Disease? That their promise has gone up in smoke? No, it doesn’t. Those trials were too small, and each one used a different chemical and measured a different outcome. We need a much bigger trial to assess pain, stiffness, dyskinesias and the other things that matter to Parkinson’s patients. Until then, we only have anecdotes and YouTube videos to go on.

The Law – Marijuana itself is now legal in Michigan, however it is still illegal under federal law, so CBD oil is the form of cannabis that most people are talking about as a treatment for neurological disorders. So, what is CBD oil, and is it legal? Remember the two important cannabinoids: THC and CBD. THC is the one that gets you high, and CBD is the one that is supposed to treat seizures and other neurological problems. CBD oil is a product made from cannabis that has CBD without the THC. (No more than 0.5% THC and at least 10% CBD) It has the purported therapeutic value without any habit-forming potential. You would think such a product would be legal. You would be wrong.

The Future – If cannabinoids are to play a role in the treatment of Parkinson’s disease, and I believe they can, then we need two things: rigorous science and common sense. First, we need very large, well run studies that can answer the question of what Parkinson’s symptoms respond to what doses of CBD and what complications we need to look out for.

Second, common sense needs to prevail, and CBD needs to be reclassified by the DEA. As I am writing this, that is being considered. Up until now, CBD has been in the same category as peyote and LSD, even though it has no addictive potential.

Let’s hope that changes soon. It would be best for advancing science and helping patients.

The Michigan Parkinson Foundation strongly advises you to consult your physician before you start taking Cannabis.

Dr. Greg McLauchlin is an Assistant Professor of Neurology at Baylor College of Medicine.

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