

# A Shaky Walk Downhill:

## A Philosopher Moves Into Parkinson's World

© David Kolb, 2016

<b>1. Writing toward Parkinson's .....</b>	<b>2</b>
After the Diagnosis .....	5
Testing and Hoping .....	7
<b>2. Parkinson's Outside and In.....</b>	<b>10</b>
Parkinson's Disease from the Outside: Motions .....	10
More than Motion .....	13
Parkinson's World from the Inside: Space .....	14
Fighting Back: Forced Exercise .....	17
Balances .....	18
Parkinson's World from the Inside: Time .....	19
<b>3. The Philosopher at Bay .....</b>	<b>23</b>
Back to the Greeks .....	25
What I Learned .....	30
The Present Moment .....	32
Deepening the Present .....	33
Authentic Life .....	35
Forced Exercise Again .....	40
<b>4. Decline and Dementia .....</b>	<b>41</b>
How is it Going? .....	41
Authenticity with Dementia? .....	44
Identity .....	46
New Selves for Old .....	49
Deepening Awareness .....	50
<b>A Conclusion.....</b>	<b>53</b>

David Kolb, Charles A. Dana Professor Emeritus of Philosophy at Bates College in Maine,  
now lives in Eugene OR.                      dkolb@bates.edu                      www.dkolb.org

## 1. Writing toward Parkinson's

In the fall of 2005, while I was working on my fifth book, I noticed that my typing was not what it used to be. In 2016, I can type only with difficulty.

In the '50s my family used a black portable Underwood with round black keys and type bars that came up to hit the paper, if they didn't tangle with one another. In college, a secretarial job provided me with a heavy gray Royal office typewriter that dwarfed our home machine. In that job I became a skilled and rapid typist. This influenced how I began to write and compose. My standard yellow pads began to recede, used only for outlines or jottings.

Later my parents gave me a portable of my own, and I composed everything directly on the typewriter. I could type much faster than I could write, then go back, edit and retype. I was ready for word processing, though it didn't then exist.

I needed that fast typing when I became a college philosophy major, with long essays to write and rewrite. I was drawn to philosophy by its meticulous study of texts and arguments for my big-picture questions about science and religion. I was particularly excited by a style found in Plato that begins with a concrete ethical or political question then rises to very abstract issues about reality and knowledge, then returns to the concrete questions.

I went on to graduate school in philosophy and a professional career. I composed class material and handouts, exams and reports. My little portable typewriter had morphed into a electric Olivetti Lexikon, a wonder to work with. Modeled on the IBM Selectric, its little ball spun and hit the paper; it never jammed and I could type even faster.

My thinking and writing worked together, bringing ideas to paper in a graceful dance. Thinking things out was hard but getting ideas onto paper was

easy. I could type a two-page single-spaced commentary on a student's paper as quickly as I could have handwritten half a page of comments.

When I was teaching at Bates College, computers arrived. In 1984 I purchased a machine from Epson. Then the Bates College computing committee selected IBM style personal computers for all faculty, so a new PC replaced my quickly obsolete Epson. In 1992 I started exploring non-linear writing (hypertext), and the best authoring program ran only on Macintosh, so I purchased a Mac and have used them ever since. Each change in technology improved my writing and composing.

I wrote articles and books, many focused on German or Greek systematic texts; those often dealt with complex abstract questions, or started from but did not return to their concrete beginning problems. To get back to concrete issues I began writing about how the high principles of order and creativity I had been discovering might lead to new modes of architecture and new non-linear modes of writing. But none of this was as concrete as philosophy suddenly became when I discovered the cause of my deteriorating typing.

By 2005 I was having trouble typing accurately. I could still work rapidly but mistakes kept increasing. I noticed an occasional tremor in my left arm, so my wife Anne and I began to worry. During that fall and winter I went through neurological tests, including a spinal tap for MS. MRIs revealed a scattering of white spots in the middle of my brain, slices of spheres of dead cells around small blood leaks. There were no incidents I knew of connected with the leaks, but we worried they were mini-strokes. The white spots seemed to be increasing. We feared imminent catastrophe; several close relatives had died from severe strokes. Was it all over? Further brain scans suggested that the spots were not increasing, though that uncertainty still remains.

After all the tests, we still did not know the cause of the tremor and typing difficulties. In October 2006 we retired and trekked across country from Auburn,

Maine, to Eugene, Oregon. The tests continued under a new neurologist, doing another brain scan, movement and pattern tests, checking my reactions to a medication that helps Parkinson's but little else. Finally in January 2007 my neurologist announced "you have Parkinson's disease, and in about 10 years you are going to need a great deal of help."

My long dance with keyboards had ended. No longer could I move my fingers freely and speedily. I can, some days, type awkwardly with endless mistakes and extra letters inserted by twitching fingers. Some days I can do better. Other days I can't type at all; my hands won't do what I want. Having been a good touch typist makes things worse, since I'm trained to leave my fingers on the home keys — a mistake with Parkinson's edgy fingers. Better to stand off and dictate, jiggling with the tremors, trying to enunciate clearly enough that the machine will understand what I am saying, concentrating on the content — until I face the problems of editing and re-editing. It is possible, though awkward, to edit with voice commands, but they take focus off the content, so I usually edit by hand, and the missed keys, repeated letters, accidental deletions return again.

My ideas, once borne easily on a smooth flow of thought to fingers to screen and paper now have to wind through twisty channels and swirl around obstructing rocks in order to arrive where they can spread out peacefully.

Skill and speed ran up against Parkinson's disease. I can write, but the symptoms remain stubbornly present. But I am stubbornly present too and I don't plan to stop writing and creating.

We all realize, whether from friends and family members, or from those ads for smiling happy retirement villages with nursing homes lurking behind them, that we face lingering decline. We all are marching downhill. Parkinson's throws that abruptly in my face every day. In this essay I hope I can express something

from my life with Parkinson's that may help all of us living on the downward slope. That is what this essay is really about.

### **After the Diagnosis**

We were embarking on retirement, in a new city with only a few acquaintances, a continent away from our Maine friends and habits. Suddenly we were told that we must expect steady degeneration and increasing limits on what I would be able to do. The diagnosis wasn't a complete shock, but it felt like a judge's sentence.

I feared what Parkinson's would do to my lifespan and my professional work. There is a "young onset" variety of Parkinson's that advances more rapidly and can devastate someone in mid-career. Michael J. Fox has spoken eloquently about his experiences acting and working while facing that version of Parkinson's. But I retired from teaching at 67, and had been envisioning years of travel, relaxation, and continuing professional activity. Suddenly I didn't know what to expect. One Parkinson's patient may decline gradually for twenty years, while another goes from leading hikes in January to being unable to walk without assistance in November. Anne and I had little to go on except my neurologist's ten-year estimate. What would this mean to our hopes? How would this affect my plans to attend professional meetings and continue to write? We didn't know and no one could tell us. We made plans to travel while we could, and I accelerated my unfinished writing projects.

We researched on the web and in print and talked with other sufferers. We observed that my symptoms were not increasing too quickly, so we began to feel less uncertain. It seemed as if we could go on for some years much as we had planned. This turned out to be true, but my symptoms slowly and inevitably increase, interfering more and more.

We were getting to know people with the disease, but it took time to find the nerve to go to a support group. I was afraid I would be crushed by the thought "that's me in the future." That feeling did arise, but along with it came a sense of relaxed sharing and mutual support. No need to hide symptoms or be embarrassed. Talk frankly about problems and fears. Anne and I now rely upon that community and give mutual support as we can. Over time, some of our friends have gotten seriously worse, causing greater stress on their care partners. When symptoms become more serious and the medication regime becomes more difficult, changes may have to be made in a house, or people may have to relocate, and both stress and expense increase.

When a person suffering from Parkinson's meets another for the first time the most frequent question is "when were you diagnosed?" The answer tells how much time the other person has had to face up to the disease and its implications. It also lets each person compare their own progress in the disease with the other's, since progress varies enormously from person to person — though "progress" seems the wrong word to describe the trajectory of a degenerative disease.

The next question asked is "what meds are you taking?" There is as yet no medication that attacks the unknown cause of Parkinson's disease. So medications are prescribed to alleviate the symptoms, not to slow or stop the disease. When it was discovered that Parkinson's cuts the brain's production of dopamine, a neurotransmitter crucial to motion and mood, attempts were made to supply dopamine directly. Unfortunately, when given orally, dopamine causes nausea and cannot cross into the brain. The first effective medication arrived in the 60s: L-dopa, a precursor chemical that gets to the brain and is used by working cells there to produce dopamine. This revolutionized the treatment of Parkinson's. But the effect depends on those working cells, and they get fewer over time. Also, it is difficult to maintain a steady flow of L-dopa, and side effects require companion medications. That is why we ask one another about

medications, to locate each other on the slope of decline, and to find out if the other person might have discovered personal tricks that help relieve the symptoms.

Researchers continue to seek better ways of delivering a steady supply of L-dopa to the brain. But they also seek ways of interfering directly with the mechanism, whatever it is, that destroys dopamine producing cells.

### **Testing and Hoping**

Shortly after my diagnosis I enrolled in a clinical test designed to see if large doses of the amino acid creatine could improve the metabolism of mitochondria in brain neurons and slow down the progression of Parkinson's. The study was to take seven years. I was assigned packets containing five grams of white powder to mix with liquid and drink twice a day. I kept to this regimen for five years; I did not feel any positive or negative effects. But the regimen did produce scary fantasies about trying to explain to Mexican police or Turkish border guards why I was carrying dozens of sealed packets containing an unidentified white powder.

That study brought me to Oregon Health Sciences University in Portland for repeated physical and cognitive tests following a set protocol. Talking with the doctors conducting the study gave me a second perspective on my disease.

In the study, the doctors evaluated whether or not the drug worked by repeating standard tests and administering a lengthy questionnaire about symptoms. Everything depended upon my memory of recent events and the skill of the doctor looking and listening. This method does not lead to fine discrimination of small effects. A blood test or a scan is needed, something objective that could conclusively identify Parkinson's and measure small changes in the disease. Such "biomarkers" would make it easier to evaluate proposed therapies. At the moment no such biomarkers exist but research is seeking them.

Ultimately the doctors concluded that while the drug we were testing was not harmful, neither was it beneficial. So the study was closed down several years early, and it turned out that I had been taking the placebo.

It was nonetheless good to have participated in the test, and I learned what was percolating at a major Parkinson's research center. I would like to find another such study – it's often difficult for Parkinson's researchers to find volunteers for studies. The Michael J. Fox Foundation provides a web tool that can find studies in your local region.

Unfortunately, so far all the attempts to improve brain function by strengthening mitochondria have turned out not to work. For a while I had been taking expensive heavy doses of Coenzyme Q-10, since initial tests had suggested that it could help. But a larger testing showed no effect. Another hope gone.

We keep wishing for a magic molecule that would make the degeneration stop, or even self-repair. Likely the disease is too plural to be caught by any single molecule. Hope goes on. Stem cells come and go as a possibility; surgery has good effects but not for every case; new interventions are proposed but none of them have proved out yet, and the proving is a slow process.

Diagnosing Parkinson's is a matter of a clinician noticing symptoms and matching them up with a standard list. In other words, it depends on interpreting signs. Because the diagnosis is an interpretation, as a patient I can say to myself that maybe it's mistaken, maybe it's some other disease, maybe it won't really get worse and worse. At each stage I have dwindling hope that this will be the last degeneration. At each stage that hope is dashed.

I am aware of what's likely to happen to me, pleased that it's not coming too quickly, trying to help others, and happy that I still can write and travel. Anne and I keep learning, but now when we go to a Parkinson's conference most of the information seems familiar. Given the slowness of research, and the fact that

most new ideas do not work out, I realize that barring amazing medical advances, big changes will come too late to help me in any significant way.

## 2. Parkinson's Outside and In

### Parkinson's Disease from the Outside: Motions

Dr. James Parkinson called the disease he identified in 1817 "the shaking palsy." Now it is called Parkinson's Disease (PD). Parkinson's is most noticeable in its effects on bodily movement. The most visible symptoms are tremors, slowness of movement, and problems with balance and walking.

Tremor is usually the first symptom that a patient recognizes. There are also changes in gait, slowed motions, and stiff muscles. "Normal" motion becomes difficult, stiff, slow or jerky. Tremor feels like my body has decided to go on its own. My hand or foot or lips move in a rhythm I do not decide and can't quite stop. It gets in the way. Typing, handwriting, holding a spoon or fork become difficult. As a "resting tremor," it also comes on when I am not doing anything. At a concert, when I listened to the music my legs can shake so badly they disturb the person in the next seat. The leg's rhythm has nothing to do with the music. I try consciously to relax the leg and the tremor lessens, but if I concentrate on the music the tremor returns.

When you think of motion you probably first think of walking and running, but you also move when rising from a seat, reaching for a cup, turning to look behind, and all the hand and head motions that add texture to our spatial life. Parkinson's make these, too, more difficult to do with smooth grace.

The advanced Parkinson's gait is a hunched slow shuffle, barely lifting the feet. But even early in the disease, my walk slowed down without my noticing. I think I am clipping along but then I realize I am taking smaller slower steps. Briskness is an effort, though one worth making. Trying to walk with an upright posture rather than leaning forward requires constant vigilance. Neurologists become expert in reading patients' condition from observing them walk down a

hall. Now, navigating a large room smoothly without weaving from side to side is something I have to concentrate on, rather than something I do automatically.

At other times your body won't move. Suddenly you cannot take a step. You might be walking across the room but at the door you freeze. A ticket line is moving at intervals but when it's time to step forward you can't take the step. You seem to have forgotten how to walk. So you employ some tactic: you hum a march, or step backwards then forwards, find a visual pattern on the floor, or some other personal trick. I don't experience freezing (yet) but people I know do. It happens unexpectedly and can be dangerous in crowds or when crossing a busy street.

Sometimes the disease makes me want to get up and move around; it's hard to sit still. At Parkinson's information conferences and support groups, the need for people to move around is acknowledged and encouraged. But then sometimes it's so hard to move that I can only sit clenched.

To outside observers the most disturbing signs of Parkinson's are involuntary movements (called *dyskinesias*). Tremor is disconcerting but serious dyskinesia can be shocking. If one takes too much L-dopa, the medication causes uncontrollable random motions of head and arms, even flailing limbs and a twisting torso that make it impossible to stand or walk. At a conference I once saw a man who seemed to be writhing on the floor in painful agony, but in fact was experiencing dyskinesias, without pain because dyskinesia is not a response to pain but an involuntary movement caused by excess dopamine. We talked, and he told me that if he didn't take the medication he would be unable to move, having to crawl around the floor of the conference. He was on a tightrope, too much or too little medication causing huge problems. Later that day I saw him sitting quietly in a chair taking notes; he had gotten the balance correct. But there is no one right dosage; it can change hour by hour.

A friend in my local Parkinson's community writes:

On the whole, I feel rather fortunate. I have not met many people with PD who are up and about 15-20 years after diagnosis. I do not mean to suggest that it has been easy. It hasn't.

I went through a spell between 5 and 10 years ago where I was inadvertently overdosing the carbidopa/levodopa to lessen the tremor and the rigidity. I would have these awful dyskinesic periods that would last most of the afternoon. I would often flail and thrash about during much of the time. I would also experience disruptive dyskinesias during those (rare) times we had dinner with other folks. It was very difficult coordinating the time and amount of doses with the time and amount of food consumed.

I recall reading in one of my PD reference books that most people with PD prefer the dyskinesias to the slowness and rigidity associated with insufficient carbidopa/levodopa. I was in that category until I had a very disturbing hallucination episode.... [Three neurologists] agreed that overdosing of carbidopa/levodopa was the likely culprit. I spent a lot of time experimenting with different doses and time intervals, all with a view toward minimizing the carbidopa/levodopa.

Dyskinesias bring tremendous social awkwardness. You know that the people around you are puzzled, perhaps repelled, uncertain if you are able to respond to them. Michael J Fox has done a great service by appearing in public venues and on TV with varying degrees of dyskinesia. He helps people to realize that the patient is still there, alert and trying to interact despite the disturbing movements.

## More than Motion

As well as conscious motion, Parkinson's also interferes with activities normally on autopilot. Balance, facial expression, loudness of voice require mindful attention. Constipation becomes an issue. Breathing, sleeping, regulating body temperature and blood pressure, can all become irregular. The most threatening may be difficulty swallowing and so a lack of nourishment. These and other functions are affected because the autonomic nervous system becomes unreliable. Not everyone with the disease experiences all of these symptoms, but most suffer from some of them.

As the disease progresses more and more things which were automatic have to be done consciously. But self-consciousness can make it difficult to do all this at once. For example, when I'm concentrating on balance my face may become fixed and masked. Or when I'm concentrating on facial expression my voice may sink or I may trip over my feet.

An audience of Parkinson's sufferers can be daunting to an unprepared speaker, because one can't easily tell how the audience is reacting. The typical Parkinson's "masked" face looks as if the person were annoyed. I suspect that before I knew that I had the disease, when I would see students in my office, they would think me unresponsive and annoyed with their presence, which wasn't true, but at that point I had not learned that I needed to enliven my facial expressions.

I know I often fail. A member of a civic committee I joined remarked that while she found me generally affable and receptive, she had been "surprised a few times by what appeared to be an almost cold, dismissive, or otherwise not so pleasant response that did not add up. I just assumed I had been on the west coast for too long and that you were 'one of those stoic people' I knew in the Netherlands and on the east coast." She was relieved to learn of the masked face

problem with Parkinson's. She added that a tremor is easy to interpret but the masked face is not. She compared this to the difference between people's reactions to blindness versus their reactions to hearing loss, which latter is often misinterpreted as disinterest or lack of attention.

So I can feel out of place, exceptional, imagining that everyone is looking at me. One of the benefits of a support group is being with people who have similar afflictions, where I don't stand out as unusual.

### **Parkinson's World from the Inside: Space**

What I've been describing are symptoms an outsider can observe. What does it feel like from the inside, from the patient's point of view? The disease shrinks possibilities and refigures spaces and their meanings while it twists and alters the feel of time.

Start with a normal experience: I'm standing at my desk and I know that behind me are five bookshelves, to my left a window. Ten steps to my right is a bathroom. I orient these locations by my own body. Stepping into the bathroom I see the bathtub faucet. I know how to use it, how it fits the routines of daily life. I know what baths are and when to take them. The way I turn the faucet on fits into a network of perceptions and actions I did or did not do, might or might not do next.

Back in high school, studying French and Latin led me to read linguistic theory that showed me how much the meaning and impact of words depends on the connection between the word I chose and the words I could have used in its place. College philosophy courses brought home to me how much the meaning of what I see in front of me depends on connections with what I just saw and what I expect to see next. I expect the faucet to spout water, not air or wine. Reading architectural theory taught me how much our experience of a space

depends on the bodily movements it makes possible or impossible, as well as the social norms about what I should or should not do there.

I know it's possible but not socially acceptable to wash muddy boots in the bathtub or use the tub for a cat's litter box. I sense hovering around the bathtub positive and negative ways of moving my body and performing actions. They locate the faucet and tub in lived space the way a visual horizon locates a building. (On the other hand, I remember the first time I saw a bidet and had no idea what it was for or what do with it.)

Knowing my way around, how to move within that horizon of activities shows me what the faucet and tub are, and connects them to a larger world. I know my family's standards of cleanliness, and these tie the faucet to cultural norms for proper behavior, and those norms bring in contrasts of class and status.

Spaces and objects around me show themselves in terms of remembered and anticipated activities and movements of my body. As Parkinson's makes those anticipated movements more awkward, my experience of space changes. I'm retracing a hike I walked five years ago, and see a familiar slope. Awareness of my changed body overlays the slope with a new gradient of difficulty. The visual data may not have changed, but I don't see raw visual input, I relate to defined objects with meanings and feelings in an organized world. I see a slope that is *too steep for me to climb*. Things appear more difficult, not to be tried, less reachable than before. Lived space acquires steeper contours and new distances as one's horizon of possibilities alters.

Parkinson's changes my awareness of my bodily possibilities and so alters that horizon of possible actions that locates and gives practical meaning to objects around me. My world becomes constricted. The slope is too steep, the room too wide, the door narrow, the pavement treacherous, the soup spoon dangerous, the party or lecture or trip worrisome, embarrassing.

I recall a brief change in my world long before Parkinson's. One summer in the '70s I was standing in a parking area at the top of Independence Pass near Vail in Colorado, above 12,000 feet. An easy rise nearby looked like it might offer a wider view; the slope not too high or steep. But as I tried to climb, every ten steps I had to pause for breath. I don't remember how far up the hill I went, but I surely remember how my world changed as I struggled. I was walking in a space whose measure of distance and difficulty had suddenly changed.

Parkinson's brings permanent changes to my physical world. I find new kinds of steepness and distance. Problems with balance affect the stability of my world and can fragment it. When smells and tastes are dulled by Parkinson's, my world becomes muted. Shaky hands change my perception of what's possible. Opportunities disappear.

Presumably a mole burrowing through the earth, or a deer walking warily through the trees does not find its world narrow, but rather spreading outward with possibilities in all directions. The mole or the deer never thinks that its possibilities are limited compared to a bird in the air or to a wild horse on an open plain. We do not experience a limit *as a limit* unless we are aware of wider possibilities beyond it. A prison cell would limit me because I would know that I could do so much more outside. It's the comparison of those two sets of possibilities which makes me experience the smaller set *as* a constriction.

Parkinson's limits my world, but it does not chop off my world at a certain point. Rather my world shows a twisted metric that measures distances and actions in new ways, and puts parts of my space far away, or gives them a texture that I cannot pass. This frustrates me because I still see the wider possibilities that I once had.

That constricted world, if not challenged, grows tighter. The disease urges me to cut back on movement, and if I move, to move in low gear. As it tightens its grip the sufferer moves less and less, finally left without the strength to walk or

swallow. A relative with Parkinson's ended up bedridden, without the strength to pick up the phone, barely able to swallow. His daughter said that his "weakness during the last couple of years can only be described as total." He died, as do many end-stage Parkinson's patients, from pneumonia.

### **Fighting Back: Forced Exercise**

Parkinson's will constrict my life more and more. I can feel it happening. Can I resist that decline? A physical therapist told me that "with Parkinson's, motion is life and lack of motion is death." He was talking about not letting Parkinson's keep you immobile or moving always in low gear. Push your limits; keep moving even if your spatial world gets twisted and filled with new distances and obstacles. Keep trying for graceful movements through the tremors and stiffness and freezing.

Parkinson's works in many ways to slow me down: stiff muscles, fatigue, tightly clenched hands and feet, tremor, sapped motivation. And, in less dramatic ways, it makes me forget that I could exert more effort. I must challenge that restriction, try to move faster, with more grace, at a higher exertion level. Exercise, physical exercise, is just about the only recommendation that a neurologist can currently give when a patient asks what might resist this disease.

Indeed, researchers have found that exercises that push you out of your comfort level, *forced exercise* (for instance riding on a tandem bicycle with a trainer who increases the pace) can improve mobility and brain function dramatically, at least for a time. While those experiments involved exertion forced by machines or trainers, if I push myself to walk faster I do feel a good effect. It is important to move more and faster and more intensely. It is important to move in new ways: walk, dance, martial arts, whatever challenges me. I get used to being awkward and accept that I will never perform adequately, but the effort to perform new motions brings new energy. That energy shines a ray of hope on my activities. It's not just that my body feels better, but that my world

expands and takes on new meaning. Expanded, more forceful and graceful ranges of motion change the world that surrounds me.

I need to be aware how the felt meanings and possibilities of my spaces are shaped by what my body feels capable of doing. I need to increase my bodily awareness of where I am in space and how I am moving; learn to read my world by watching how I move or imagine moving. Since perceptions are shaped and given tonality and coloration by bodily capabilities, forced exercise to extend those capabilities can make my perceived world richer.

It is standard to tell people who are aging to keep their brains active by challenging the brain to learn new things, new languages, new kinds of puzzles, new interests; keep learning. These are necessary for the Parkinson's sufferer as well. But the Parkinson's patient can remind the normal aging person about the importance of physical motion and of making new efforts toward grace and smoothness, no matter how awkward the result.

I hold an ideal of supple movement that will make me more aware of what I lack, but will require work to train my brain and muscles to respond better. I must try for those large graceful movements no matter what they look like to other people. Repeat and repeat. Then repeat again.

## **Balances**

Parkinson's upsets my balance both literally and figuratively. It can make me unable to respond quickly to a stair, or a rock in the path, or a sudden change of direction. If I were prone to freezing I could find myself falling if I froze when walking quickly. It's not that I would lose the information from my eyes and inner ear, but that the response would fail to reach my legs and feet. Even without freezes, the feedback my balance depends on becomes irregular and confused. Quick turns cause me to stagger into a door frame or the person next to me.

There are more balances than the physical. Parkinson's upsets my intellectual and emotional balance. Its unexpected fatigues disrupt my schedules. Its mild depressions rob me of energy; its deeper depressions grey my world. Even when my world is bright, Parkinson's slows down "executive function," my ability to plan and to keep everything in order.

I have noticed increasing difficulty planning and coordinating. About the time I was diagnosed with Parkinson's I became involved with a local neighborhood organization, eventually serving as the chair of its board. There were many activities to keep aware of, and many lines of communication. At first it was easy to keep track, as I used to do when I was the chair of an academic department. But as my disease progressed it became more difficult for me to pull myself together enough to keep the overview and planning in mind. It is not impossible but it keeps taking more and more effort and concentration.

Parkinson's is a conundrum! In order to heal, it requires you to exercise and yet it zaps you of your energy, fatigues you and robs you of your strength. It requires you to have a positive attitude and yet the very nature of the condition causes you to feel anger. It demands your patience and yet the constant daily challenges of doing even the simplest things can be incredibly frustrating. It requires you to surrender and yet as you lose your abilities and independence your natural tendency is to fight back. It requires you to have hope and yet as the symptoms continue to progress you want to give up.<sup>1</sup>

### **Parkinson's World from the Inside: Time**

Parkinson's is a *chronic* disease. As that adjective suggests, it affects *time* as well as space. A chronic disease is prolonged in duration, does not resolve

---

<sup>1</sup> Fred Phillips, My Journey with Parkinson's ... A Natural Approach: Post 39 ... The Conundrum That is Parkinson's Fred Phillips <http://fredphillips.wordpress.com/2014/01/29/my-journey-with-parkinsons-a-natural-approach-post-39-the-conundrum-that-is-parkinsons/>.

spontaneously, and is rarely cured completely. It is not a limited episode that begins and then ends. Most chronic diseases have complex causes and develop slowly. They persist over time.

"Chronic" comes from the Greek word for time (*khronos*). Chronos is also the name of a mythic figure, a Titan, the father of Zeus. Chronos swallowed his children, to avoid being replaced by them. A chronic disease gradually swallows its victims. Zeus and his mother Rhea outwitted Chronos, so Zeus went on to rule. We are not so fortunate; we have no tricks that will outwit the chronic disease.

Parkinson's alters and constricts my spatial world but also changes my experience of time. This is odd, since we all, healthy or Parkinson's afflicted, know that we are going to decline and die, and Parkinson's just makes that more obvious. But it's not the end that Parkinson's emphasizes but the long drawn-out decline. I know that barring unlikely medical advances the disease *will* progress. The disease takes its own path, which changes my path through time. Everything is shadowed by a steady loss of possibility. I see what I am doing today — buttoning a shirt, driving a car — with the knowledge that soon this will become difficult or impossible.

Parkinson's world has a distinctive *temporal*, as it does a spatial, shape and tone. It is definitive decline, yet fuzzy: you know things will get worse but you can't say how or when. Different paces of decline converge in the later stages of the disease; to reverse the usual image, there are many ways down the mountain, but we all end up at the bottom.

Most people fantasize aging easily, moving along with only minor losses, a period of mildly diminishing activity, followed by a sudden crash, say a heart attack or dying in one's sleep. But few manage to live that fantasy. There are so many ways of dying slowly. Among them Parkinson's — which can come on earlier — opens a remorseless decline. Parkinson's hits me in the face with

decline every day. My downward path may be suddenly interrupted by an auto accident or quick disease, but as I look ahead the path moves down inexorably. I see it in a friend who suddenly gets worse. I see it in myself when my denials of change get brushed away by a comment from a third person or a more penetrating look in the mirror.

I watch myself and others for signs of decline. A friend said "every six months I discover a new loss." I wonder what next. Because my progression has been slow, I miss the fact that something has faded out in the last three months. Is this the way I used to move or speak or think? But self-observation is not so accurate: I think I am walking quickly or talking loudly, but others know better.

I had been happy that in my dreams I never had any Parkinson's difficulties. . . until recently. Now I have been besieged by dreams of frustration and incapacity. In a dream I am confused, unable to grasp the situation, can't get a suitcase packed, can't read the money in my wallet, don't respond to a conversation that is going too fast for me, can't walk well or control a tremor — fears of future deterioration and cognitive decline.

If inevitable decline were not enough, there are also abrupt daily and weekly changes. How I feel, how much energy and clear headedness I can muster depends on my stresses and tensions, but even more on unknown random factors. Then there are what we call "on/off" periods. My neurologist recommends that I take L-dopa in a time release format. This means that I get little sudden relief from taking the medication, only a gradual improvement, then a gradual wearing off. But that is beginning to change, and I now carry a quick-acting pill for first aid when symptoms worsen. But people who take only the quick acting form of L-dopa, and everyone at later stages, experience on/off episodes. As one friend put it, he takes the medication, and in a short while he feels a general relaxing throughout his body and is able to move and speak more

freely. When that wears off he is once again stiff and awkward in his movements and slow in his thoughts and speech.

As the illness continues, off periods become a constant threat. People learn private signals, a tingling in a foot or a warning clench of a muscle, which tell them that the medication is wearing off. Over time we all fine tune the medication. On/off problems are constant topics of conversation. We learn little tricks from one another.

Combining unavoidable steady decline with short-term changes every day and hour gives my lived time a jerky texture similar to Parkinson's space. Time speeds and slows, the measure of the time-distance between events stretches and squeezes. This loss of possibility, this downhill time, joins Parkinson's shrunken and twisted space.

### 3. The Philosopher at Bay

Time goes on, and I am never without symptoms. Every few months, I go to see my neurologist, and he performs the usual tests, cycling motions with arms and legs to measure stiffness, extending the arms to measure tremor, watching me sit and raise my arms and walk across the room or down the hall. We talk over my situation and any changes my wife or I have noticed; we recalibrate my medications. I take four different medications related to Parkinson's, but a friend takes eight.

That's the way it goes, a few tests, an adjustment, an appointment in a few months to check again. We usually talk a bit about recent research. My situation is not so complex as it will become later, so the amount of fine tuning necessary is not as great as it will be once my on/off periods become sharper.

After my diagnosis and especially after my problems with movement and cognition became more intrusive, I asked myself: what kind of life could I now lead? Devoted to philosophy, I found myself worried about whether I could continue my calling, and I looked to the thinkers I had come to love, to see what I might appropriate to help myself.

There are plenty of philosophical issues in Parkinson's neighborhood: big fuzzy issues like "the meaning of life" and "the problem of evil," practical moral issues such as how to apportion scarce time and care-giving resources. These big questions have long histories and they touch everyone as we age.

My aim here, though, is more personal and practical: what qualities of life and attitudes do I try for? What can I learn about how to approach life in Parkinson's twisted space and time? I seek a mode of coping with the disease. I am not looking for a philosophical definition, but a "care of the soul," as Socrates said, a way of envisioning and approaching my downward stumble.

Now should be the time for all good philosophers to come to my aid. Who could help? Many of my own writings have dealt with German philosophers and ideas too technical or abstract for immediate application to my illness, though they do provide me general insights about the connections between necessary order and chance contingencies. The philosophers I wrote most about offer high theories about order and disorder, and the creative importance of breaking through to new frameworks and social practices. They help understand how social and artistic novelty happens, but they say little about how to cope with an unchanging chronic illness.

To discuss illness I decided that I needed a notion of health, and the one that worked best for me came from my earliest philosophical stars, Plato and Aristotle, who argued that healthy functioning meant that the activities an organism was formed for were being smoothly carried out at the most *excellent* level possible for that organism. Thus I found myself phrasing my question in terms of what the ancient Greeks called *areté*, excellence. An excellent racehorse runs well and wins without injury. An excellent knife cuts smoothly and easily. Excellent soldiers are skilled and brave, but not foolhardy; they know when to fight and when not to fight. An excellent musician possesses skills with musical instruments, emotional sensitivity, plus stamina for long hours of rehearsal and performance. What would an excellent human life with Parkinson's be and feel like? What attitudes and traits of character should I strive to develop? What habits should I develop and what goals should I aim for, to navigate downhill space and time? How does one decline with grace and excellence?

It seems obvious that I should try to develop empathy, courage, and patience, traits that anyone suffering a long-term disease will need for dealing with pain, depression and lack of energy. Are there other habits and character traits that will make a life with Parkinson's as excellent as it can be?

Contemporary thinkers in Europe and America would tell me to weigh consequences and act to maximize good results, though they'd disagree about what and who counted in that calculation. Some would urge me to follow my intuitions about the obligations around me. Others would urge me to behave as reason dictates — but what does it dictate?

It was only later, when thinking about time and reading a poem, that I realized that what I sought was found by combining some recent ideas with ideas from Greek thinkers who had not been emphasized in my studies.

### **Back to the Greeks**

One of my college professors, an amazingly learned and quick witted teacher of Greek and Latin, led my class through dramatic, poetic, historic, rhetorical texts. I came away with a special appreciation for the Greek and Roman poets such as Sappho and Horace, and the philosophers Plato and Aristotle, as well as less widely taught philosophers such as Plotinus, Epicurus, and the Stoic writers Marcus Aurelius and Epictetus.

In the winter of 2014, I looked at a poem on my mirror and realized that my philosophical search for an excellent life with Parkinson's was edging me towards the Stoics and Epicureans. Some years earlier I had posted on that mirror the words "THINK LOUD." This slogan comes from a Lee Silverman Voice Training class which had helped me combat the tendency of Parkinson's patients to speak too softly while imagining that they are speaking loudly.

I liked having the reminder on my mirror so I decided to post other things there. I posted two poems by the Roman poet Horace (65-8 BCE) on my mirror, telling myself that I was doing this to strengthen my Latin reading skill.

But when I thought about the poems I had chosen, I realized that I was facing my illness and decline.

One of the poems I posted is quite long, but here is its first verse:

O Postumus, my friend, think of the years,  
 And how, my Postumus, they slip away,  
 Till old age brings the furrows ploughed by tears  
 And death, which piety cannot delay.

(Translation by Len Krisak. *The Odes of Horace* (Fyfield Books))

The second poem was the one I found most important. Here is the whole short poem:

Leuconoë, don't ask, we never know, what fate the gods grant us,  
 whether your fate or mine, don't waste your time on Babylonian,  
 futile, calculations. How much better to suffer what happens,  
 whether Jupiter gives us more winters or this is the last one,  
 now debilitating the Tyrrhenian Sea on opposing cliffs.  
 Be wise, mix your wine, since time is short: limit that far-reaching hope.  
 The envious moment is flying now, now, while we're speaking:  
 Seize the day, place in the hours that come as little faith as you can.

This poem is the source of the familiar phrase *carpe diem*, seize the day (the Latin verb *carpe* suggests harvesting, not grabbing or stealing). I was deeply struck by the poet's insistence that we should live our present life to the full (not forgetting, though, that rhetorically the poem is trying to get a woman into his bed by encouraging her to drink her wine and live up the moment).

Horace, like many Romans of his time (the first century B.C.E.) was familiar with the Stoic and Epicurean teachings that originated in Greece several centuries earlier. He learned from both, despite their fierce disagreements. I found myself resonating with Horace's feelings about life and death, so I asked myself whether my search for an excellent life with Parkinson's should attend to those philosophers.

Those two philosophical schools gave deeply opposed answers to many large philosophical questions about what was real, what we could know, and how we should act. But I was surprised to discover that their teachings about how to deal with illness were almost identical. Their attitudes are so similar that Marcus Aurelius, one of the greatest Stoic writers (who was, as it happened, a Roman emperor) can praise Epicurus, the founder of the rival school, for dealing with illness as a true Stoic should. Marcus writes in his diary:

Epicurus says, In my sickness my conversation was not about my bodily sufferings, nor, says he, did I talk on such subjects to those who visited me; but I continued to discourse on the nature of things as before, keeping to this main point, how the mind, while participating in such movements as go on in the poor flesh, shall be free from perturbations and maintain its proper good. Nor did I, he says, give the physicians an opportunity of putting on solemn looks, as if they were doing something great, but my life went on well and happily. Do, then, the same that he did both in sickness, if you are sick, and in any other circumstances. (*Meditations*, book X)

Epictetus, a Stoic writer who influenced Marcus Aurelius (and was, as it happened, a slave), begins his teaching manual by saying:

Some things are in our control and others not. Things in our control are opinion, pursuit, desire, aversion, and, in a word, whatever are our own actions. Things not in our control are body, property, reputation, command, and, in one word, whatever are not our own actions.... Remember, then, that if you suppose that...what belongs to others is your own, then you will be hindered. You will lament, you will be disturbed, and you will find fault both with gods and men. (Epictetus, *Manual (Enchiridion)*, 1)

Further on Epictetus writes:

Sickness is a hindrance to the body, but not to your ability to choose, unless that is your choice. Lameness is a hindrance to the leg, but not to your ability to choose. Say this to yourself with regard to everything that happens, then you will see such obstacles as hindrances to something else, but not to yourself. (Epictetus, *Enchiridion*, 9)

A Roman Stoic writer adds:

Pain is slight if opinion has added nothing to it; ... in thinking it slight, you will make it slight. Everything depends on opinion; ambition, luxury, greed hark back to opinion. It is according to opinion that we suffer. ... So let us also win the way to victory in all our struggles, – for the reward is ... virtue, steadfastness of soul, and a peace that is won for all time. (Seneca, *Epistles*, lxxviii. 13–16)

Then I found Epicurus himself writing, in one of his letters:

These are the root of all evil: fear of god, of death, of pain, and desire which goes beyond what nature requires for a happy life. . . . This is the height of pleasure: to be free of all pain and discomfort in both the body and the mind. When this pleasure is present, all pain, of both body and mind, is absent.... Illnesses which cause excruciating pain last only a short time and then you are free. Illnesses which cause mild pain may last long but it is possible to live in such a way that the pleasures of life far outweigh the discomforts. Either way, pain is nothing to fear. (Epicurus, *Letter to Menoecius*)

Epicurus died, perhaps from prostate cancer, after weeks of illness. At the point of death, he wrote in a letter to his disciple Idomeneus:

"On this blissful day, which is also the last of my life, I write this to you. My continual sufferings from strangury [blockage of the bladder, resulting in severe pain] and dysentery are so great that nothing could

augment them. But the cheerfulness of my mind, which arises from the remembrance of our past conversations, counterbalances all these afflictions. I am asking you to care for the children of Metrodorus, in a manner befitting the devotion you have given to me and to philosophy since you were a youth" .... Hermippus relates that he entered a bronze bath tempered with warm water, asked for a cup of undiluted wine, and drank it. He then bade his friends to remember his doctrines, and expired. (Diogenes Laertius, *Lives of the Philosophers*, 022 and 016)

I found these Greeks urging self-control and discernment. We can't stop our immediate reactions to pain and illness, but we can discern the true from the false opinions arising from those actions.

Today we use the word "stoic" to describe an attitude of resigned acceptance and controlled emotions.<sup>2</sup> As Marcus Aurelius said,

From Apollonius I learned freedom of will and undeviating steadiness of purpose; and to look to nothing else, not even for a moment, except to reason; and to be always the same, in sharp pains, on the occasion of the loss of a child, and in long illness. (*Meditations*, bk I)

These philosophers tell us to acquire an attitude or trait that the Stoics called, in Greek, *ataraxia*, unshakableness, Their Epicurean rivals called their version *apatheia*, not suffering when things come at you. Both emphasize facing and controlling the exaggerated reactions and desires that increase pain. But there's more to what they recommend: they require wider vision and purpose.

---

<sup>2</sup> The name Stoic originally comes from the location where the early Stoics discussed their teachings, a public colonnade in Athens; such a building was called a *stoa*.

## What I Learned

Both the Stoics and the Epicureans tell me that I can control my reactive opinions and feelings. This may seem like urging me to just try harder, use increased willpower, but they are actually urging me to take a larger view of myself and my place in the cosmos. This will make room for me to pull back from the immediacy of my illness or suffering.

In the summer of 2014 there were weeks when my symptoms increased: my energy was low; I was dizzy, had problems with balance, mental confusion. I lost weight. I couldn't motivate myself to get the exercise that would stabilize or improve my situation. I fell into a spin of fear: I told Anne that "the disease is getting much worse; I'm descending to a lower level; I won't be able to continue doing what I'm doing; it will be over before I realize it; how do I rearrange my life?"

As these fears spiraled, I tried to take a wider view and control my reactions. I told myself that what I feared could be true, but that in the past there had been other descents and I had come out of them, if not to the earlier, at least to a good level. Getting that perspective helped slow the fears and freed me to take the steps I needed. By the end of July I was back to "normal." I know full well that these episodes will happen again and that at some time the fears will be justified, but I have proved that I can handle my reactions to these episodes and stay on an even keel despite the fears.

This better control of my fears did not come merely by increasing my resolve to tough it out. The key was seeing my fears in a wider context. That's what the Stoics and the Epicureans say we should do, understand the context of our momentary experiences. They urge us to see ourselves in a larger context.

The two ancient schools differed intensely, though, on what that context was. For the Stoics my illness is part of a plan, a role written for me in the play of a world guided by a rational spirit. In this it resembles — and it influenced —

standard Christian and Jewish appeals to divine providence. The Stoics do not demand that I *understand* my role in that play. I should fulfill my calling, confident it contributes to an overall pattern. (Needless to say, this made Stoicism popular with governments.) My disease fits in with an overall order of the world that I can never fully grasp. At one time I might have found a related solace thinking about God's unknowable plans, but time and philosophy had led me away from such beliefs.

The Epicureans tell me to see my illness as a random result of chaotic activity. Their world contains only the purposeless collisions of tiny atoms rebounding in an infinite void. Everything happens by chance. For them there is no deep reason or plan for my illness. I can learn to deal with it calmly and generously, refusing to allow the overall tenor of my life to be determined by such random events. This seems truer to me, as far as it goes, but it doesn't go far enough to help me live my daily life.

The Stoics recommended following the roles we find ourselves assigned in private and public life. So Marcus Aurelius writes his Stoic diary while administering the Empire and leading military campaigns. The Epicureans taught the search for pleasure (governments did not favor the Epicureans). The Stoics accused the Epicureans of promoting wild and lascivious pleasures, but this was false. Epicurus taught that what leads to serenity is a simple lifestyle that is not too busy, one that does not demand we engage in disagreeable public tasks nor require us to push ourselves to the limits of our power and strength. Epicurus called his place of teaching "the garden." That reminds me of what Parkinson's sufferers are often urged to do: enjoy the present moment.

But the Epicurean vision discourages community involvement and civic projects; an excellent life for them is to live our private lives simply and pleurably with a few good friends. This feels too constrained for me, since I seek a way to live the present moment more widely and compassionately.

Private enjoyment may well be all I can hope for later in the disease, but for now I seek to help my community.

Also, there is the problem that both those ancient philosophies were offering their advice about illness to people suffering from illness that would either be cured or soon lead to death. Can their suggestions be applied to *chronic* illnesses that go on and on and on? It is not true that in a chronic illness "the pain soon ends," and with Parkinson's it is not so clear that "it is possible to live in such a way that the pleasures of life far outweigh the discomforts."

A chronic disease amplifies mortality. The healthy person and the Parkinson's sufferer both face the ultimate closure of their futures. But Parkinson's patients, and all who suffer serious chronic disease, face that end as an everyday loss. It affects every action and enjoyment and project, no matter how small. We must make great effort just to get our daily lives going well enough. I can learn from the ancients how becoming aware of a larger context might change my way of living through my illness. How can that advice be connected to Parkinson's injunction to live more in the present moment? To apply the ancients' advice to *chronic* illness, I need a closer examination of how to "seize the day."

### **The Present Moment**

I've described how tremors, dyskinesia, and slowness blur motions and alter my awareness, and how "with Parkinson's, motion is life and lack of motion is death." I keep trying for a quality of graceful mindful movement. Asking what qualities would make a life with Parkinson's as excellent as it could be, I can ask what would it mean to move gracefully and mindfully though the awkward twists of Parkinson's *time*?

In fact we Parkinson's patients are often counseled to change the way we move through time. Go more slowly. Pause, look around, enjoy the present moment. Because the disease forces us to pay more conscious attention to actions

that most people perform automatically, Parkinson's victims often say that the disease has offered them a gift. Parkinson newsletters and books contain testimonials about how, despite its depredations, "Parkinson's made me more aware of my life" or "enriched my awareness." We hear the usual self-help mantra about "living in the present moment." Be here now. Stop moving anxiously through time.

At first glance this seems silly advice. We can't be urged to move through time differently; time marches on; it would seem that we can't change its pace. Yet we can change its quality.

### **Deepening the Present**

What is the present? An isolated frame of a movie? I can imagine resisting time's flow, shutting out past and future in an immediate experience of sensuous presence. I can shut out distractions and look more intently. I can concentrate on a flower, slow down, be aware of sights and sounds and smells and music and landscape. A mountain landscape or a blooming tree in spring can stop me in my mental tracks and make me *see*. A Rembrandt portrait, a wild iris in the grass, an unexpected melody, a surprising architectural effect will pull me out of distracted busyness. The intensities that result from such encounters can wake me up, change me.

I've read how brain damage can do even more, removing language while leaving purified perception. For instance, neuroscientist Jill Bolte Taylor describes how bleeding in her brain silenced her language ability. At the moment when others were seeing her as unable to communicate and bodily crippled, she was discovering something very positive:

When I lost my left hemisphere and its language centers, I also lost the clock that would break my moments into consecutive brief instances. Instead of having my moments prematurely stunted, they became

open-ended and I felt no rush to do anything. Like walking along the beach, or just hanging out in the beauty of nature, I shifted from the doing-consciousness of my left brain to the being-consciousness of my right brain. I morphed from feeling small and isolated to feeling enormous and expansive. I stopped thinking in language and shifted to taking new pictures of what was going on in the present moment. I was not capable of deliberating about past or future-related ideas because those cells were incapacitated. All I could perceive was right here, right now, and it was beautiful. My entire self-concept shifted as I no longer perceived myself as a single, a solid, an entity with boundaries that separated me from the entities around me.... My soul was as big as the universe and frolicked with glee in a boundless sea. (Jill Bolte Taylor, *My Stroke of Insight*, 68f)

Dramatic though it was, her immersion in the present did not freeze an instant; it opened her to a flow. Even without such extreme experiences, immersion in the sensuous presence of a natural scene or an art work can be a vivid, even life changing event. But these are not static experiences; they have their own internal flow. And, for all their importance, these experiences are not yet living *in our daily present as it fully is*.

To experience such intense moments *as a series* is to involve more than one present moment. Belonging to a series means that each moment contains in itself a past and a future.

Earlier I discussed how the present gets its meaning from being caught up in projects relating past and future. I see the hill as hard to climb because I have already related my past experiences with Parkinson's to my thought of climbing it. The hill enters my world *as difficult*. All sorts of neural events and unconscious inferences may be going on behind the scenes, but my world comes already

meaningful in terms of projects, both mine and my community's, and those projects have already tied together the moments and motions of time.

Moments in time get their meaning within those cross-temporal relations. A *moment in a series* is more than an instantaneous slice. It moves in time, rising from a past and opening up a future: fluid life, not the repetitive freezing of instantaneous moments divorced from one another. To be *fully* in the present moment includes what it retains of the past and its projections of the future, with a general sense and import for the whole.

To live fully aware with Parkinson's in the present moment means keeping aware of my past flexibility and future descent. To leave those out would avoid the present moment as it is, pretending I can forget the illness. What I need is a way of being toward and with the world across and beyond the disease, neither denying it nor allowing it to fill my entire horizon. Seizing the day and living in the present moment should not constrain me to immediate perceptions; it should expand my awareness.

### **Authentic Life**

Most of the "treatments" recommended for Parkinson's, especially physical exercise, imply facing up to degeneration and taking active steps to slow it down. It's not about quaffing pills while enjoying the present sights, sounds, relationships and tastes. It's about seeing these present moments within a wider horizon that emphasizes their fragility, makes them valuable, and spurs us to enrich them, and this in turn calls us to find or create tasks and meanings larger than our own physical condition.

We all know that in any moment we could die from a brain embolism or a car crash or a sudden explosion or a myriad other causes. So are we to go on with our activities and goals and turn our eyes from those dire possibilities? Perhaps it would be better to be always in the midst of this or that project, projecting its

goals and activities, not looking too far ahead, until something strikes you from outside. Why not? Just ignore the shadow ahead.

However, Parkinson's strikes from inside, and the blow has already landed before you become aware of it. That sense of having been overtaken, with its certainty of decline, means that your activities and goals show a new fragility. Possibilities are always fragile, always dependent on factors not all of which you can control, but with Parkinson's that loss of control is doubled and thrust at your face.

Should I ignore that shadow and go on living through ongoing absorbing or boring episodes, with no particular thought about the inevitable ending that will suddenly cut off these activities? I can do that, just go along with projects and social roles that I have accepted as "what one does." Most of us live that way most of the time. We are defined by an anonymous "they" that we find ourselves among without ever having chosen to be with "them."

Another way of avoiding the shadow would be to flit from one enjoyment to another, each one isolated in its own stretch of time, an intense episode then a dull episode, a new interest to yet another, abandoning each, not trying for any unity in my life., always moving on from one rounded pearl of experience to another, always beginning again.<sup>3</sup>

It might be possible for me to live a series of isolated experiences, perfect or not, taken individually . But Parkinson's forces me to keep my life as a unified whole in view. Every day, as I grope for a lost ability or feel today weaker than last month or last year, Parkinson's slams me with a vision of its long path foreshadowing my death. And, as Tolstoy and Heidegger remind me, I die alone; no one can do it for me. This should make me realize that no one can live my life for me, though I keep forgetting and letting "them" do it.

---

<sup>3</sup> Søren Kierkegaard in the 19th century called such a life "aesthetic," Don Juan always moving on from one conquest to another, always beginning again, never taking up his life as a whole.

Boredom or anxiety or strong experiences of love or action or art — or an illness such as Parkinson's — call me to "take up" my life as "my own" (Kierkegaard and Heidegger call this "living authentically.") I can "seize the day," including its past and its possibilities and its projects, not just its isolated moments.

I can take up my existence. I can find in my past and my present moments possibilities and tasks that call me toward a future of renewed action. I can embrace the limitations of my life and situation by "resolutely" responding to new possibilities arising from the intersection of my past and envisioned futures. I can unify my time, not fritter it away in one excitement or project followed by another. Living authentically means embracing my existence, with purposes given urgency by my limited time and finite meaning.

This is to live with Parkinson's within a horizon of tasks and projects that, dramatic or not, keep me from simply identifying myself with the restrictions and slowdowns of the disease. I accept the full reality of the disease, with its degeneration, but meaningful tasks can open to me if I bring myself together enough.

All this sounds quite inspiring, but is it really useful for me or for anyone with Parkinson's? When philosophers and artists talk about "authentic living" they love words like "courage" and "resolution" that imply forceful striving forward. That's one thing Parkinson's won't let me do, either literally or figuratively.

Might we say that someone working on a limited task for a local community, or a Parkinson's support group, or even someone whose activities can extend only as far as stringing beads in a nursing home, might still be living a resolutely authentic life, involving more than self care or mere endurance?

Parkinson's patients often dedicate themselves to tasks defined by the disease, becoming activists searching for a cure, crusading for public acceptance and funding, or creating groups to help fellow sufferers.

This essay you are reading has been one of my projects; it has haunted me for the past four years, gradually coming together from scattered notes. I have not been sure what it could be or who might read it but I felt a need to think it through and speak out. Some people might be helped by reading it, as I was helping myself by writing it.

But a Parkinson artist or writer or scientist or politician may also take up tasks that have nothing to do with the disease. Since my diagnosis, I have been teaching and serving on the governing council of the Osher Lifelong Learning Institute (OLLI) at the University of Oregon. It's fun to share with others and work for worthwhile goals. But there are problems. Last month I was standing in front of a philosophy group talking about Plato, my arm extended pointing toward a diagram on the screen. But my hand could not stop shaking; the audience looked at me not the screen. Then I realized my speech was indistinct; I slowed down and enunciated more precisely. Five minutes later I could not recall the name of a Platonic dialogue I have taught repeatedly. These symptoms unnerve me. Until recently I have been ashamed as they obtruded more and more. I tried to hide them, tucking my hand in my pocket, steering discussion away from names I couldn't remember. But now I've resolved to let the symptoms hang out, hoping that all of us in the room might find a better way to live with my disease.

My challenge is to create something that orients my time and space to more than just coping with my daily twists, blockages and disruptions.

Working with these continuing education and neighborhood organizations keeps my increasingly restricted life open to the messy joys, sorrows, and challenges other people face. I share moments of humor and joy, companionship

in success as well as in frustrations and bureaucratic slow-downs. As a Parkinson patient and intellectual, I am tempted to drop back and withdraw. While I do enjoy doing philosophy on my own, engaging with other people keeps me hungry for more life and new projects.

My local world will shrink as Parkinson's goes on, but the larger background world does not, though it may become difficult to keep that wider horizon in view. An authentic self takes up its projects with awareness and responsibility to bring and receive meaning in the world. There is no magic formula. The best I can do is look for open responses, creativity and compassion.

Realizing this, I removed Horace's poems about death from my mirror and replaced them with some of his poems that celebrated love, engagement, and their unexpected consequences. In particular I liked a poem where the poet pretends distance but in the end has to admit his own fascination.

What perfumed slender lad now comes to woo you,  
 Pyrrha, mid the roses in the pleasant grotto?  
 For whom do you bind your golden tresses in your artful  
 Artless fashion?  
 Poor boy! Amazed, he will rue the broken promises  
 And stare at scowling gods and stormy seas;  
 He's unsuspecting  
 And hopes to love you ever, your golden charms  
 Remaining always lovable to him alone.  
 He's yet to recognize the deceitful breeze.  
 How I pity  
 Those you dazzle, gleaming in your untried splendor.  
 A tablet on the wall of Neptune's temple  
 tells I offered to the mighty God of the sea  
 my dripping garments.

Here Horace remembers the stormy conclusion of his passion for a lady as unpredictable as the sea, but he cannot avoid still feeling her attraction. I have long enjoyed this poem (in fact I made that translation as a homework assignment in 1960). In writing the poem, Horace doesn't deny his desire for the lady. He creates a wider space to be with his feelings in a less pressured way, with rueful irony. I can try to live with irony and openness about my disease, as part of living in wider horizons.

### **Forced Exercise Again**

In this section I have been investigating the space and time of Parkinson's world, wondering how I can respond authentically. I found a richer meaning in the common slogan that we should live each moment to the fullest. While full living certainly should include as intense sensory perceptions as I can manage, it should also include the context, history, and horizons that make sensory perception meaningful. Plus discerning possibilities in our world, seizing them in order to enrich the density and authenticity of life with Parkinson's.

This authentic life may not be "easy." It demands energy. But I remember that research has shown that "forced" physical exercise at a higher pace than the patient is accustomed to works better in reducing Parkinson's symptoms. It turns out that living authentically can be a temporal equivalent to spatial forced exercise. If we move through time "more intensely," out of our steady comfort zone, life may become more fully itself, despite Parkinson's.

## 4. Decline and Dementia

In my introduction I affirmed that "I am stubbornly present and I don't plan to stop writing and creating." Now, beginning this last section, I ask myself how well I am facing my disease. I worry whether my response is adequate, especially as my long-term philosophical identity changes. I do take more time now for reading novels and seeing films, if not for smelling the roses (Parkinson's deadens your sense of smell). What's next?

### How is it Going?

People have said, you seem to be doing very well despite the disease. Look, you travel – you spent three weeks in Turkey. You are still writing and you give talks.

It's true, my activities have not yet been deeply curtailed by the disease. But it's also true that my space and time have changed in the ways I described. Some activities and goals become too distant, others become twisted, accomplished only with difficulty, and all are threatened by a new fragility.

For the first two or three years, my disease was not too noticeable to the uninitiated. I heard my sister saying that you couldn't tell that I had Parkinson's. Especially if I kept my left hand in my pocket. But that's no longer true. Recently people have looked at me briefly and said, you have Parkinson's. Others have said or thought, what's wrong with your hands or your face? Or, what did you just say?

Until recently, I could wake in the middle of the night without a tremor, but when I stood up or walked around, symptoms came. Now as soon as I wake I shake. Later in the disease, I may not be able to get out of bed until I take the meds. It's strange knowing what's likely to come next but with no idea when.

Four years ago an immigration control guard in Sydney, to whom I had only handed a document, said to me that he had the same disease, and he didn't consider it fair since he had always taken good care of his body, eaten well, exercised. Why should he be afflicted with this illness, weakness, difficulty in performing his job? We commiserated with one another on the inability to identify any reason for our fates. A year later I was bargaining with a rug salesman in Turkey who was a retired doctor, who interrupted our conversation to say "You have Parkinson's, don't you?". Then he asked me about my drug regimen.

Later on that trip, we were taking a taxi from a hotel to an apartment in Istanbul. I had spoken a few sentences to the taxi driver in my scanty Turkish, giving him the address of the apartment. We exchanged a few words as he drove, with me in the back seat. When we arrived and I was paying him he said to me, you have Parkinson's. I said yes. He said that his father had Parkinson's and was very shaky. He said that if I wanted treatment the such and such clinic in Istanbul was the best in town and could be very helpful. I thanked him. We parted smiling.

Recently in several conversations I had occasion to bring up my Parkinson's and the person I was with said "I had noticed that already." But hearing these incidents my friends will say, but you have been traveling. You were in Istanbul when that happened with the taxi driver. You were speaking a little Turkish, for heaven's sake. That's true. But they don't see my difficulty with travel, my fatigues, disorientation, and little things like not eating soup, which I now avoid ordering. They may not realize that I now avoid pouring liquids or carrying full glasses and bowls.

They don't know how hard it has been to compose my last several public talks when I find increasing difficulty concentrating my mind on the task at hand. I'm beginning to feel an on/off rhythm with my meds. Compared with that trip to

Turkey in 2014, on a trip to Arizona in 2015 I was much more slowed down by fatigue and difficulty walking long distances.

If I am not careful my voice becomes softer and my articulation less clear. My dictation software makes more errors now, complaining because I don't pronounce the words as carefully as I used to. Correcting those errors with the keyboard is more difficult than it was even a year ago.

My hands shake more noticeably, often both of them, and my left leg sometimes shakes even when I am standing. Unless I write slowly and large I can't read my own handwriting. I walk more stooped over. Unconscious movements in my lips and face bother people. With concentration I can stop the dyskinesia, for a while.

It's likely that I'm getting to the end of stage two of a five-stage disease. While my neurologist's ten-year prediction turned out too pessimistic, the disease is catching up. Meanwhile, I see my friends in the support group growing weaker and less able to stand or walk straight, less able to do what they could six months before. My wife, who attends a caregiver group, hears sobering stories of the advanced stages of the disease. I don't hear those details, though I understand in general what is likely. With all these signs, I feel the accelerating motion downhill.

I remember a remark from my neurologist. Like most doctors, he dictates a summary for the patient's chart; sometimes he dictates in my presence. A few years ago I thought I heard him use the phrase "mild dementia." You can imagine how that shook me and twisted my time horizon.

These days I find myself forgetting plans I had agreed on, overlooking promised tasks, losing details and names, standing in bland confusion. Two years ago I started a medication given to Alzheimer's patients; recently I have started a second. I have had one or two frightening episodes of disorientation

while driving. In these moments of confusion and forgetting the monster lurking on my path down the mountain bares its teeth: dementia.

### **Authenticity with Dementia?**

Researchers are unsure what percentage of Parkinson's patients will suffer from dementia if their disease goes on long enough. The figures range from twenty to eighty percent; the higher estimates are the most recent. Everyone with Parkinson's suffers mild cognitive declines, first noticeable in executive function. To plan, to stay concentrated, to do more than one thing at a time, these become more difficult, as does the management of scheduling and keeping one's life efficiently on track.

Later come increased difficulties handling large data sets, losses of memory, and eventually dementia. But dementia has degrees and kinds. There is some evidence that the kind of dementia associated with Parkinson's disease can (but may not) differ from that associated with Alzheimer's. With Parkinson's there seems to be less erasure of the personality and the past, rather an increasing difficulty in accessing them. An uncle who died from advanced Parkinson's disease was demented some of the time but not always. My cousin wrote to me,

During the late-middle period Dad was more often delusional--for example, believed he was back in his parents' home on Greendale Ave. in Edgewood PA. For quite a long while he insisted he was in Canada and would demand to go home--even when he was at home. By far the worst, however, was when he was sure there were spiders, etc., or opening cracks, on the ceiling of his room. Dad's dementia was much worse at the middle stages than during the last year. I suspect the medication regime at the nursing home/hospice, where he spent the last 13 months was strong on sedatives and antipsychotics and at some point opiates, and the environment there was calm and comforting--

plus the staff were attentive and quite humorous (what Kolb could resist that?). Palliative care all around.

Thinking about my uncle's situation, I imagine myself bedridden, with a feeding tube, distracted and confused. I worry about restricting Anne's life and her contributions to others. Yet I will need the help. At some point I might come to the point where it would be time for what the ancient Stoics called "the reasoned dismissal," taking my own leave from life, and I do live in Oregon, where that is legal. But could I reason, in that condition?

Dementia destroys context and wide vision. Must I then admit that what I have proposed for an excellent life with Parkinson's cannot succeed? Cognitive decline weakens any technique that relies on reflective awareness, and diminishing executive function weakens authentic response. Will my prescription fail, or lead me to despair?

There are many kinds of vision and context. I hope that the kind of awareness of the moment that I am trying to describe is not hyper-intellectual, and authentic response does not depend on extraordinary executive function. My wife and I were visiting a famous potter in Japan. He handed me a large faded ceramic. I was impressed by its feel. Then he said, "That pot is from China and it is 3000 years old." My visual impression of the pot had not changed, but suddenly my experience of it was more resonant and deeper-- and a bit scary, so I put the pot down. What had changed was the horizon of meaning and activities surrounding the pot, a change stimulated by what he said, plus some background awareness of Chinese history. It was not a great theoretical enlightenment; it was a different feel to the pot in my hands.

On a trip to Turkey we visited ancient sites, some pre-Greek, others Greek, most with Roman buildings. I have a lot of academic knowledge about ancient civilizations, especially Greek and Roman. My experience of those ruins was deepened by that background, but not as if particular facts or quotations kept

coming to mind. It was that the places had connections which I knew could be explored, an experiential heft against my background knowledge of how people lived long ago. Again, that requires knowledge, but it is not an awareness which is a presentation of that knowledge. It is a sense of experiential directions and connections to actions and to values.

I'm not denying the intellectual component in such awareness, but the awareness which makes the present moment thicker and more hefty does not require explicit recall of facts, figures and histories. The world broadens and deepens its connections. Maybe I will forget facts and dates, but might I retain at least a background sense of values, history and people's modes and moods of being in other times? I don't know whether that is possible.

Authentic response depends on the ability to heed a call more than on the ability to plan and execute with precision. Taking up my existence as a whole does not depend on having a clear intellectual vision so much as on having a felt sensitivity to where and how I am, and a sense of myself as responsible. Contextual awareness and authenticity do not depend on cognitive abilities functioning only at their highest level. But they will decline even more; so while my prescription for an excellent life with Parkinson's can remain usable amid decline, dementia will steadily gnaw away at it.

## **Identity**

With dementia threatening my friends and me, what can I say as a philosopher caregiver, to those who are becoming diminished? How should I regard friends fading away due to dementia? Even more, if I am the person fading, what can I say to myself? How should I regard myself, as long as it is possible for me to do so?

What kind of continuity does a self have as it declines? Who am I as I diminish? The eager five-year-old is replaced by the surly 15-year-old and again

by the smiling 35-year-old. We say these are "the same person," and yet in some ways they are not. John was a thief and murderer; then he reforms, and we say he is "a new person," yet in some ways he is not.

I imagine myself living with a sense of decrease, a shrinking world, a past growing unreachable, a present growing more and more confusing. I would be aware that I could not act or remember as I once did. Enough connections would remain that I would be mourning my losses. In such a case, what could I say to myself? Is there still a life to live authentically? How much would this fading person still be me?

We need some distinctions. There are many kinds of identity. Physical identity: Am I the same person who was seen on the security camera? That should be easy to decide. Legal identity: Show me your papers. Responsibility: When I signed the contract to buy the apartment was I as rational then as I am now? That is harder to decide. Psychological identity: Am I the same me as I was as a teenager? That depends on your criteria; the answer can be both yes and no. I imagine a nephew saying "I can hardly believe that Uncle David is the same person; he seems so changed by his illness." Recent psychological research suggests that in such cases people do judge identity over time based on how much the person remembers, but they put more weight on how closely a person's basic attitudes and values remain the same.

Then there are puzzling examples that are not yet real. Suppose my mind has been uploaded to a computer and then, claiming to be the dead philosopher Kolb, the machine demands to receive the royalties from "my" publications (don't I wish!). Is it entitled to the money? Or consider this: "Sorry, Kolb, the Enterprise transporter has malfunctioned and now there are two of you. What should we do?"

I have become interested in philosophical theories and neurological research that see the self as not one continuous substantial entity but as an ongoing

process tied together by memory and habit. Flexibility with the notion of personal identity can also be found in Buddhist theories.<sup>4</sup>

If a self is an ongoing process rather than a fixed material or spiritual entity, then we can say that self-identity is not all-or-nothing. As memory and habits lose connection and continuity, the old person diminishes and a new person arrives by degrees. Derek Parfitt suggests that relations between past and future selves are more like relations between generations of humans than relations between two temporal parts of one continuing entity.

When I thought about relations between generations I found myself thinking about reincarnation as an image for dealing with dementia. In Hinduism the standard Indian cosmology of cycles and reincarnations combines with the affirmation of an underlying unchanging self which reincarnates until attaining liberation from the cycle. Early Buddhism accepts the standard Indian cosmology and reincarnation. But the Buddha insists that there is no underlying self. In fact, the illusion of a continuing self and attachment to it is one of the principal causes of the suffering which he seeks to heal.

If you believe in reincarnation, and you believe that a self is an ongoing process and that a future self is "the same" to the degree that there is continuity of memory and values, then you should conclude that a reincarnated future person with no memory of my life would not be *me*, even though it may be deeply influenced by a causal network that includes my past actions. But, putting aside a belief in reincarnation, didn't I just describe the situation of a deeply demented future me?

---

<sup>4</sup> Buddhist philosophers extended this "no-self" doctrine. Not only is there no self which continues through reincarnation, but there is no self which continues day to day. Yet there is an obvious experienced continuity in our lives. This is explained through the Buddhist doctrine of dependent origination. Any entity, mental or physical, has no independent existence by itself; it emerges in and through connections with other entities that themselves share no lasting independent existence. The different selves that we are from reincarnation to reincarnation, or even from day to day, are linked through their interdependence with other entities and their past history (the law of karma).

## New Selves for Old

What if I think of the person with dementia not as a diminished old self, but as a new person causally connected to past selves years or months or days or maybe only hours ago? Identity between new and old would come in degrees depending on how much memory and habit remains. This means that as a caregiver I would not see my demented friend as a tragically reduced version of someone I was still trying to hold on to. Instead I would see a new person more or less continuous with the former person, to be treated as a self with its own possibilities rather than described in negative terms. This would encourage me to explore the world of this new person and discover its possibilities as well as its limitations.

From the outside, the demented person is by degrees becoming a new person. As awareness of past and self-reflection decrease, old habits and buried tendencies might surface in irregular ways, the results of causal chains from long ago.

As a caregiver I should try for discovery and participation. Would this weaken emotional connections between the caregiver and the new person? That too would be a matter of degree. Emotional connections, love and concern, need not depend on some metaphysical continuing identical self, once we accept the idea that all personal identity is subject to constant refiguration.

If a more flexible notion of self-identity as coming in degrees might be helpful when dealing with a friend or loved one's dementia, could this also be helpful *to me, from the inside*, if I am the philosopher slipping into dementia?

Some believers in reincarnation say things like "I am sure that in an earlier life I was a princess along the Nile". Analogously, in dealing with dementia from the inside, I could say "I am sure that in an earlier life I was a philosopher, teaching

in college, writing essays. I'm not that person now and my world has a new shape that I can explore and act within." Would this help?

How satisfying is that? In truth philosophy does not deal well with dementia. Most philosophical advice for crafting one's life, at least in the traditions descended from Socrates, depends upon awareness backed up by argument. Socrates' injunction to "care for our souls" rings shallow if our souls and our ability to care evaporate. There would come a time when severe dementia removes any ability to take any attitude towards myself, to be reflective.

At best there would remain that Stoic and Epicurean advice to cultivate as far as possible an unruffled state of mind that accepts what has been given and tries not to overreact. Live the present moment in its full concreteness with past and present, accepting it in light of some larger view of the world. Yet as that larger view fades it might be better to phrase my advice to myself in Buddhist terms: try not to be attached to the past nor to cling to the present nor to push away the future states. Give up the craving for strong identity and continuing powers. Let the present incarnation and its possibilities be. Take them up as best you can.<sup>5</sup>

### **Deepening Awareness**

Earlier I discussed how the idea of seizing the day or living authentically in the present moment leads to expansion, not contraction. Intellectual-emotional expansion creates room and perspective, but now we see those wide horizons shrinking due to dementia.

My life lately has been taken up with the disease, but also with writing, travel, working with a neighborhood association and a lifelong learning center, occasional lectures, lots of exercise, some exploration of math and science, and reading lots of fiction. I've been busy, not focused on the disease and its

---

<sup>5</sup> The Buddha refused cosmological stories of the sort the Stoics and Epicureans depended on. From the Buddhist point of view such theories and stories function as "skillful means" to help us attain piece of mind. There may come a situation when those particular skillful means are no longer appropriate.

symptoms, but not denying them either. Going back to the image of a horizon that I used earlier, I try to live in a world across and beyond the disease rather than letting the disease occupy my entire horizon.

But as dementia chips away at that horizon, how can I live authentically? Here, whether or not we find the image of reincarnation helpful, I can learn from Eastern traditions another way of widening the present. This does not make the problems go away or find a perch above or below them. It's not a sinking below, nor is it a rising above, as if I could leave behind the sordid realities of the disease. It's a surrounding, letting be, compassion toward myself. This can be practiced; it's another kind of care of the soul.

Meditation teachers say that when feeling bodily pain one should stop fleeing it, just let it be, examine its qualities, and see how its negative aspects are partly due to the attempt to get rid of it. This will not make the pain disappear but will reduce its urgency. Sometimes I can manage that. Can the same be done with the shakes and tremors and restlessness of Parkinson's? I have tried with occasional success, but have more often failed at the task.

It's very difficult to sit and relax in a chair or in a meditative position when my feet and hands are shaking and my body refuses to be still. How can I deal with this uncontrollable movement? It's not a matter of going to a level below the Parkinson's, which I cannot do, but, as with a pain, of embracing and accepting the shakes and tremors and restlessness, and not letting them disrupt a calm mind. Yet Parkinson's also makes my mind jittery and flighty. I have to find ways to accept the symptoms by expanding and surrounding them, viewing my diseased self with open, rueful acceptance rather than fight and flight. This is another kind of achievement, difficult, but less dependent on my cognitive abilities remaining sharp. This gets harder and harder but it does not depend

upon intellectual self-reflection. It can be practiced; it's a spiritual formation, or care of the soul, making a life.<sup>6</sup>

True, there would finally come a time when severe dementia removes my ability to take *any* reflective attitude towards myself. What I am proposing would not help for that late stage dementia. But then, nothing else does, except compassion.

---

<sup>6</sup> This would not imply an expansion of "myself" as if the disease affected only a small part of some larger entity. There are traditions that make such a claim, but I see no way to talk usefully about such a larger self. The Buddhist practices do not rely on any particular story about the reality of this or that entity or self. There is a Buddhist ontology of interdependent entities, and it makes a great deal of sense. But even that story is not required, although thinking about it may help.

## A Conclusion

At the beginning of this project I wrote that I hoped to "express something from my life with Parkinson's that might help others deal with living on a downward slope." A chronic disease amplifies aging. Does the Parkinson's world tell us anything about "normal" aging, that fantasy of easy decline and sudden cut-off we all wish for but almost no one achieves? It is "normally" easier to live in denial until, perhaps, near the end. But Parkinson's hits you with daily opportunities to take up your situation in the world. Parkinson's forces those of us with the disease, and its example urges everyone else, to walk self-consciously down that mountain, finding creative possibilities in each moment of our ever diminishing experience.

On the way down the mountain, we should try to respect the death and birth of selves and worlds, and our own births from moment to moment. We can learn compassion that is aimed as much at our own weakness as at the sufferings of others. We can try to enrich our shrinking worlds, for as long as we can. Near the bottom of the mountain, dementia can kill Chronos and break up our life in time; even the sense of passing moments could be taken away. Then, in our end as in our beginning we will depend on the care and compassion of others.<sup>7</sup>

---

<sup>7</sup> Many friends and colleagues have helped me in writing this essay. I thank Anne Niemiec, Nancy Kolb, Mark Johnson, David German, Francina Verrijt, Meta Maxwell, Tony Meyer, Lynn Ash, Toni Burbank, George Kaufman, Jack Meacham, James Ward, Lyn Blatch, Tony Koltz, and James Earl. Lee Eide helped with design. A selection of my philosophy and architecture writings can be found at [dkolb.org](http://dkolb.org).