

THE PD MOVERS WE KEEP MOVING

Living and Thriving with Parkinson's Disease in Our Black and African American Communities

ILLUSTRATIONS BY RANDELL PEARSON



DEDICATED
*to all people and families
living and thriving with
Parkinson's Disease*



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The PD Movers - We Keep Moving

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THE PD MOVERS WE KEEP MOVING

**Living and Thriving with Parkinson's Disease
in our Black and African American Communities**

**Narratives by Bernard and Denise Coley, Sandra Coplin,
Victoria Dillard, Richard and Angela Huckabee, Lorraine Haye,
Don Ransom, Hiral Shah, and Kermit Smith**

**Edited and compiled by Danielle Kipnis, Michele Lin,
Hiral Shah, Lori Quinn, and Anita Parker**

Contributions by Alissa Pacheco, Chelsea Macpherson, and Elizabeth Delaney

Illustrations and Book Design by Randell Pearson

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INTRODUCTION

In the Spring of 2021, the PD Movers were invited to come together to develop an Educational Guide for Parkinson's disease (PD) designed specifically for the Black and African American community. What follows is the result of those discussions, along with bonds of kinship, friendship, and mutual respect.



BERNARD COLEY is a care partner for his wife with Parkinson's disease. Along with his wife, he advocates for participation in Parkinson's related research, engages in outreach work in Black communities, and supports Parkinson's related organizations. He desires to serve the PD community and inspire other care partners to find the silver linings while taking care of Parkinson's patients.



While battling the disease herself, **DENISE COLEY** actively serves on the boards and committees of various Parkinson's disease organizations, participates in support groups and studies, and mentors PD patients. She hopes to educate under-engaged communities and empower PD patients to live a better quality of life.



SANDRA COPLIN felt scared when she was diagnosed with Parkinson's disease, but relieved that the diagnosis allowed her to move forward. Fearing the unknown, she is beyond grateful to have her faith, family, friends, and physicians by her side to support her as she walks on her path.



Due to a scary experience with medications, **VICTORIA DILLARD** tried to manage Parkinson's disease on her own. After several years, she bravely mustered up the courage to ask for help. Today, she counts her blessings, including her family, friends, doctors, and the PD community, all who have supported her through the rough days.



LORRAINE HAYE is a caregiver for her mom with Parkinson's disease. As she navigates her role, she learns the importance of being patient with her mom, forgiving herself when days don't go as planned, and relying on her faith to help sustain her and practice gratitude.

THE PD MOVERS • WE KEEP MOVING



ANGELA HUCKABEE is the wife and care partner of Richard Huckabee, who has Parkinson's disease. She admires her husband's determination to fight this disease and is hopeful for the future.



For **RICHARD HUCKABEE**, it was a long journey to his diagnosis of Parkinson's disease. After nine years of experiencing symptoms, several misdiagnoses, and even losing his job, he finally received a proper diagnosis. He feels strongly that there is no excuse for his prolonged diagnosis just because he, a young Black male, does not fit the typical PD profile of an "old white male." Richard would like doctors and neurologists to talk to their patients more about the negative side effects to medications, especially dopamine agonists.



ANITA PARKER is a licensed social worker and serves as the Community Outreach Director of St. Luke A.M.E. Church. She is a community partner to the research team and a staunch advocate for bringing resources to NYC Black and Hispanic communities.



DON RANSOM is a man of many talents. He was a musician in high school, served in the United States Air Force, was an employee of the United States Postal Service and is a dedicated athlete. He longs for the way his life used to be, but is grateful that he is able to share his journey and story with others, hoping to impact others and make it better for them.



DR. HIRAL SHAH is an Assistant Professor of Neurology at Columbia University Irving Medical Center in the Division of Movement Disorders and Medical Director of the Parkinson's Foundation Center of Excellence. She is committed to learning how to identify, address, and overcome barriers of stigma and discrimination to improve care access for vulnerable individuals who suffer from mental health conditions and neurodegenerative disorders.



KERMIT SMITH, an enthusiastic football coach and avid traveler, had his life upturned when he was diagnosed with Parkinson's disease. Through his faith and the help of a neurologist and psychologist, he finds the strength to continue doing what he loves.



THE PD MOVERS - OUR STORIES

We are the PD Movers and we are here to share our stories with you. We have Parkinson's disease or care for someone with it. We have faced challenges from diagnosis to living with the disease each day, but we have learned to live and thrive with PD. These are our stories.

Kermit asks, "Don, what was your life like before you were diagnosed?"

NOTE: The shadowy figure seen in some of this book's illustrations is the metaphorical representation of Parkinson's disease.

D O N R A N S O M

In high school, I played the trombone, tuba, and sousaphone. I became a certified electrician and joined the United States Air Force where I was an Aviation Technician. After, I worked for the United States Postal Service as a carrier, sorter, desk clerk, and bulk mail clerk for 35 years. I also played baseball, softball, basketball, volleyball, tennis, bowled, and ran marathons recreationally. My diagnosis came in 2005, and it truly has been a journey.

What about you Richard and Angela?





ANGELA AND RICHARD HUCKABEE

RICHARD: I had a great job where I was working in the oil industry in upper management. I was getting promotions, winning all kinds of awards, thriving, and enjoying life! One day it all stopped.

ANGELA: He was frustrated, out of sorts, falling behind on his work duties. I noticed he was very stiff when he walked. His arms did not move. His voice was changing, he was off balance, and overall moving extremely slowly doing most activities. I thought it was the stress of his position at work. Over time, the symptoms worsened and my husband was fired from his position. I tried to be a supportive and encouraging wife along the way. My husband repeatedly told me that he just did not feel like himself.

RICHARD: I was diagnosed with Parkinson's disease on February 13, 2013. However, my Parkinson's journey started nine years earlier, in 2004, when I first noticed those significant differences in my health.

How did you all know things were changing?

VICTORIA DILLARD

My left index finger would move on its own.
Up and down, up and down, up and down.
I would watch.
Then it became worse. It became Parkinson's disease.





BERNARD AND DENISE COLEY

BERNARD: My wife, Denise, was diagnosed with Parkinson's disease in January 2018. Our family knew something was going wrong for years, but those random incidents had no name. Denise was dropping dishes, walking slowly, misspeaking more often, taking longer to complete work and routine tasks, and most noticeably, suffering through fatigue and sleeping a lot.

DENISE: Yes, over a ten year period, I slowly started experiencing non-motor symptoms, including fatigue and insomnia. I also experienced motor symptoms such as trouble balancing, falling, an absent arm swing, and small cramped handwriting. (I later learned the medical term for this is "micrographia.")

I thought the muscle fatigue was from my marathon training and participation; but my concerns escalated when my children told me that I was shaking during Thanksgiving dinner in 2017. I never imagined that the symptoms over the previous ten years were related to each other.

To be honest, I was not prepared for the "P word" and immediately did not hear anything else. I promptly told the doctor that he gave me a death sentence as I watched my life plans vanish into thin air in seconds. During the initial six weeks, I had a pity party and went through the stages of the grief cycle.

BERNARD: While my wife drifted into a pity party, I found myself having to make a choice: Would I join her or forge another path? I knew that Parkinson's disease was not a death sentence, but beyond that, I knew little about it.

ANGELA AND RICHARD HUCKABEE

RICHARD: I also had a long road to diagnosis. After MRIs, full body scans, and stress tests (running on a treadmill), I was incorrectly diagnosed with Lyme disease, low vitamin D, and a variety of other disorders. I was given the wrong medications which worsened my symptoms.

After nine years of searching for what was going on, my doctor sent me to a neurologist.

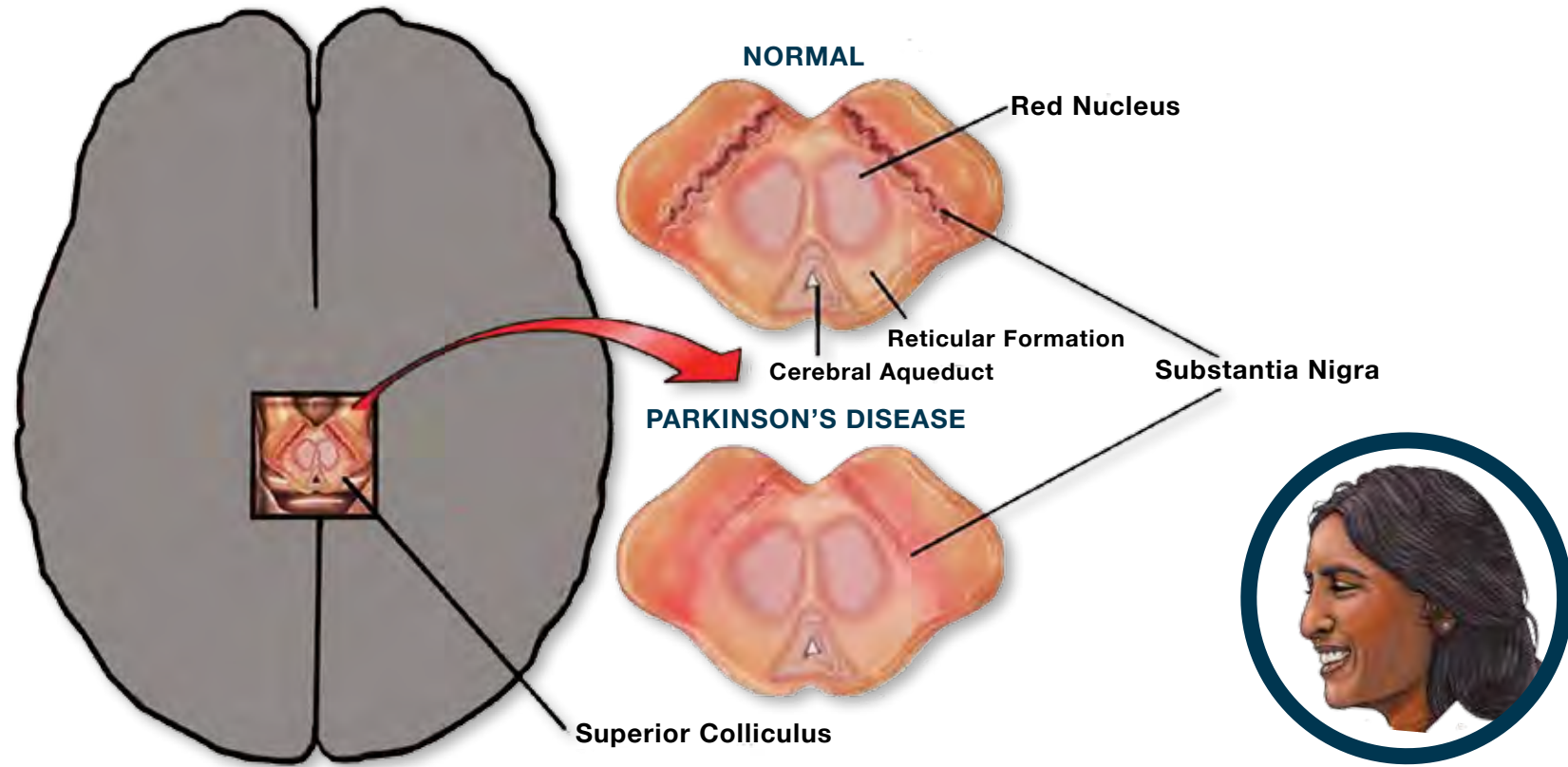
I still remember the details of the visit. I touched my nose with my index finger, touched his index finger with my right hand followed by my left, and held my arms straight out for about a minute. I tapped my index finger to my thumb as wide and as fast as I could for both hands. Finally, he observed me walking. After this ten-minute examination, he diagnosed me with Parkinson's disease.

I was relieved and happy after nine years of searching, struggling, complaining, declining, and wondering what in the world was happening. I was also devastated.

ANGELA: I was pretty relieved to know what the problem was, and hopeful that he would be able to live a normal life with Parkinson's disease.

After the diagnosis and retirement, he was able to focus on his health, exercise, education, and determination. Determined is a word I definitely use for my husband. He is determined to fight this disease. As my husband's care partner, I continue to be hopeful, thankful, and pray to ask God to help my husband remain mobile and in his right mind.





UNDERSTANDING PD

DR HIRAL SHAH

Thank you all for sharing - you all noticed something was wrong, but did not understand what was causing these changes. It is too often that people with Parkinson's disease have their early symptoms unrecognized, leading to unnecessary delays in diagnosis and treatment! Let me share a little bit about Parkinson's disease.

Parkinson's disease is a disease of the brain where the neurons, or brain cells, that produce a neurotransmitter (a chemical) called dopamine degenerate slowly over time. Because of this lack of dopamine, people experience symptoms of movements (motor symptoms) as well as other symptoms that do not affect one's movements (non-motor symptoms).

The main motor symptoms include tremor when sitting quietly, slowness of movements, stiffness of the limbs, and imbalance. These are some examples of the way these symptoms manifest:

- shaking of the limbs that tends to increase with stress, anxiety, or excitement
- soft voice
- difficulty using the hands to write, button, or cut food
- changes in walking and balance

Some examples of non-motor symptoms include changes in memory or thinking, sleep disturbances, loss of sense of smell, constipation, urinary symptoms, and lightheadedness when standing.

It is important to know that no two people are affected by Parkinson's disease in the same way, and not everyone experiences all of the symptoms. If you notice any of these symptoms, it is always wise to seek evaluation by your medical doctor or a neurologist (a specialist in the evaluation of the nervous system). There are even specialists for Parkinson's disease called movement disorder specialists.



DR. HIRAL SHAH AND SANDRA COPLIN

DR. HIRAL SHAH: When you see your doctor, they will ask you about your symptoms and how they affect your life. They will also take a careful history of your medical problems and medications, as well as your work and family history. Finally, they will do a physical examination by looking at your eye and body movements, feeling your muscles, and watching you walk. With this information alone, a doctor or specialist usually can make a diagnosis of Parkinson's disease. Sometimes, they will request an MRI of the brain to make sure no other abnormalities could be causing your symptoms. Infrequently, they may do a DAT scan, which is a special picture using Nuclear Medicine techniques to examine the dopamine production in your brain.

When seeing your doctor, always advocate for yourself. Write all your questions down in advance so you don't forget to ask and take someone with you to the visit. I know it is a difficult and stressful experience for many. If a diagnosis is made, your doctor will be a part of your care team for the long haul, so it is important you have trust with that individual!

SANDRA: Yes, it was so important to build trust with my doctor.

When I finally decided to return to my doctors, they were astonished that I had not been on any medication for years. A neurologist walked into the examination room. We exchanged greetings and he listened to everyone's assessment of my symptoms. He completed the examination, rotating my foot clockwise then counterclockwise, touching my nose then reaching out to his index finger, making me stand up and sit back down.



Breaking Down the Myths

MYTH

Parkinson's disease only affects older white men.

Parkinson's disease is a death sentence.

There is nothing you can do to improve Parkinson's disease.

The medications for Parkinson's disease stop working over time.

Tremor and slowness of movements are a natural part of aging.

of PARKINSON'S DISEASE

FACT

Parkinson's disease affects individuals of all genders, races, and ethnicities.

Those with Parkinson's disease can lead a productive, full, and long life.

There is scientific evidence that medication and lifestyle modifications, such as high intensity exercise, can help improve functional abilities and potentially slow disease progression.

Medications require adjustment over time, and there are also advanced treatment options.

Tremor and slowness of movements can indicate Parkinson's disease, and there are effective treatments to improve the symptoms.



LORRAINE HAYE

My name is Lorraine and I am a caregiver for my mom, Linnette. It is hard to watch someone you love live with these symptoms.

Often I believe that PARKINSON'S DISEASE IS A THIEF!! It took my mom and replaced her with someone else I don't know. My once vibrant mom loved dancing to her island music and cooking traditional Jamaican dishes, but now has become childlike.

Before I go visit and care for my mom, I have plans to do this and that, thinking that if I try this, maybe it will help "fix" her. A lot of the plans include requesting medications or devices, hoping that they will slow down, ease, or get rid of certain symptoms.

Each day is different. She has insomnia, so sometimes she wakes up at 10 a.m. or 2 p.m.. On one particular day, she woke up at 12:30 p.m. and there went most of my morning plans. She is much slower now. Depending on the day, the walk to the bathroom can take several minutes, followed by a bath, grooming, and dressing. The tasks are exhausting for both of us.

In the afternoon, I try implementing another plan. Sometimes the plans happen, sometimes they don't. I've learned that, as long as the plan is not an important appointment, it's best to just go with the flow. She gets stressed seeing me stressed, but as a caregiver, I need to make her life stress-free. This is easier said than done.

As her caregiver, I now make all of her life decisions. This is uncharted territory. Sometimes I fail and sometimes I succeed, but I seek help for things I don't know.

K E R M I T S M I T H

I agree, Lorraine, Parkinson's disease does feel like a thief.

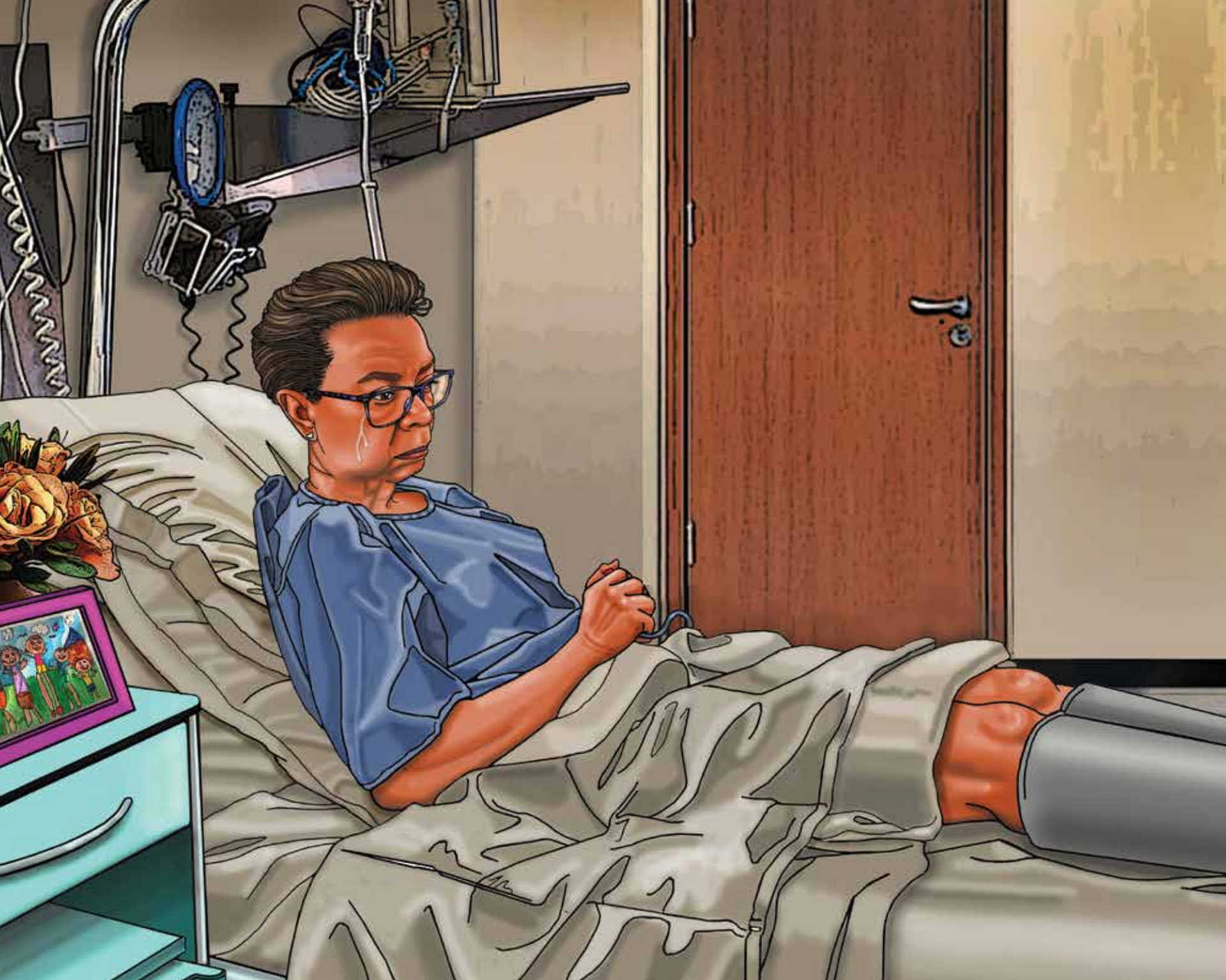
I liken living with Parkinson's disease to residing with an unwelcome guest. Go away! Leave me alone! This guest ignored my imploring and decided to make my body his home. With every year that went by, Mr. Parkinson's disease became more comfortable residing in my once happy abode. This atrocious guest paid no rent, offered me no entertainment, and provided me with no comfort or amusement.

He followed me to football practice, sat with me when I watched basketball games and movies, invited himself to accompany me to the theater, but he never made me laugh or brought me a moment of joy. This most unwanted guest totally disrupted the fabric and rhythm of my life. In spite of all of my dissent and anger, his credo became, "Mi casa es su casa!" (My house is your house!)

Everyday, all aspects of my life — emotionally, physically, and spiritually — became more challenging. Emotionally, it made me doubt myself. Physically, it played havoc with my body. Spiritually, it caused me to question my faith in God.

Yes, I regard Mr. Parkinson's disease as an opportunistic, unsought guest who took advantage of me when I was experiencing a very low ebb in my life.





SANDRA COPLIN

Kermit, you are not alone in feeling this way. I questioned my spirituality.

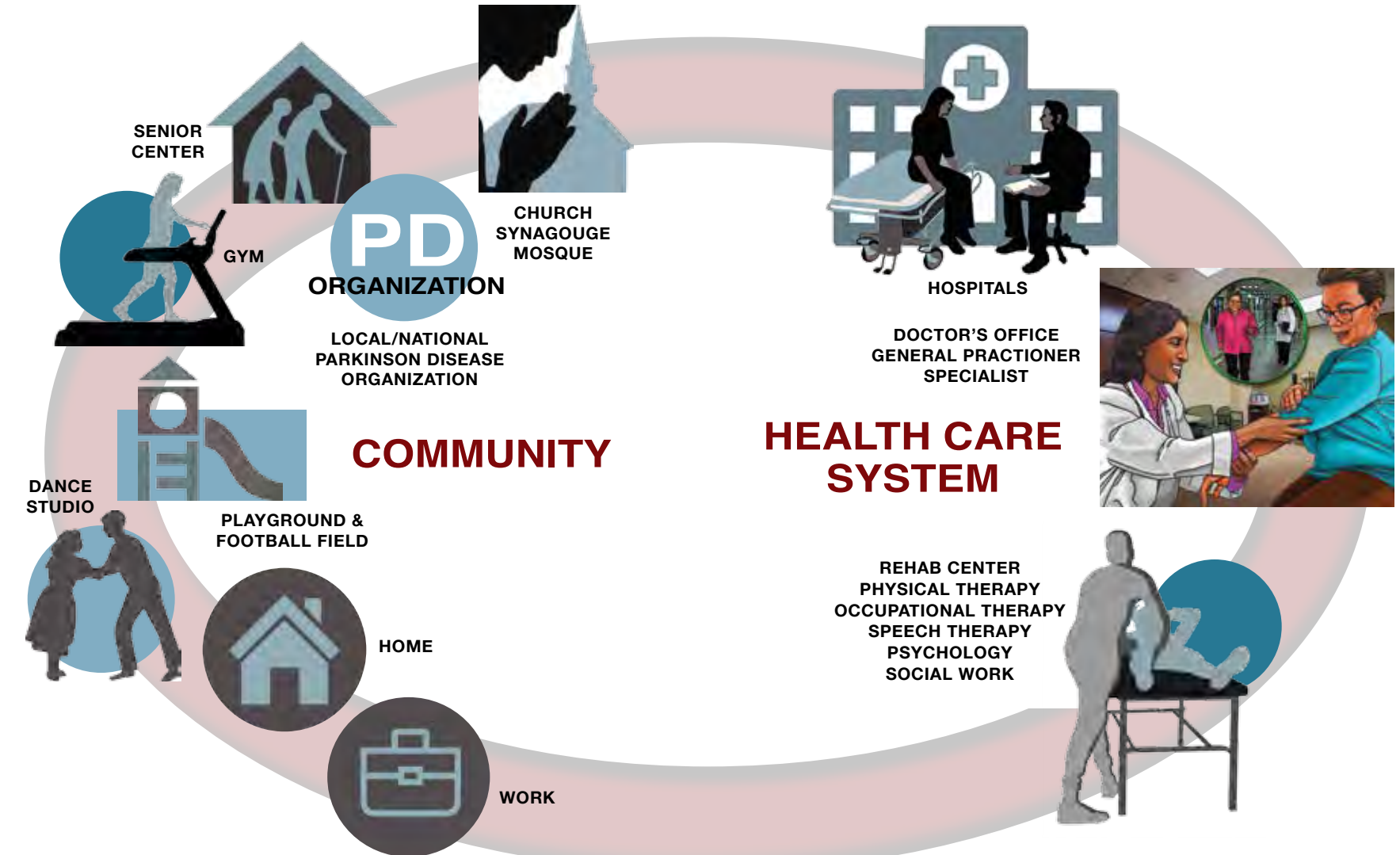
I was having an emotional breakdown. I've never been a weepy individual, but the tears were flowing nonstop. The hospital staff was very comforting. This medical emergency was only another challenge to overcome should the Lord deem it so. My Lord and my God, thy will be done.

TREATMENT

DR SHAH: There are mental, physical and spiritual solutions for individuals with Parkinson's disease and their care partners to thrive. Treatment strategies should keep in mind one's priorities, fears, and needs. Treatment requires trusting relationships with the care team. The team may include a care partner (family or friend), neurologist or movement disorder specialist, physical therapist, occupational therapist, speech therapist, palliative care specialist, pain specialist, psychiatrist or psychologist, social worker, faith-based leader, and community leader. Everyone's treatment journey is different - as exemplified by the PD Movers' stories. Additionally, care partners should prioritize self-care as well!

Treatment includes the following:

- (1) Medication management - take medications on time, monitor for side effects
- (2) Rehabilitation - physical, occupational, and speech therapy
- (3) Healthy lifestyle - diet, physical activity and exercise, and adequate sleep
- (4) Self-monitoring - observe daily life, emotional impacts
- (5) Psychological strategies - join a support group, self-care, identify healthy coping strategies, recognize anxiety & depression
- (6) Cognitive remediation - learn compensatory strategies and use memory aides
- (7) Maintaining independence - mobility aids and in-home supports when needed (e.g., home health aide)
- (8) Hobbies and socialization - social engagement, activities with family and friends, spiritual support group
- (9) Education - information from care team and organizations (e.g. Parkinson's Foundation, American Parkinson Disease Association, Michael J. Fox Foundation)



RICHARD HUCKABEE

I was very happy to have a movement disorder specialist. He encouraged me to work hard and put in the effort — take my medication as prescribed and on time, and exercise until I sweat.

He also changed my medication to give me optimal success in my daily life and routines. I left my new neurologist's office on cloud nine! I was thinking the combination of these three medications was the next best thing to a cure. Little did I know what waited for me on the other side...

“Hi, my name is Richard H. and I'm a compulsive gambler.” I was at a Gamblers Anonymous meeting, sharing my story. For six months, I had a new and uncontrollable urge to gamble and I could not understand why. I was sneaking around, lying to my wife, and feeling ashamed.

I played the slot machines at a casino that recently moved to my area. I hated slot machines and could not understand why all of a sudden, I had this insatiable desire to play them. I played for hours while my wife was at work. This was causing me tremendous problems at home.

I also shared with the group that I have Parkinson's disease. I had recently discovered that one of my medications had a side effect of compulsion. Other members of the group stood up stating they too have Parkinson's disease. I couldn't believe all I was hearing and it made me very upset. Why were none of us warned?

I went back to my neurologist and told him all about my gambling urges and episodes. My wife told him about her research findings. That visit he took me off the medication, and we all agreed no more dopamine agonist medication for me.





K E R M I T S M I T H

I sought the help and guidance of my primary care physician and he sent me to a neurologist. One fateful day I heard him say, “Mr. Smith, I think you are in the initial stages of Parkinson’s disease.”

Me, Parkinson’s disease? I thought that Parkinson’s was a disease of prize fighters or football players and those who had suffered multiple concussions. Since I fit none of those categories, I needed to believe that the neurologist was most assuredly mistaken.

My PD guest detested that I was introduced to a wonderful and competent neurologist who considers me a partner in my care, assists in the management of my medications, and helps navigate the complexities and perplexities of the health care system. I was also introduced to a psychiatrist who assisted in returning to me the strength of spirit needed to resume football coaching and traveling. The two of them helped me understand the mental aspects of Parkinson’s disease. The physical aspects were fairly easy for me because I believe in keeping my body in good condition; therefore, going to the gym as my doctors recommended was already my habit.

How have you managed the difficulties of PD, Denise?

DENISE COLEY

My initial internet searches were about exercise. I enrolled in Rock Steady Boxing classes. In these classes you not only exercise, but are also introduced to a gigantic support group. This was an important strategic decision in my Parkinson's journey and has made the biggest impact in my life. Within months, I was boxing and participating in tai chi classes, attending a support group, and trying complimentary therapies like acupuncture, holistic medicine, and myofascial massage.

Since that day in the waiting room, I choose to fight against falling into depression. I chair a Mission & Outreach Committee. I share my story with public speaking. I mentor other PD patients. I lend my voice and participate in research studies to help find treatments and cures. I listen to others struggling with PD to find what is working for them. I fight to make my life as meaningful as possible without pity or remorse. Every day is another opportunity to help someone in the PD Community and spread the word about the many free and readily available resources for people living with PD.

How do you face the daily challenges of PD, Victoria?





VICTORIA DILLARD

Now my days are almost normal. My health comes first with strenuous exercise and a healthy diet of mostly fruit, vegetables, and lean protein. I pray for strength and balance and on the rough days, I pray for rest. I give myself permission to accept each day as it comes. I count my blessings, my children, my family, my friends, and the Parkinson's community, doctors included, who have joined my circle of life.

EXERCISE

Parkinson's Exercise Recommendations

Parkinson's is a progressive disease of the nervous system marked by tremor, stiffness, slow movement and balance problems.

Exercise and physical activity can improve many motor and non-motor Parkinson's symptoms:

Aerobic Activity	Strength Training	Balance, Agility & Multitasking	Stretching
<p>3 days/week for at least 30 mins per session of continuous or intermittent at moderate to vigorous intensity</p> <p>TYPE: Continuous, rhythmic activities such as brisk walking, running, cycling, swimming, aerobics class</p> <p>CONSIDERATIONS: Safety concerns due to risks of freezing of gait, low blood pressure, blurred heart rate response. Supervision may be required.</p>	<p>2-3 non-consecutive days/week for at least 30 mins per session of 10-15 reps for major muscle groups, resistance, speed or power focus</p> <p>TYPE: Major muscle groups of upper/lower extremities such as using weight machines, resistance bands, weights or body weight</p> <p>CONSIDERATIONS: Muscle stiffness or postural instability may hinder full range of motion.</p>	<p>2-3 days/week with daily integration if possible</p> <p>TYPE: Multi-directional stepping, weight shifting, dynamic balance activities, large movements, multitasking such as yoga, tai chi, dance, boxing</p> <p>CONSIDERATIONS: Safety concerns with cognitive and balance problems. Hold on to something stable as needed. Supervision may be required.</p>	<p>10-15 days/week with daily being most effective</p> <p>TYPE: Sustained stretching with deep breathing or dynamic stretching before exercise</p> <p>CONSIDERATIONS: May require adaptations for flexed posture, osteoporosis and pain.</p>

See a physical therapist specializing in Parkinson's for full functional evaluation and recommendations.

Safety First: Consult your doctor on periods when taking medication if not safe to exercise and discuss with your physical therapist.

It is important to **modify and progress** your exercise routine over time.

Participate in 150 minutes of moderate to vigorous exercise per week.

AMERICAN COLLEGE OF SPORTS MEDICINE
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Parkinson's Foundation
LEADING THE WAY

Register: 800.473.4635/Parkinson.org

Exercise and rehabilitation therapies, including physical, occupational, and speech therapy are critical components of Parkinson's disease management.

Physical activities are any activities that get your body moving – these can be things such as gardening, walking the dog, or taking the stairs. Exercise is a form of physical activity that is specifically planned and structured. For example, riding a stationary bike or taking a yoga, tai chi, or boxing class. Research has shown that exercise and physical activity are particularly important for people with neurodegenerative diseases such as PD. Exercise has been shown to improve fitness, mobility, posture, and gait. It is important to develop a routine early in the PD lifecycle; studies have also shown that exercise in the earliest stages can potentially alter the progression of the disease by slowing the degeneration of motor and cognitive functions.

The Parkinson's Foundation along with the American College of Sports Medicine (ACSM) has created Exercise Guidelines for people with Parkinson's disease. Many PD organizations have great exercise resources for you – exercise guides, articles, virtual and in-person exercise classes, and more. We also recommend that people consult with a physical or occupational therapist so they can provide proper guidance and support.



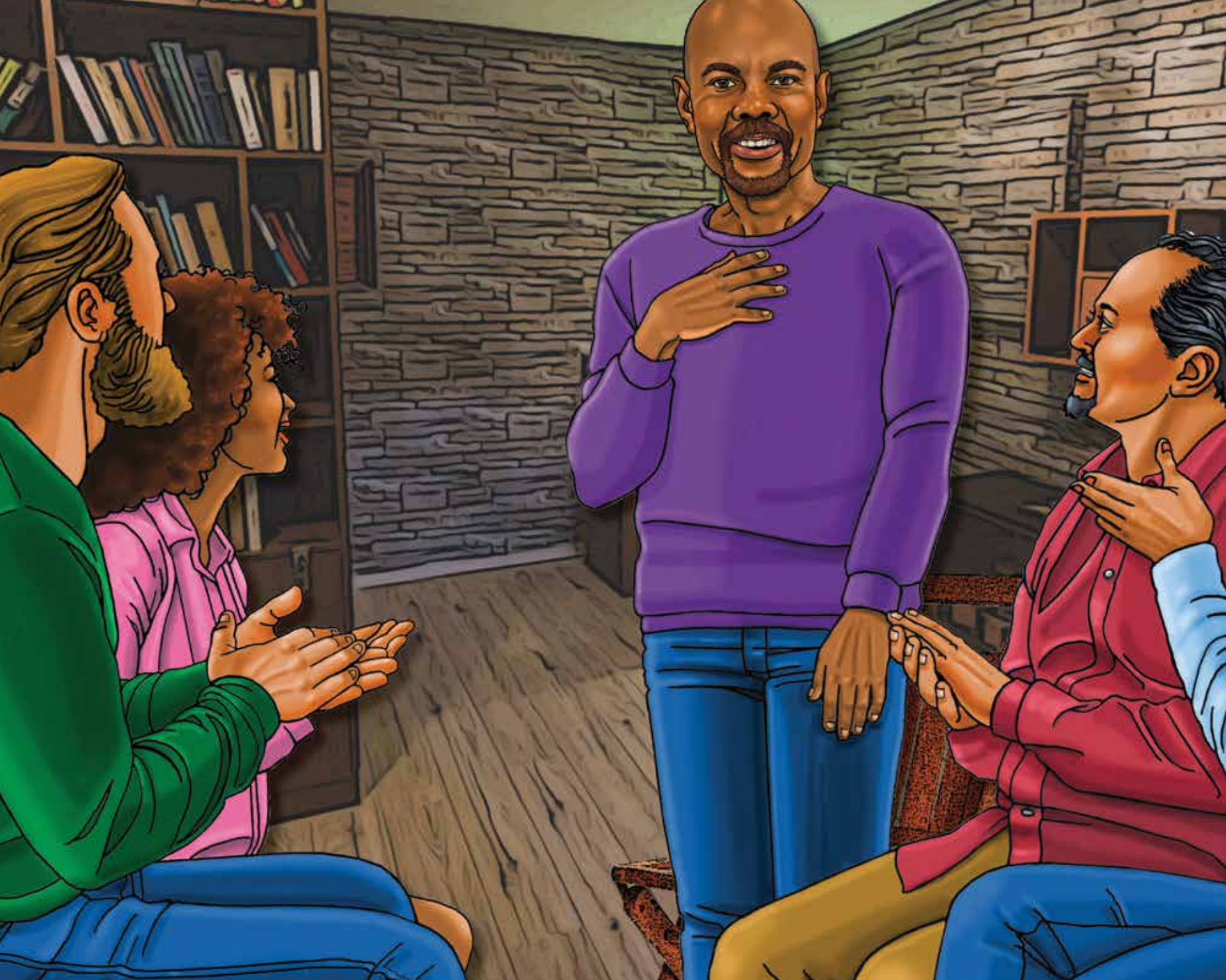
DENISE COLEY

From the moment of PD diagnosis, my first step was to get informed and find ways to get connected. I began an important daily habit of doing PD research. I visited all the PD websites, signed up for emails, read blogs and newsletters to learn any new information.

My purpose was to have an impact on the PD community and help bring Parkinson's disease awareness to the less engaged communities, so that everyone with PD can have hope and a better improved quality of life.

Bernard and I became Parkinson's Advocates in Research (PAIR) and joined The World Parkinson's Coalition, PD Avengers, and the Parkinson's Foundation People with Parkinson's Advisory Council (PPAC). Through these organizations, we share perspectives on Parkinson's disease research and advocate hope.





RICHARD HUCKABEE

Involvement in organizations has made a big impact on my journey too.

When I decide that I don't like what I purchase from a store, I can get back a full refund. I wish I could return Parkinson's disease for a refund, but I can't. So, I have decided to just hang it in the back of my closet. I can't help but to know it's there, but I can help how I'll live my life.

My physical therapist recommended that my wife and I join a research study (the first of many) that involved dancing and drumming classes for people with Parkinson's and their care partners. Through participating in the study, I improved my coordination, balance, and strength.

However, the real blessing was the wonderful friends we made. We meet every Monday morning for breakfast, continued fellowship, support, and hiking. We call ourselves "the Breakfast Club." We have become a family, supporting each other, sharing ideas, and helping each other get better every day.

I am involved in many organizations and attend all the classes that I can. InMotion is a wonderful place that provides PD specific exercises and education among supportive staff, coaches, and volunteers. Other classes are Better Every Day class, boxing, yoga, cycling, tai chi, art, drumming, singing, and support groups. I am also involved in the Parkinson's Foundation, Michael J. Fox Foundation, Davis Phinney Foundation, and Cleveland Clinic Support Group. I am a PD research advocate, a PD Avenger, and now a PD Mover.

My life has significantly improved and I have a zest for life and my journey. I wake up every morning with gratitude and praise!

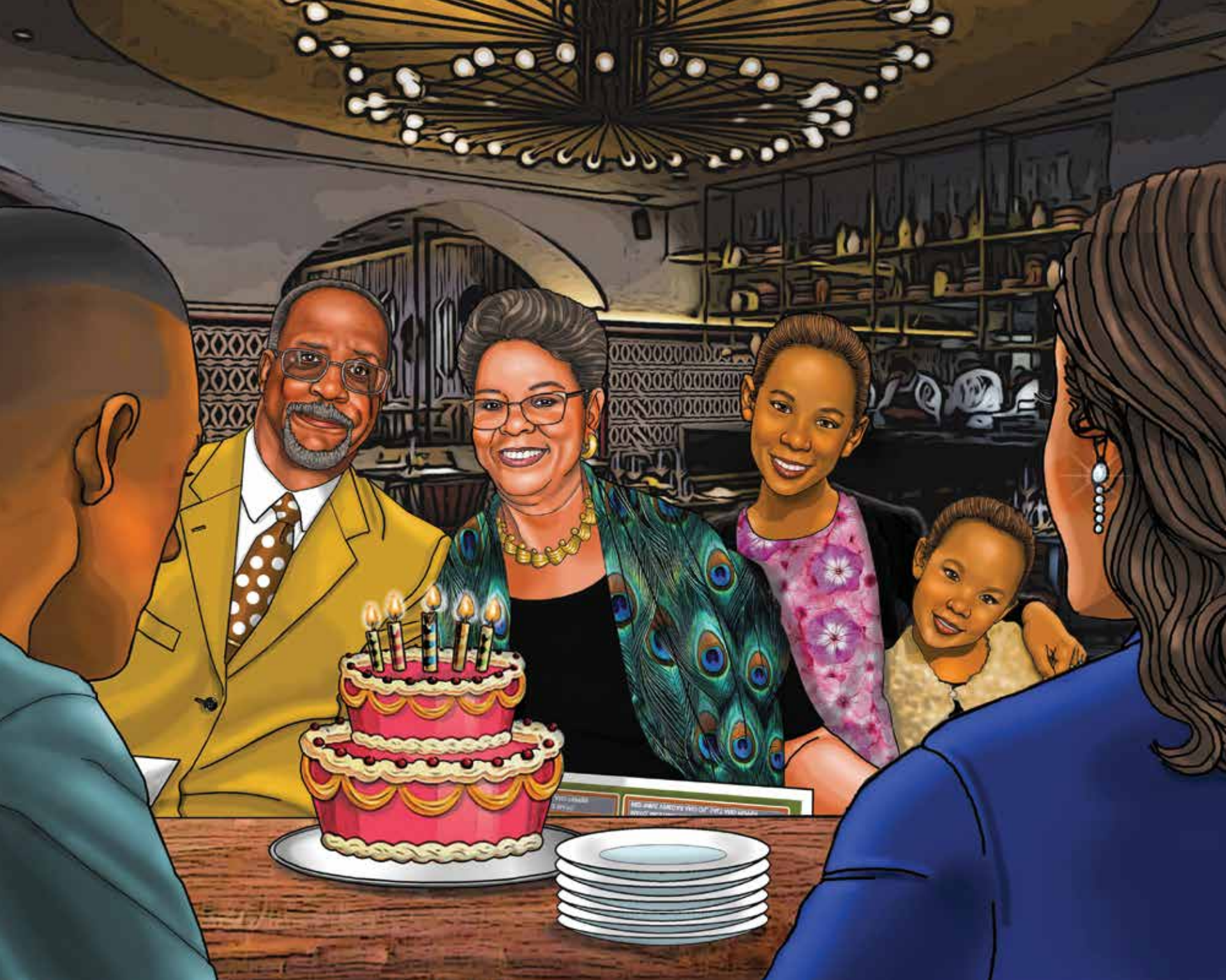
D O N R A N S O M

I too will continue to fight!

I have had good days, bad days, terrible days, sour days, crying days, screaming days, depressed days, and days of longing for my life to be the way it used to be. Days when I can go running for ten miles, play a game of tennis with my cousin, go bowling with my wife and children, sit and watch an entire television program without nodding off, and eat a meal without making a mess at the table. Days when my wife does not have to work so hard to take care of me.

I am an athlete. I am Don Ransom, Sr., and I am living with Parkinson's disease. I feel lucky every day that I wake up six feet above the ground. Through it all, I am grateful that I can share my story, give others a bit of knowledge about Parkinson's disease, and maybe make it a better journey.





SANDRA COPLIN

Family and faith are an important support for me.
I constantly look at the screen saver photo of my granddaughters.
Then, as it has been my entire life, my faith uplifts me.
My medical emergency was simply another challenge to overcome, should the Lord deem it so.
Whatever the outcome, I do not walk this path alone.

SANDRA COPLIN

I have Parkinson's disease, yet I am blessed and grateful.

Blessed and grateful for the strength provided me by the support of my faith, family, friends, and physicians.

Blessed and grateful my PD diagnosis was not a brain tumor as I had feared. For me, fear of the unknown is the worst. Knowledge of this diagnosis allows me to move forward.

Blessed and grateful this diagnosis came at a time in my life when I've accomplished and achieved most of my goals.

Blessed and grateful it wasn't a diagnosis or death involving any of the children in my family as it did years ago.

Blessed and grateful to be a member of the PD Movers.

I am blessed and grateful. Lord Thy will be done.

Amen.





LORRAINE HAYE

My faith in God sustains me. Many times I pray and cry everyday because the demands are great. Yet I am learning to be more thankful for each day and the small victories.

I also remember the evenings that my mom and I laugh together, a reminder that she was not stolen at all. She was right here all along!

RICHARD AND ANGELA HUCKABEE

Amen!

RICHARD: Gamblers Anonymous suggested I get a sponsor. I heard the voice of Jesus saying He has always been my sponsor. That He has sponsored me since the day I was born! My wife and I started doing our bible study together again. I couldn't believe it, but the bible study series topic was on overcoming addictions! God was truly in this!

I made a commitment to dedicate myself to a life of service, to improve the lives of others, yet I expect and require nothing in return. What Satan meant for evil and to tear me down, God meant for good and to lift me higher!

ANGELA: I believe God gave my husband to me for a reason. We are good together. We continue to travel, hike, exercise, pray, worship, and enjoy life together. I am hopeful!

I continue to pray and ask God to help my husband remain mobile and in his right mind. I am encouraged by my 86-year-old mother. She often reminds me to live for today and enjoy our life right now. Stop looking down the road.





BERNARD AND DENISE COLEY

BERNARD: Yes Angela, I agree we have an important role as care partners. My advice to care partners is to educate yourself about PD and to find the silver linings in tasks you will have to undertake to support your Parkinson's person. Resentment is a waste of valuable energy. Here are some of my personal silver lining examples: I am in the best physical shape that I have been in many years because I engage in regular fitness activities with Denise. I turned the daily task of preparing the family meals into an international food tour, learning to make nutritious comfort food meals from recipes around the world. Artistic plating and serving presentations help Denise deal with a loss of appetite and increase her interest in eating nutritional foods. The pictures and stories I post online have helped inspire others in the Parkinson's community and brought me new friends. I do outreach work to bring PD knowledge and resources to my Black communities, and I advocate for our participation in research studies to improve outcomes for Black people. Finally, I have learned a lot about medical research and research advocacy, engaging researchers and physicians in ways that they find valuable to their Parkinson's related work. Your efforts will help you cope with the sense of losing control over your life. PD is not going away, but neither am I. Now, I am able to help my wife and others in the PD community improve their PD journey and live better day by day.

BERNARD AND DENISE COLEY

DENISE: Thank you, Bernard!

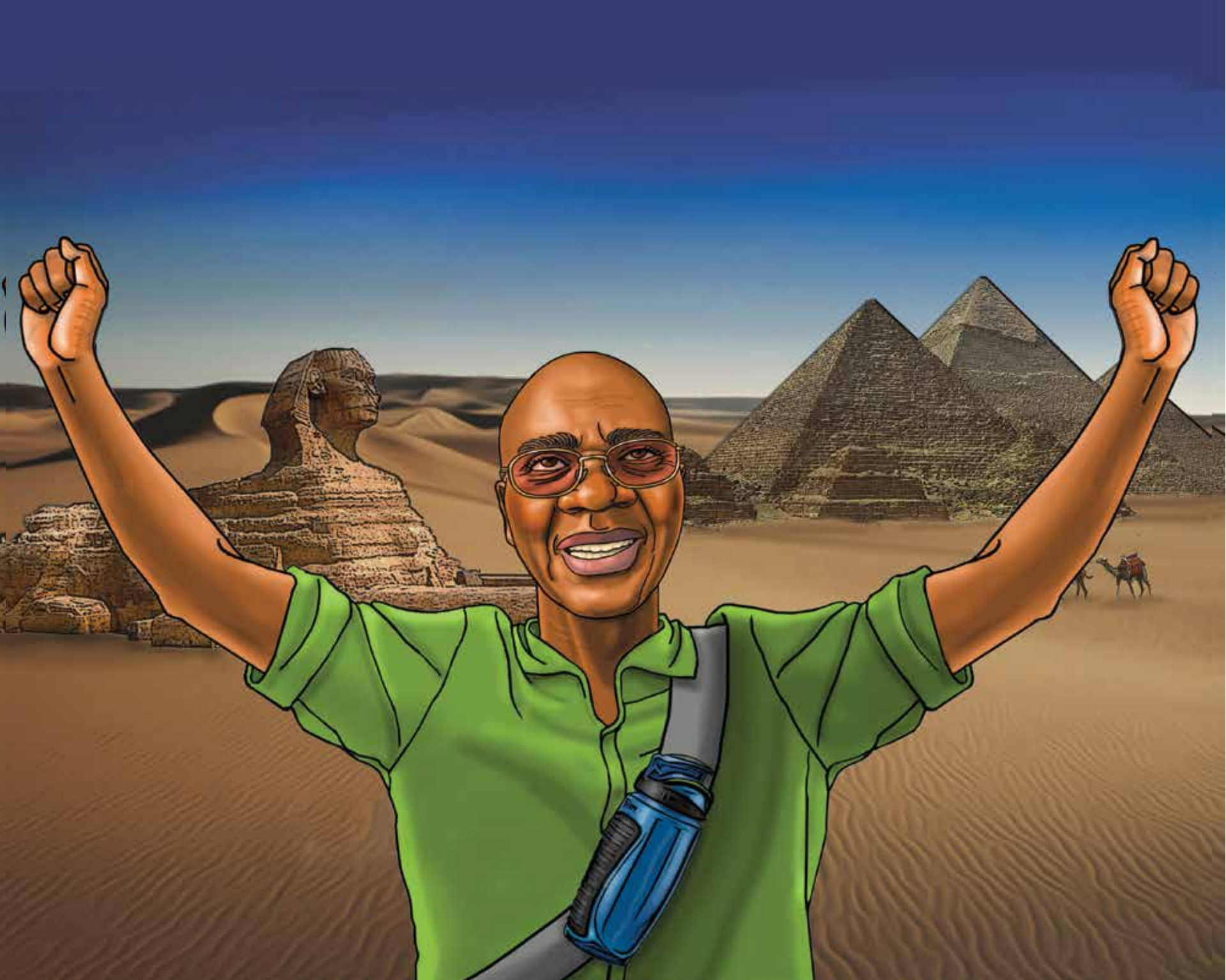
I found my purpose was to have an impact on the PD community and to help with bringing Parkinson Awareness to the under-engaged communities so that everyone can have hope and a better quality of life.

Since that day in the waiting room, I now participate in support groups, Parkinson's events, clinical trial studies and serve on Parkinson's organizations, committees, board and councils.

Today is another opportunity to help someone in the PD Community.

I stay mindful that this is a unique journey for each person with Parkinson's, but we choose to have hope and work on quality of life. Each day is a new opportunity to make a small step forward.





K E R M I T S M I T H

I have learned to thrive even in my PD guest's presence and neither of us is going anywhere. Sometimes he demands his squatter's rights, but many days I am the one who calls the shots. My guest and I will never become "best friends forever," but we are learning to live with, understand, and respect one another.

I resumed my football coaching career. I traveled to Egypt and toured Ethiopia. I am studying Egyptian hieroglyphic writing and I keep my mind and body engaged through the practice of tai chi. Broadway's theaters were a lost, but now reacquired friend and my oft excursions to view the best of film has resumed. I was back! I am back! Day by day, I am becoming spiritually healthier and stronger.

I am Healthy.
I am Strong.
I am Disease Free.
I am Blessed by My Ancestors.
I am Blessed by GOD.

RESOURCES

Please scan the QR code below to access the PD Movers website with current resources and additional educational materials that can help YOU live and thrive with Parkinson's disease.



Please visit PD MOVERS online at:

-  @PD Movers
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ELIZABETH DELANEY joined the Columbia University Irving Medical Center (CUIMC) Movement Disorders team as a Licensed Clinical Social Worker and Center of Excellence Coordinator in June 2017. She is also the social work manager for the department of neurology. Her interests include mental health of the chronically ill and disabled, and health care disparities.

DANIELLE KIPNIS is a yoga instructor and dancer specializing in yoga, breathing, and movement for neurodegenerative disorders as well as emotional and physical traumas and pain. She received her Masters in Applied Physiology at Teachers College, Columbia University, and is continuing in the program, pursuing her PhD in Kinesiology. She is grateful to be a part of this project and help share the PD Movers' stories to make Parkinson's disease care more accessible.

MICHELE LIN is currently a student at Barnard College of Columbia University and a research assistant at the Neurorehabilitation Research Laboratory (NRL). She is honored to be part of a meaningful project that she hopes will touch lives in the Black and Brown community. Her future plans include pursuing a career in healthcare administration or management in order to improve patient experience and satisfaction, as well as communication and transparency within healthcare.

CHELSEA MACPHERSON is a Doctor of Physical Therapy specializing in adult neurorehabilitation. She is a PhD candidate at Teachers College, Columbia University where she studies exercise induced neuroplasticity and physical activity behavior change across neurodegenerative diseases. She currently holds a position on the Academy of Neurologic Physical Therapy's Parkinson Disease Knowledge Translation Taskforce which is aimed at synthesizing and translating scientific evidence to disperse applications, products and tools for clinicians, and people with Parkinson's to use readily.

ALISSA PACHECO is a Licensed and Board Certified Occupational Therapist who is currently in pursuit of her EdD in Movement Science and Education at Teachers College, Columbia University with a focus on Motor Learning & Control. She has over ten years of clinical experience in neurorehabilitation. Currently, she is the Manager of the Neurorehabilitation Research Lab at Teachers College and an interventionist for research studies involving the self-management of physical activity routines in early-stage Parkinson's Disease.

ANITA PARKER is a licensed social worker and serves as the Community Outreach Director of St. Luke A.M.E. Church. She is a community partner to the research team and a staunch advocate for bringing resources to NYC Black and Hispanic communities.

RANDELL PEARSON, this book's illustrator and graphic designer, is an independent visual artist with over four decades of professional experience in both the corporate and private sectors. He has garnered awards from the Art Directors Club of New York, The Society of Illustrators (NYC), The Type Directors Club (NYC) and the Society of Publication Designers (NYC). His work has been exhibited at the Brooklyn Museum of Art and Parke-Bernet Galleries (NYC). He has received special recognition from the late Coretta Scott King, actress Jane Fonda and America's Cup winning sailor and businessman, Bill Koch, to name just a few of many notable individuals who have appreciated his work.

LORI QUINN is Professor in the Department of Biobehavioral Sciences at Teachers College, Columbia University, and holds joint appointments as Adjunct Associate Professor in Rehabilitation and Regenerative Medicine (Physical Therapy) at Columbia University Medical Center. Dr. Quinn is a research physical therapist and is the director of the Neurorehabilitation Research Lab at Teachers College. She is the principal investigator of several ongoing clinical trials of exercise and physical activity interventions in people with Parkinson's disease.

HIRAL SHAH is a movement disorders specialist who is committed to reducing health disparities for the Black and Brown Community with Parkinson's disease and is inspired by the stories of her patients. She believes that storytelling is a powerful method to teach and inspire others to live and thrive with Parkinson's disease.



THE PD MOVERS - WE KEEP MOVING is a compilation of narratives of African American and Black individuals and caregivers who are living and thriving with Parkinson's disease. Our goal is to inspire and connect individuals in the community by sharing the experiences of these remarkable individuals. We also hope these stories will educate others by removing the mysteries and misconceptions of Parkinson's disease and provide useful resources regarding diagnosis and treatment to allow others to thrive with Parkinson's disease.

