Living and Working with “HOPE” in the Presence of Parkinson’s

Frank C. Church, PhD
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Blogs at https://journeywithparkinsons.com/

“HOPE”
H = Hope/Health(y)
O = Optimistic/Positive
P = Persistence/Perseverance
E = Enthusiasm for life, for career, and for exercise
Table of Content

• Preface: 5-pages of the blog post Living and Working with “HOPE” in the Presence of Parkinson’s;

• Part 1: Some of Frank’s quotes about living with Parkinson’s (four 1-page handouts);

• Part 2: Suggestions, character traits, and tips for the journey through life and career in the absence and presence of Parkinson’s (seven 1-page summaries);

• Part 3: Health and exercise while living with Parkinson’s (five 1-page summaries);

• Part 4: Historical time-line of Parkinson’s disease (six 1-page reports).
Introduction to Blog Post

"Life is difficult. This is the great truth, one of the greatest truths-it is a great truth because once we see this truth, we transcend it." M. Scott Peck

"Life is hard. Life is beautiful. Life is difficult. Life is wonderful." Kate DiCamillo

Introduction: A student and loyal reader of this blog recently asked “What do I do with all of the advice/tips/suggestion posts from the blog? ”My reply was they help me balance out my day-to-day life; especially for work and to protect my time for exercise and time to spend with the significant people in my life. I typically print out the 1-page summaries and keep them in a folder, or post them at work, as reminders to what I value. “What about all of your supportive and descriptive statements about living well with Parkinson’s disease? I bet your readers of the blog would enjoy having some of your statements compiled like your advice posts, don’t you agree?” My response was you want me to make some 1-page handouts of my comments? Yes, I could do that. That kind of a handout could help me as well; they could also serve as a roadmap to where the blog has traveled. Interesting questions/suggestions, thanks for asking them.

"If you don't know where you are going, you might wind up someplace else." Yogi Berra
The Tenacity of Hope

The tenacity of hope: There are 4 broad goals to this blog: i) describe living with Parkinson’s (“Life Lessons”); ii) report emerging medical strategies for treating/managing/curing Parkinson’s (“Medical Education”); iii) support mechanism to anyone with Parkinson’s or any of the neurodegenerative disorders (“Strategy for Living”); and iv) educate by presenting scientific aspects of Parkinson’s (“Translating Science”). Throughout many of the posts here, I firmly believe that words/concepts like hope, positive, persistent, staying happy and healthy, exercise (a lot, daily if possible), and refuse to give up are all important 'life-lines' for us to adopt in our dealing with this disorder. Today's message returns to hope and “HOPE”. Hope is defined by the Cambridge dictionary as “the feeling that something desired can be had or will happen”. I use HOPE as an acronym in Parkinson’s and it stands for:

H = Hope/Health(y)
O = Optimistic/Positive
P = Persistent/Perseverance
E = Enthusiasm for life, for career, and for exercise
The Tenacity of Hope (continued)

Steve Gleason said "Life is difficult. Not just for me or other ALS patients. Life is difficult for everyone. Finding ways to make life meaningful and purposeful and rewarding, doing the activities that you love and spending time with the people that you love - I think that's the meaning of this human experience." I really like the sentiment of his statement and admire his courage through adversity. It reminds me that we are a community with a shared theme; while we are spread out throughout the world, we understand one another because Parkinson's has been sewn in to the fabric of our lives. I am also convinced that staying hopeful and using HOPE gives us tenacity to deal with the subtle changes being forced upon us by the ever present Parkinson’s.

"Your qualifications, your CV, are not your life, though you will meet many people of my age and older who confuse the two. Life is difficult, and complicated, and beyond anyone's control, and the humility to know that will enable you to survive its vicissitudes." J.K. Rowling
Living and Working With HOPE

Living and working with HOPE: This current post reinforces the meaning for HOPE. It reminds me of Stevie Nicks and Fleetwood Mac’s Landslide where she sings "Can I sail through the changin' ocean tides? / Can I handle the seasons of my life?" We confront both of these questions daily with Parkinson's. My hope is you find reassurance that your life and world are still meaningful, and you are not battling Parkinson's alone. We know and we understand what you are confronting each day; thus, be persistent and remain hopeful.

Here is a link to a SlideShare file that will allow you to easily read/view all of these 1-page handouts. You do not need a login, it's free. You can read, clip and copy individual slides (1-page handouts); it even will let you download the entire file: click here to view Living and Working with “HOPE” in the Presence of Parkinson’s. Alternatively, here is the URL: I have enjoyed re-reading the old blog posts these were derived from (some of these were previously posted and several are new) and they are presented as follows:
• Part 1: Some of Frank’s quotes about living with Parkinson’s (four 1-page handouts);
• Part 2: Suggestions, character traits, and tips for the journey through life and career in the absence and presence of Parkinson’s (seven 1-page summaries);
Living and Working With HOPE (continued)

• Part 3: Health and exercise while living with Parkinson’s (five 1-page summaries);
• Part 4: Historical time-line of Parkinson’s disease (six 1-page reports)

"Life is like riding a bicycle. To keep your balance, you must keep moving." Albert Einstein

"Know that wherever you are in your life right now is both temporary, and exactly where you are supposed to be. You have arrived at this moment to learn what you must learn, so you can become the person you need to be to create the life you truly want. Even when life is difficult or challenging—especially when life is difficult and challenging—the present is always an opportunity for us to learn, grow, and become better than we’ve ever been before.” Hal Elrod

Part 1: Some of Frank’s quotes about living with Parkinson’s

• Believe in Life in the Presence of Parkinson’s
  (go here to read blog post: https://journeywithparkinsons.com/2016/08/14/believe-in-life-in-the-presence-of-parkinsons/)

• 7 Hopeful Quotes From the Blog to Support Your Life with Parkinson’s Disease
  (taken from http://journeywithparkinsons.com)

• 8 Quotes From the Blog on Living Positively with Parkinson’s Disease (taken from http://journeywithparkinsons.com)

• 8 Quotes From the Blog to Support Your Journey with Parkinson’s Disease
  (taken from http://journeywithparkinsons.com)
Believe In Life In The Presence Of Parkinson’s

I’m a healthy person that happens to have Parkinson’s; this is what I believe:
I believe daily exercise enhances my life in the presence of Parkinson’s.
I believe people-with-Parkinson’s can become healthier with exercise.
I believe sustained exercise can promote neuroplasticity to re-wire my neural network.
I believe I have the ability to do the repetitions to re-train my brain.
I believe staying positive will help control the course of my Parkinson’s.
I believe having courage will provide mettle in the battle against my disorder.
I believe being persistent allows me to restrain my Parkinson’s.
I believe motivation begins from within, and there can be no backing down to this disease.
I believe if I don’t give up I can slow the progression of my disorder.
I believe if you pity me it feeds the hunger of my Parkinson’s.
I believe if you join my team, you can help me stall this slowly evolving disorder.
I believe attitude is the fuel to sustain the effort to combat Parkinson’s.
I believe in science that new therapies/strategies against Parkinson’s are on the horizon.
I believe exercise with ability, motivation and attitude will work to my advantage each day.
I believe that each new day renews my chance of slowing the beast named Parkinson’s.
My daily mantra is to never give up; I refuse to surrender to Parkinson’s.

Frank C. Church, PhD
UNC School of Medicine
14 AUG 2016
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<tr>
<th><strong>Remain Authentic</strong></th>
<th><strong>Gain Control Of Your Symptoms</strong></th>
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<td>“The song of the journey ahead for us is about living authentically in the presence of Parkinson’s.”</td>
<td>“Each day we wear a cape on our back labeled with the letters PD. Each day we bring a positive reaction to handle our symptoms, I am convinced when we begin to fade those letters; we begin to gain control of our symptoms.”</td>
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<th><strong>Be Hopeful</strong></th>
<th><strong>Your Inner Strength</strong></th>
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<th><strong>We’ve Got Time To Live</strong></th>
<th><strong>Renew Your Life</strong></th>
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<td>“There’s time left in your life to sing, live, love, work, manage your disorder. There’s time left in your life to accomplish much, if not all. Remain hopeful, mindful, positive, courageous, and persistent. Let our journey continue.”</td>
<td>“Awake each morning: Each new day renews our life, our contract to keep living. Strive to live-forward, and always remember that we’re still in the driver’s seat of our world. Live decisively even as we accept the problems from Parkinson’s.”</td>
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<tr>
<th><strong>You Are Still You</strong></th>
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<tr>
<td>“Always remember, your life matters now with Parkinson’s as much as it did before Parkinson’s. Stay hopeful as you navigate adversity, stay you in spite of your Parkinson’s.”</td>
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### 8 Quotes From The Blog On Living Positively With Parkinson’s Disease
(from [http://journeywithparkinsons.com](http://journeywithparkinsons.com))

#### Then And Now, Life Is Still Good

“Imagine yourself then, imagine yourself now with Parkinson’s. What are the differences? Life was good back then, life is still good. The strength and resilience of friendships then was ever present, and now this is even more important. The bonds in love before were strong but now even more crucial to augment survival.”

#### A Shining Beacon Called Hope

“To me, hope is a source of clarity. If you remain hopeful, there’s a strong likelihood that you will succeed in your endeavors. In managing a chronic progressive illness, you’re sometimes making decisions almost hourly about what to do next, how best to respond, thinking what is going to happen next? Reminding yourself there is hope allows you to more easily plan the response and follow the appropriate path.”

#### Stay Courageous And Be Strong

“Brené Brown says that “Courage is to tell the story of who you are with your whole heart”; to me that says our courage and strength will shine through as our heart confronts our misfortune named Parkinson’s.”

#### Be Persistent

“Our most difficult life-challenges could create the greatest time of our lives. As President Coolidge remarked “Nothing in the world can take the place of persistence” says to me we must always keep going in dealing with our disorder. No doubt this is a tough situation having Parkinson’s, but being persistent is not giving up without trying. Staying persistent is creating new options, and it continually requires the courage of one’s convictions.”

#### Don’t Give Up, Don’t Ever Give Up

“The life goal has always been simple: thrive not survive; work hard; strive to excel and learn from your failures; compete hard and have fun; when you fall down get back up; love your friends and family and always support them; stay positive and don’t dwell on the negative; and never give up, never ever give up.”

#### Acknowledge And Accept Your Disorder But You Are Still Alive And Strong

“Accept the cards you are dealt, but you decide how to play the hand with ______ [you fill-in-the-blank (for me, it’s Parkinson’s)]: I accept my Parkinson’s, but I refuse to let it define me. I accept that my future days will range from great to not-so-great, yet I won’t make excuses. I accept the challenge of living with the insidious Parkinson’s, and its subtle evolving manner. I accept that my life, work, and leisure time will remain focused for years to come with my disorder in the background.”

#### Take Life Moment By Moment

“Taking life as it comes, mindful to remain in the present moment is so vital to thriving (and living) with Parkinson’s. Feeling your breath moving in and out of your lungs will help you to focus in the current time. Try not to worry about a future event; strive to live in the present moment.”

#### Enjoy Today

“Today renews your lease on the rest of your life, enjoy it (get up, get out, get going). Today acknowledge your Parkinson’s; give it a nudge because you are ready for the battle and for life.”
8 Quotes From The Blog To Support Your Journey With Parkinson’s Disease  
(from [http://journeywithparkinsons.com](http://journeywithparkinsons.com))

<table>
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<tr>
<th>Live Your Life Moving Forward</th>
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<td>“Life with Parkinson’s is best lived in the current moment without either focusing on the past or dreading the future.”</td>
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<tr>
<th>Use Your Team For Support</th>
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<tr>
<td>“We are identified by our characteristic symptoms of our unwanted companion named Parkinson’s. We are all in this together, united by our disorder; held together by those who love and care for us.”</td>
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<tr>
<th>Keep Living Strong</th>
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<td>“I truly believe that the effort most people are using to handle their disorder puts them in a healthier and better lifestyle to manage their symptoms. An emerging predominate picture of Parkinson’s today is a person striving to live strongly.”</td>
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<th>The Journey Continues, Keep Going</th>
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<td>“The journey with Parkinson’s requires effort, teamwork, awareness, and a heart-fueled positive attitude to keep going.”</td>
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<tr>
<th>Personalize Your Disorder, Get To Know You</th>
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<td>“Consider your disorder, you must be able to embrace this unexpected turn in your life and manage the best you can. Personalize your disorder and understand its nuances on you; then you will be able to successfully navigate life in its daily presence.”</td>
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<th>Living Means Adapting</th>
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<td>“Living with Parkinson’s requires you to adapt to its subtle but progressive changes over a long period of time; you need to remain hopeful and live your life.”</td>
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<tr>
<th>Exercise For Your Life</th>
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<td>“A regular aerobic exercise program likely helps to promote the appropriate conditions for the injured brain to undergo neuroplasticity.”</td>
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<tr>
<th>Stay Positive</th>
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<tr>
<td>“While we wait for the potion that slows progression, we exercise and remain hopeful. While we live with a neurodegenerative disorder, we strive to remove the label and we stay positive.”</td>
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Part 2: Suggestions, character traits, and tips for the journey through life and career in the absence and presence of Parkinson’s

• 11 Tips And Character Traits For Living Better With Parkinson’s (go here to read blog post: https://journeywithparkinsons.com/2016/01/02/12-traits-that-bolsters-life-with-parkinsons/)

• Happiness and Parkinson’s: 10 Simple Suggestions to Make Your Life Happier (go here to read blog post: https://journeywithparkinsons.com/2015/10/07/happiness-and-parkinsons-10-simple-suggestions-to-make-your-life-happier/)

• 7 Tips and Healthy Habits for Working with Parkinson’s (go here to read blog post: https://journeywithparkinsons.com/2017/12/28/%ef%bb%bf7-tips-and-healthy-habits-for-working-with-parkinsons/)

• 10 Life Lessons With Parkinson’s Disease (go here to read blog post: https://journeywithparkinsons.com/2015/08/21/10-life-lessons/)

• Live a better and healthier life by following this circle of words (go here to read blog post: https://journeywithparkinsons.com/2018/01/13/a-good-life-with-parkinsons/)

• 9 Life Lessons from 2016 Commencement Speeches (go here to read blog post: https://journeywithparkinsons.com/2016/06/01/9-life-lessons-from-2016-commencement-speeches/)

• 10 “P-Words” That Will Help Your Career Even in the Presence of Parkinson’s (go here to read blog post: https://journeywithparkinsons.com/2017/06/28/10-p-words-that-will-help-your-career-even-in-the-presentation-of-parkinsons/)
11 Tips and Character Traits For Living Better With Parkinson's
(from http://journeywithparkinsons.com)

You will have good hours/days and you will have some not so good hours/days; here are some tips and character traits that will help keep you balanced and hopefully having many happy 'life-filled' days ahead.

“Do not confuse my bad days as a sign of weakness. Those are actually the days I’m fighting my hardest.” Unknown

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<th>Persistence</th>
<th>Hope</th>
<th>Mindfulness</th>
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<td>As President Coolidge remarked “Nothing in the world can take the place of persistence”; says to me we must always keep going in dealing with our disorder. Staying persistent is creating new options, and it requires the courage of one’s convictions.</td>
<td>We must stay the course, treat our symptoms proactively, and use this hope to try to stymie the expected Parkinson’s progression. “No matter how dark the moment, love and hope are always possible.” George Chakiris</td>
<td>Being mindful brings us to dwell only on the immediate time, the current moment. “Mindfulness helps you go home to the present. And every time you go there and recognize a condition of happiness that you have, happiness comes.” Thich Nhat Hanh</td>
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<tr>
<th>Courage and Strength</th>
<th>Gratitude And Contentment</th>
<th>Exercise Is Your Friend</th>
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<td>Your own strength provides the fulcrum where resistance resides to confront the effects of the disorder. “Strength does not come from winning. Your struggles develop your strengths. When you go through hardships and decide not to surrender, that is strength.” Arnold Schwarzenegger</td>
<td>Being grateful and content relieves stress and rejuvenates the heart; ultimately, this will enrich our response to Parkinson’s. “When we give cheerfully and accept gratefully, everyone is blessed.” Maya Angelou</td>
<td>Exercise improves balance, reverses joint stiffness, improves mobility, and bolsters your spirit. “Choose the body in which to dwell.” Lailah Gifty Akita</td>
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<tr>
<th>Understand Nutritional Needs</th>
<th>Believe</th>
<th>Sleep, Sleep Some More</th>
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<td>There is no special diet for Parkinson’s; however, a well-balanced, nutritious diet is extremely beneficial. “Healthy habits harbor happiness.” Zero Dean</td>
<td>Believe that remaining positive is life re-affirming. “Believe you can and you’re halfway there.” Theodore Roosevelt</td>
<td>Sleep is a crucial daily-life event for all of us with Parkinson’s. “With the new day comes new strength and new thoughts.” Eleanor Roosevelt</td>
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<th>Journey On</th>
<th>Stay You</th>
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<td>The stumbling blocks of Parkinson’s are ever present and our journey will be up and down. Include all of the people capable of assisting your journey. Your team will follow the path of your journey, they matter in your life; and your maximum effort in this journey matters a lot. “Everyone is handed adversity in life. No one’s journey is easy. It’s how they handle it that makes people unique.” Kevin Conroy</td>
<td>Always remember, your life matters now with Parkinson’s as much as it did before Parkinson’s. “In the midst of winter, I found there was, within me, an invincible summer.” Albert Camus</td>
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**Happiness and Parkinson’s: 11 Simple Suggestions to Make Your Life Happier**

(from [http://journeywithparkinsons.com](http://journeywithparkinsons.com))

| 1. **Stay in the present moment:** Life is always fluid, constantly moving. Your Parkinson’s is always present, yes, it’s a nuisance. Being able to focus on the current moment, whether good or bad, hard or easy, is better; don’t complicate the thought dwelling on yesterday, tomorrow, or your disorder. |
| **2. Go for a walk outside; stretch frequently; and exercise daily:** You already know how I feel about all forms of exercise, stretching frequently, and trying to exercise daily. And for anyone with Parkinson’s, exercise is essential and beneficial. |
| **3. Eat better and your body will be happier:** We all know this, you are what you eat. A good meal>>bad meal. Your body, mind and your battle with Parkinson’s will all benefit if you carve out time to eat better. |
| **4. Mindful Meditation, even for 5 minutes will make a difference:** In managing Parkinson’s, we should work to release/relieve mental stress. Meditation reduces stress and allows us to become more mindful. Simply stated, meditation creates in you a stress-free, relaxed, and happy place. |
| **5. Do something nice for someone else:** Be kind to others, you’ll feel better. Doing something nice for someone else reminds you that you’re human; the happy-feeling should momentarily put your Parkinson’s behind shutters. |
| **6. Smile more:** It just matters to smile, get out behind the "Parkinson’s mask"; smile big, smile more, keep trying. |
| **7. Eat some chocolate (or share it with others):** Ignoring #3 above to eat better, chocolate falls in a unique sinful food class. Chocolate has compounds called polyphenols that can boost happiness. These same polyphenols may even benefit your health (but remember to only consume chocolate in small quantities). |
| **8. Listen to a song or watch a YouTube music video:** Sing along, re-live an earlier happy-memory, focus on the beat, get up and dance. |
| **9. Practice gratitude:** Be thankful for what you have today. Be thankful for your career, your life. Practice gratitude to help soothe passing moments of pain, doubt, or difficulty. Express your gratitude to family/friends/loved-ones; they’ll themselves will be grateful for you. |
| **10. Sleep more:** Sleep repairs and rejuvenates our bodies and minds. Sleep renews our daily lease on life to begin again. Unfortunately, many people with Parkinson’s say that sleep disorders and fatigue are some of the most difficult aspects of the disorder. For those of us with Parkinson’s, we must keep trying to get more sleep. |
| **11. Stay hopeful, be positive, remain persistent because as long as you’re alive, you can do it all.** As always, stay focused and determined; strive for health and strength. And through it all, try to incorporate happiness into your daily life to help manage your Parkinson’s. You can do it, really, you can do it all! |

*See yourself happy and with Parkinson’s:* Living with Parkinson’s is like getting dressed wearing a blindfold; you remember exactly how your clothes are supposed to fit but the process is slow and awkward, and the result is imperfect. Ultimately, your life-years are subtly altered as this disorder slowly and frustratingly evolves in complexity. Here are some simple ‘happy’ suggestions.
### 7 Tips and Healthy Habits For Working with Parkinson’s Disease
(from [http://journeywithparkinsons.com](http://journeywithparkinsons.com))

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<th>Without a doubt, your Parkinson’s will affect and alter your life, whether it’s only a nuisance or truly becomes a disability. Due to the variability in expression of symptoms, you may continue to work for many years following the diagnosis; however, many will need to retire sooner then planned or they may just be unable to continue working. “The best preparation for good work tomorrow is to do good work today.” Elbert Hubbard</th>
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<td><strong>Executive Function</strong>&lt;br&gt;Executive function describes the group of mental skills that help you get things done. The frontal lobe of the brain controls your ability to execute these skills. Executive function allows you to manage time, pay attention, plan and organize, remember details and the ability to multitask. Many with PD show a slow erosion of executive function; keep going as best you can. “The essence of strategy is choosing what not to do.” Michael Porter</td>
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<td><strong>Be willing to discuss your disease</strong>&lt;br&gt;To most people, Parkinson’s is a mystery. And it gets more difficult, not easier, when your colleagues acknowledge that they know about Michael J. Fox, Robin Williams and Mohammad Ali. Educating your colleagues about you, your issues, your disease gives you so much credibility and bolsters respect among your peers. “This above all; to thine own self be true.” William Shakespeare</td>
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<td><strong>Exercise, sleep, and eat well</strong>&lt;br&gt;In the absence of regular exercise, adequate sleep and a healthy diet you’ll be unable to work effectively. Just do it, do it, and do it; everyone around you at work will care for you even more, why? Because you are now positively feeding your entire body-mind. “A lifestyle is what you pay for; a life is what pays you.” Thomas Leonard</td>
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<td><strong>Gadgets can make a big difference</strong>&lt;br&gt;Technology today is simply amazing; take advantage of it to keep going in your job. For example, if you type a lot on a keyboard/computer, use dictation with Dragon®. If your posture is poor from sitting all day at a monitor, get the BackJoy® and help support your back better. Just two examples of many. “Technology feeds on itself. Technology makes more technology possible.” Alvin Toffle</td>
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<td><strong>Stress reduction and mindfulness</strong>&lt;br&gt;Cortisol is produced from stress; both of which are unhealthy for your work. Mindfulness reduces stress to reduce cortisol levels, a winning scenario for you at work. Take time during the work-day to practice mindfulness; even 5’ improves your body-heart-mind-soul axis “Men for the sake of getting a living forget to live.” Margaret Fuller</td>
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<td><strong>Stay positive and go forward</strong>&lt;br&gt;At times, you live negatively and go backwards. Focus on staying positive and practice moving forward; your co-workers will appreciate the effort. “Always turn a negative situation into a positive situation.” Michael Jordan</td>
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<td><strong>Have a career plan with accommodations</strong>&lt;br&gt;Let’s be realistic and accept the notion that our PD symptoms may eventually interfere with our work. Be self-aware of these small physical/mental changes; be prepared (proactive) and have a Plan B or a Plan C ready to implement. “I never think of the future - it comes soon enough.” Albert Einstein</td>
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# 10 Life Lessons With Parkinson’s Disease

(From [http://journeywithparkinsons.com](http://journeywithparkinsons.com))

**1. Start each day by making your bed.** Every day re-starts your life-story. Little things add up to big things. By making your bed each day says that little things still matter. With Parkinson’s, doing the daily tasks is a simple reminder you are still functioning and alive.

**2. Have good people around you.** Managing your Parkinson’s works well by assembling a good team with help from loved-ones, family, friends, and your healthcare providers.

**3. A big heart and good attitude matter.** Bringing the right attitude focused on the goal makes a difference. With Parkinson’s, staying positive and hopeful matters every single second you are breathing. Otherwise, the shadow underneath this disorder tries to swallow you.

**4. Life is not fair but keep moving forward.** Sometimes life is not fair. Get over it, you are still here; tomorrow renews your life-contract. Sure, having Parkinson’s is not fair. Stay persistent and keep moving forward as long as you are able.

**5. Failure is part of life.** An innate part of life are our miscues, missteps, and failures. But you learn and grow from these events. From failure you can gain knowledge, strength and resilience. Having Parkinson’s is not failure; although doing nothing in response to its sinister grasp is like slipping when walking down a steep and wet rocky path.

**6. Being creative and resourceful allows you to challenge life's difficulties.** Staying innovative may not always work; but it does gives you the opportunity to confront your life-challenges. I am doing as much as I possibly can to challenge my Parkinson’s. Please read, learn, plan, and initiate actions to do whatever is reasonably possible to resist this disorder.

**7. Don’t back down from the sharks.** The biggest shark in my life is named Parkinson’s. It has black lifeless eyes, leads an unforgiving, relentless and slowly moving existence like a shark. Meet it upfront and don’t back down is our best chance for survival.

**8. Be your very best in your toughest times.** During the most difficult times, you need to be at your best, strongest in character, and you will come through just fine. Parkinson’s is one of those tough times; be cognizant of your abilities and keep living.

**9. Start singing when you're up to your neck in mud.** Your approach to life will influence those near you. Stay positive, focus on hope, and don’t stray too far from your life-course. Even with Parkinson’s, you still make a difference; your life matters a lot.

**10. Never quit, never give up.** Life can be an obstacle course. It’s not the winning time that matters; what matters most is your effort to finish and not to give up. Life’s obstacle course is exaggerated with Parkinson’s. Complete the course regardless of your time. Life and love are still thriving inside of you; just don’t give up, ever. **Remain you, stay positive and hopeful. Live on, please live on.**

---

**Eleanor Roosevelt**

*The purpose of life is to live it, to taste experience to the utmost, to reach out eagerly and without fear for newer and richer experience.*
Live Better With Parkinson’s by Following this Circle of Words

Forty-winks and sleep more

“I studied, I met with medical doctors, scientists, and I’m here to tell you that the way to a more productive, more inspired, more joyful life is: getting enough sleep.” Arianna Huffington

Fit/Fitness

“I’m not telling you it is going to be easy - I’m telling you it’s going to be worth it.” Arthur L. Williams, Jr.

Fortitude

“Fortitude. ... It means fixity of purpose. It means endurance. It means having the strength to live with what constrains you.” Hilary Mantel

Food

“First we eat, then we do everything else.” M.F.K. Fisher

Flexible

“Whatever is flexible and living will tend to grow; whatever is rigid and blocked will wither and die.” Laozi

Full-time

“Your time is limited, so don’t waste it living someone else’s life.” Steve Jobs

Faith

“Faith and reason are the shoes on your feet. You can travel further with both than you can with just one.” J. Michael Straczynski
<table>
<thead>
<tr>
<th><strong>Life Lessons from 2016 Commencement Speeches</strong></th>
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<tr>
<td><img src="image" alt="Image of a table with lessons from commencement speeches" /></td>
<td></td>
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<tr>
<td><strong>Live Every Day</strong></td>
<td>“Live with the understanding of how precious every single day would be. How precious every day actually is” <a href="http://journeywithparkinsons.com">Sheryl Sandberg</a>, University of California at Berkeley</td>
</tr>
<tr>
<td><strong>Mindfulness</strong></td>
<td>“In those moments when you’re doing something that could be life-changing, whether it’s in space, or in your career, you need to constantly remind yourselves that there is nothing more important than what you’re doing right now.” <a href="http://journeywithparkinsons.com">Scott Kelly</a>, University of Houston</td>
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<tr>
<td><strong>Embrace The Unexpected</strong></td>
<td>“Don’t be so focused in your plans that you are unwilling to consider the unexpected.” <a href="http://journeywithparkinsons.com">Senator Elizabeth Warren</a>, Bridgewater State University</td>
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<td><strong>Care Is Investing In Others</strong></td>
<td>“Care is as important as career. ... Career is investing in yourself. Learning, growing, and building on the education you received here. Care is investing in others. It is learning like a gardener, or a teacher, or a coach, what to do and what not to do to enable others to grow and flourish.” <a href="http://journeywithparkinsons.com">Anne Marie Slaughter</a>, University of North Carolina at Chapel Hill</td>
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<td><strong>Mistakes Will Happen</strong></td>
<td>“Every stumble is not a fall, and every fall does not mean failure. Know the next right move when the mistake happens. Because being human means you will make mistakes. And you will make mistakes, because failure is God’s way of moving you in another direction.” <a href="http://journeywithparkinsons.com">Oprah Winfrey</a>, Johnson C. State University</td>
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<td><strong>Kindness</strong></td>
<td>“We like to feel we are civilized. How do you measure that? The usual versions look at science, technology, wealth, education, happiness. Every measure fails, except one. There is one measure of civilization and it comes down to how people treat each other. Kindness is the basic ingredient.” <a href="http://journeywithparkinsons.com">William Foege</a>, Emory Univ.</td>
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<td><strong>Life-long Learner</strong></td>
<td>“The secret to success is not rocket science. It just requires true dedication and a willingness to go the extra mile.... Let’s put it this way: I know of no Nobel Prize winner who has stopped studying.” <a href="http://journeywithparkinsons.com">Michael Bloomberg</a>, University of Michigan</td>
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<td><strong>Turn No Into Yes</strong></td>
<td>“When life tells you no, find a way to keep things in perspective. That doesn’t make the painful moments any less painful... You don’t have to live forever in that no. Because if you know what you’re capable of, if you’re always prepared, and you keep things in perspective, then life has a way of turning a no into yes.” <a href="http://journeywithparkinsons.com">Russell Wilson</a>, University of Wisconsin</td>
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<td><strong>Persistence</strong></td>
<td>“When the challenges come, I hope you remember that anchored deep within you is the ability to learn and grow. You are not born with a fixed amount of resilience. Like a muscle, you can build it up, draw on it when you need it. In that process you will figure out who you really are -- and you just might become the very best version of yourself.” <a href="http://journeywithparkinsons.com">Sheryl Sandberg</a>, University of California at Berkeley</td>
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10 “P-Words” That Will Help Your Career Even in the Presence of Parkinson’s

POSITIVITY
“There is little difference in people, but that little difference makes a big difference. The little difference is attitude. The big difference is whether it is positive or negative.” W. Clement Stone

PATIENT
“Never cut a tree down in the wintertime. Never make a negative decision in the low time. Never make your most important decisions when you are in your worst moods. Wait. The storm will pass. The spring will come.” Robert H. Schuller

PASSIONATE
“There is no greater thing you can do with your life and your work than follow your passions — in a way that serves the world and you.” Richard Branson

PERSISTENT
“You just can’t beat the person who never gives up.” Babe Ruth

PERSEVERANCE
“Our greatest weakness lies in giving up. The most certain way to succeed is always to try just one more time.” Thomas A. Edison

PURPOSEFUL
“All life is a purposeful struggle, and your only choice is the choice of a goal.” Ayn Rand

PRODUCTIVE
“Start by doing what’s necessary, then do what’s possible; and suddenly you are doing the impossible.” Francis of Assisi

POWER
“You must try to make the most of all that comes but also don’t forget to learn a lot of all that goes.” William C. Brown

PREPARED
“The best preparation for good work tomorrow is to do good work today.” Elbert Hubbard

PRINCIPLED(S)
“I wish I had been wiser. I wish I had been more effective. I wish I’d been more perspicacious. I wish I’d been more principled.” Bill Ayers
Part 3: Health and exercise while living with Parkinson’s

• With Parkinson’s we need dopamine (go here to read blog post: https://journeywithparkinsons.com/2017/07/23/part-1-of-2017-pwr-parkinson-wellness-recovery-retreat-pictures-with-great-memories/)

• 9 Things to Know About Exercise-induced Neuroplasticity in Human Parkinson’s (go here to read blog post: https://journeywithparkinsons.com/2017/02/20/9-things-to-know-about-exercise-induced-neuroplasticity-in-human-parkinsons/)

• 3 Key Steps to Maintaining a Healthy Brain (go here to read blog post: https://journeywithparkinsons.com/2017/12/28/%ef%bb%bf7-tips-and-healthy-habits-for-working-with-parkinsons/)

• 7 Healthy Habits for Your Brain (go here to read blog post: https://journeywithparkinsons.com/2016/12/12/7-healthy-habits-for-your-brain/)

• Medical Management of Parkinson’s Disease (go here to read blog post: https://journeywithparkinsons.com/2017/03/22/go-the-distance-with-mao-b-inhibitors-potential-long-term-benefits-in-parkinsons/)
With Parkinson’s we need **Dopamine**.
With Exercise we make **Hopeamine**!

*Exercise is medicine*
9 Things to Know About Exercise-induced Neuroplasticity in Human Parkinson’s
(from http://journeywithparkinsons.com)

**Safety First**
The benefit of an exercise routine/program will only work if you have (i) talked about it with your Neurologist and have his/her consent; (ii) you have received advice from a physical therapist/certified personal trainer about which exercises are “best” for you; and (iii) you recognize that PD usually comes with gait and balance issues, and you are ready to begin. Safety first, always stay safe!

**Parkinson’s Disease (PD)**
Parkinson’s is a neurodegenerative disorder. Parkinson’s usually presents as a movement disorder, which is a slow progressive loss of motor coordination, gait disturbance, slowness of movement, rigidity, and tremor. Parkinson’s can also include cognitive/psychological impairments. ~170 people/day are diagnosed with Parkinson’s in the USA; the average age of onset is ~60 years-old.

**Exercise**
Exercise is activity requiring physical effort, carried out especially to sustain or improve health and fitness. Exercise is viewed by movement disorders clinicians, physical therapists, and certified personal trainers as a key medicinal ingredient in both treating and enabling patients at all stages of Parkinson’s.

**Neuroplasticity**
Neuroplasticity describes how neurons in the brain compensate for injury/disease and adjust their actions in response to environmental changes. “Forced-use exercise” of the more affected limb/side can be effective in driving neural network adaptation. Ultimately, this can lead to improved function of the limb/side.

**Brain Health**
With or without Parkinson’s disease, taking care of your brain is all-important to your overall well-being, life-attitude, and health. For a balanced-healthy brain, strive for: proper nutrition and be cognitively fit; exercise; reduce stress; work and be mentally alert; practice mindfulness/meditation; sleep; and stay positive.

**Synapses**
Are junctions between two nerve cells whereby neurotransmitters diffuse across small gaps to transmit and receive signals.

**Circuitry**
A key result of neuroplasticity is the rerouting of neuronal pathways of the brain along which electrical and chemical signals travel in the central nervous system (CNS).

**Brain/Behavior Changes**
The collective results found an increase in corticofugal excitability, brain grey matter volume, serum BDNF levels, and serum TNFα levels. These results imply that neuroplasticity from exercise may potentially either slow or halt progression of Parkinson’s.

**Parkinson’s-specific Exercise Programs**
- PWRiMoves
- LSvT BIG
- LIM Yoga
- Rock Steady Boxing
- Dance for PD
- Tai Chi for PD
3 Key Steps to Maintaining a Healthy Brain

- Nutrition
- Exercise
- Sleep
7 Healthy Habits For Your Brain
(from [http://journeywithparkinsons.com](http://journeywithparkinsons.com))

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<thead>
<tr>
<th>Food and cognitive fitness</th>
<th>Exercise and neuroplasticity</th>
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<td>Boost your cognitive fitness by eating brain-healthy foods: green and colorful vegetables/ fruits (lots of berries), salmon, avocados, nuts and seeds. Reward your brain with ‘good’ lipids, antioxidants, vitamins and minerals. “I’m always trying to find brain food and indulge in knowledge that’s gonna be useful.” Big Boi</td>
<td>Your brain will excel if you exercise; in fact, your brain will remember better and soar to new heights with oxygen flowing briskly through your body. Exercise makes you stronger because it strengthens your mind-body link. “Exercise is really for the brain, not the body. It affects mood, vitality, alertness, and feelings of well-being.” John Ratey</td>
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<th>Work, keep active mentally</th>
<th>Stress Reduction</th>
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<td>Your brain will never stop working; stay active and focused as long as you can. A healthy and engaged mind throughout the rest of your work years is a great and meaningful reward. Take advantage of your very own brain power-connection. “Keep your brain active. Engage your brain. Your brain is the most fantastic machine ever created, and it needs to be exercised.” Peter Kinderman</td>
<td>Chronic stress over-produces cortisol, which is unhealthy for your brain. It’s really important to get control of your stress levels; your brain will say thanks. “There is more to life than increasing its speed.” Mahatma Gandhi</td>
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<th>Mindfulness/meditation</th>
<th>Positive is better than negative</th>
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<td>Renew your brain, calm your body, stay in that moment and focus on it totally, all-within itself. The result is a clean-slate; your brain ready to focus and your body relaxed ready to move-live. “Mindfulness practices enhance the connection between our body, our mind and everything else that is around us.” Nhat Hanh</td>
<td>Your brain gets in a rut if you live in the negative. Focus on staying positive, practice on reducing the negative thoughts; your brain will applaud your effort. “You have to train your brain to be positive just like you work out your body.” Shawn Achor</td>
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Sleep
Sleep rejuvenates, replenishes, and energizes your brain, body; reward yourself. Don’t forget to sleep (how much you need all depends on you), it matters that much. “Sleep deprivation is the most common brain impairment.” William C. Dement
Medical Management of Parkinson’s Disease

- Levodopa replaces dopamine
- COMT* inhibitors sustain levodopa
- MAO-B inhibitors maintain existing dopamine**
- Dopamine agonists mimic dopamine

*Not discussed here are anticholinergics, selective serotonin inverse agonists (SSIA), NMDA antagonists, and acetylcholinesterase inhibitors. *COMT = Catechol-O-methyl transferase inhibitors act either extracerebrally or cross the BBB. **MAO-B = monoamine oxidase B. ^Dopaminergic neurons.
Part 4: Historical time-line of Parkinson’s disease

• Milestones in Parkinson’s Disease Research and Discovery: 1a historical, 1b historical, 1c historical, 1d historical, 1e historical, and part 2- clinical trials (go here to read blog post: https://journeywithparkinsons.com/2017/04/11/milestones-in-parkinsons-disease-research-and-discovery/ )
Milestones in Parkinson’s Disease Research and Discovery (Part 1a: Historical)

Compiled by Frank <https://journeywithparkinsons.com/> and Simon <https://scienceofparkinsons.com/>

- Jean-Martin Charcot gives Parkinson’s disease its name
- James Parkinson’s essay
- Frederic Lewy found intracellular inclusions in affected brains
- Barger and Ewens synthesize dopamine
- Tretiakoff reports the loss of cells in the substantia nigra
Milestones in Parkinson’s Disease Research and Discovery (Part 1b: Historical)

Compiled by Frank <https://journeywithparkinsons.com/> and Simon <https://scienceofparkinsons.com/>

- **Hoehn and Yahr- internationally-used staging system**
- **Hornykiewicz- dopamine in PD brains**
- **Hornykiewicz & Birkmayer - 1st Levodopa trials**
- **Greenfield and Bosanquet- the complete PD pathologic analysis**
- **Parkinson’s Disease Foundation**
- **Arvid Carlsson’s dopamine studies**
- **Cotzias - perfects Levodopa**

1953
1957
1960/1
1967
1968
Milestones in Parkinson’s Disease Research and Discovery (Part 1c: Historical)

Compiled by Frank <https://journeywithparkinsons.com/> and Simon <https://scienceofparkinsons.com/>

- **MAO-B Inhibitors**
- **Deep-brain stimulation (DBS) surgery**
- **Fetal Cell transplantation**
- **MPTP**
- **Levodopa + AADC inhibitors (carbidopa or benserazide)**
- **Dopamine agonists**
- **LSVT LOUD**
- **MAO-B inhibitors**
Milestones in Parkinson’s Disease Research and Discovery (Part 1d: Historical)

Compiled by Frank <https://journeywithparkinsons.com/> and Simon <https://scienceofparkinsons.com/>

- Braak Staging of Parkinson’s pathology;
- DJ1 linked to early onset PD
- GDNF trial suggests neuroprotection
- Parkin gene associated with juvenile PD
- Alpha synuclein associated with familial cases of PD and in Lewy bodies
- Launch of MJFox Foundation
- PET scan brain imaging
- Induced pluripotent stem cells from skin cells
- Pink1 and LRRK2 associated with early onset PD
Milestones in Parkinson’s Disease Research and Discovery (Part 1e: Historical)

Compiled by Frank <https://journeywithparkinsons.com/> and Simon <https://scienceofparkinsons.com/>

- Lewy bodies found in transplanted cells
- Successful preclinical testing of dopamine neurons from embryonic stem cells
- Neuroprotective effect of exercise in rodent PD models
- SNCA, MAPT and LRRK2 are risk genes for idiopathic PD
- IPS derived dopamine neurons from people with PD
- Transeuro cell transplantation trial begins
- Microbiome of the gut influences PD
- MDS-UPDRS revised rating scale
Milestones in Parkinson’s Disease Research and Discovery (Part 2: Clinical trials either recently completed or in progress)
Compiled by Frank <https://journeywithparkinsons.com/> and Simon <https://scienceofparkinsons.com/>

- **2016**
  - Safety, Tolerability and Efficacy Assessment of Dynacirc (Isradipine) for PD (STEADY-PD) III trial
  - Opicapone (COMT Inhibitor) as Adjunct to Levodopa Therapy

- **2016**
  - Treatment of Parkinson’s Psychosis with Nuplazid
  - mGluR4 PAM (PXT002331) well tolerated in phase I trial
  - Initial results of Bristol GDNF trial indicate no effect
  - Nilotinib (Tasigna® by Novartis) indicates positive results in phase I trial.
  - ISCO cell transplantation trial begins
  - Neuropore’s alpha-synuclein stabilizer (NPT200-11) passes phase I trial

- **2017**
  - Immunotherapies proves safe in phase I trials (Affiris & Prothena)
  - MAO-B inhibitors shown to be neuroprotective.
  - Inhalable form of L-dopa
  - Exenatide trial results expected
  - Living Cell Technologies Limited continue Phase II trial of NTCELL