Metamorphosis
Progressive Supranuclear Palsy: The Story of Govindbhai

By

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ABSTRACT

The creative capstone project revolves around the story of Govindbhai, a man who was diagnosed by the ghastly neurological disease known as progressive supranuclear palsy (PSP). Very little research has been done on PSP and the treatments are essentially nil. Each day on this unfortunate journey presents perplexing new challenges to Govindbhai and his family. He began with stumbling backwards and falling down on his butt but as the disease continued to progress each and every organ system seemed to be affected. Not only the muscles for walking but the muscles used in eating, urinating, swallowing, defecating, and talking become more and more unpredictable. Besides his motor symptoms, multiple non-motor symptoms from sleeping difficulties, delusions, to dementia create obstacles for him to take charge of his very own life. He was a father, brother, grandfather who was known for his long 10-mile daily walks and quick witty comebacks. after the disease, he was no longer Govindbhai. He stopped walking. Then, he stopped talking. And at last, he stops eating. It is the story of a soul imprisoned in his own body, marked with philosophical perils that help provide guidance and support to Govindbhai and his family. The philosophical tradition most explored includes Buddhism, Hinduism, and Taoism. The book aims to answer the question of what it means to be alive. Ideas such as balance, change, karma, detachment, perception versus reality, wu-wei, and emptiness are explored alongside the symptomology of PSP.

ACKNOWLEDGEMENTS

This book is the product of experience and mentorship. I would like to begin by acknowledging my grandfather, whose experiences make up the final culmination of this book. Each and every moment of his journey through his neurological disease became a lesson from which I was able to reflect on what life really is about. I hope to convey the polarity between life and living in this book. In addition, this book would not have been possible without my amazing faculty mentor, Dr. Matthew Bond, who fostered much philosophical thought and insight into the writing process. Our biweekly discussions on a certain philosophical topic or chapter better helped me clearly see the vision and direction that I wanted to take with my writing.

Creative Writing Process:

First, he stopped walking. Next, he stopped talking. And at last, he stopped eating. The book is focused on the story of Govindbhai, a 74-year old male, who was diagnosed with Progressive Supranuclear Palsy (PSP). In the process of writing this book, both research and philosophical literary reviews were completed. Research was aimed to learn and evaluate the effect of PSP on the body and each subsystem affected. Additional literary reviews were done to evaluate the best way to integrate Eastern philosophical themes, namely Vedanta, Buddhism, and Taoism.

PSP is a rare neurological disease that appears in five individuals per 100,000, yielding a probability of 0.005%. It is often misdiagnosed as Parkinson's disease due to similar appearance in symptomology. Whereas the mechanism of Parkinson's relates to a releasing problem, the mechanism of PSP relates to a receiving problem. In Parkinson's, the substantia nigra neurons die and thus no more dopamine is released, thereby causing pathological inhibition as shown in the bradykinesia. On the other hand, in PSP, substantia nigra neurons are spared and so while dopamine is being released, the receiving centers of dopamine (basal ganglia, brain stem, and cerebral cortex) are dying from a buildup of Tau protein. In the writing process, using various research articles, symptoms of PSP were explained by biological and pathophysiological mechanisms.

In terms of the writing style, the intention was to mimic the famous neurologist author Oliver Sacks. The first step was to read Sack's book, The Man Who Mistook His Wife for a Hat, wherein an identifiable writing style was discovered. Sack divided each chapter into a different neurological disease and included personal anecdotes to describe the patient's symptoms and experiences. In addition, what was unique about Sack's style was that he would integrate the

patient's personal humanity with their neurological disorder to fully describe their holistic, conscious experience. For example, in Chapter 1 of this book, Sack's writes, "The concrete and real, as he did; and we fail to see this, as he failed to see it. Our cognitive sciences are themselves suffering from an agnosia essentially similar to Dr P.'s. Dr P. may therefore serve as a warning and parable—of what happens to a science which eschews the judgmental, the particular, the personal, and becomes entirely abstract and computational."

In Metamorphosis, a similar style was adopted wherein through the evaluation of one neurological patient, Govindbhai, we explore in each chapter, a specific symptom or set of symptoms, such as falling down more frequently, impulsive behavior, tremors, dysphagia, etc. In each chapter, along with the exploration of the specific symptom and its effect on Govindbhai's overall experience, there is a further exploration of a certain Buddhist, Vedantic, or Taoist principle. The integration of Eastern philosophy was entailed in order to bring about a more humanistic and philosophical approach to the scientific exploration of a symptom. Examples include the Taoist doctrine of Wu Wei, the art of not forcing, in relation to Govindbhai's drastic changes that occurred due to his onset of PSP. Other principles such as Karma, non-attachment, living in the present moment, impermanence, balance and imbalance, moksha, and spectrum of consciousness are explored throughout each chapter.

In order to better understand not only the set of Eastern philosophical principles but also the neurological symptom set associated with PSP, six books were read: three on caregiving and three on Eastern philosophy. The first book that was read was Walk Each Other Home: Conversation on Loving and Dying by Ram Dass. This book helped to introduce the role of a caregiver during hospice care which was essential in writing the last few chapters. The next two books that were read included Last Dance at the Savoy: Life, Love and Caregiving for Someone

with Progressive Supranuclear Palsy by Kathryn Leigh Scott and Advice from a Parkinson's Wife: 20 Lesson Learned the Hard Way by Barbara Sheklin Davis. These two books focused more on the experiences of a caregiver which gave greater perspective into the writing of chapters such as Urination, Sleeping, and Delusions. Lastly, the next three books that were read, Zen Mind, Beginner's Mind by Shunryu Suzuki, Tao: The Watercourse Way by Alan Watts, and Tao Te Ching by Lao Tzu, provided a foundational understanding of Zen Buddhism and Taoism. Overall, these six literary selections gave guidance in the development of both an extensive understanding of Eastern philosophy as well as a literary style that could be used to write Govindbhai's fictional story.

Besides Eastern philosophical ideas, other themes were also explored. The first theme that was explored was loneliness: Govindbhai had a wife and five children and yet felt lonely. In order to remove his loneliness, every day, he would take a five-mile walk to the temple and other places to fill his emptiness. After getting PSP, he would be surrounded by his family 24/7 which created a sense of comfort that would fill the emptiness that was slowly being removed from the neurological disease. This theme tends to highlight the fact that this lonely feeling or emptiness can harbor great depression and suicidal ideation in the elderly population. It looks at the sad reality of seniors who are stuck in nursing homes without any family to visit and rarely any companionship provided. The second theme that was explored included patient advocacy: it highlights the fact that a doctor, amongst all individuals, should advocate for a patient's story. In Govindbhai's case, the primary care doctor dismissed Govindbhai's story as mere acting, thereby discrediting Govindbhai and creating a sense of hopelessness within him. He was left alone to battle a formidable opponent with no support. Many patients present a story or range of symptoms that should not be neglected as mere acting or faking but should be evaluated

thoroughly. Believing in the patient and advocating for them lets the patient know that they are not alone in the battle, providing them greater security and comfort.

The third theme that was explored was caregiving and the art of selfless service. Often times, when medical narratives are presented, they dismiss the caregivers' story. The caregiver plays an integral role in the overall experience and treatment of the patient. The caregiver, their moments of glory and shame, their sense of peace and anger, and their love and hatred should all be highlighted and emphasized in medical narratives. Many caregivers experience great hardship from waking up several times in the night to withholding their own lives in order to selflessly provide care for the diseased. These experiences should be acknowledged so as to serve as inspiration for others to follow in similar footsteps, especially with a growing elderly population. The fourth theme that was explored was the concept of fate and free will, or rather, who is in control. Throughout the chapters, Govindbhai's symptoms that arise from his PSP are often associated with Govindbhai. Thus, instead of understanding that his symptoms were a result of his deadly disease, his family continued blaming Govindbhai for his various expression of symptoms from binge eating, and delusions, to frequent urination. Thus, as one of the major themes of the book, it hopes to discuss the importance of empathy: separating Govindbhai from the behavioral expression of his neurological disorder PSP. Upon damage to a certain brain region, how much free will does one really have in their expression of behavior?

The very last theme explores the core concept of the book and the main motivating driver to writing this book: what does it mean to be alive? Masashi Kishimoto writes, "The most painful thing isn't a cut or a broken nose. The most painful thing is seeing the people you made memories with slowly become memories." Neurological diseases such as Alzheimer's, Parkinson's, cerebral palsy, or Amyotrophic Lateral Sclerosis, especially in their advanced

stages, can promote a terrible quality of life. Oftentimes, by this point in time, the patient is also less likely to be present in their own body, and their consciousness is severely diminished, only a mere vessel that remains. Thus, the final chapter of the book explores the medically ethical decision-making process behind death. The Hippocratic oath says, “I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous.” More common verbiage states, “do no harm,” and yet doctors are no longer the decision-makers of many end-of-life cases. This means that many times, mute patients who are living a terrible quality of life and are naturally dying are brought to the hospital and put on artificial treatment such as ventilation, feeding tube, etc. simply to treat the family, not the patient. Many times the family is not willing to let go of the patient and thus decides on the artificial prolongment of life, even if it is against the doctor’s best recommendation. Many of these senior, elderly patients are then brought to nursing homes where they live the rest of their life as mere shells of their former selves, with no sense of life or joy, just a body for their families to hold onto. The last chapter of the book hopes to give strength to those families to stop clinging onto their family members, giving them dignity in death.

Metamorphosis

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The Story of Govindbhai

Written by Sean Patel

For Maitreya

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Falling Down

Life is a series of natural and spontaneous changes. Do not resist them; that only creates sorrow. Let reality be reality. Let things flow naturally forward in whatever way they like.

- Lao Tzu

Govindbhai, retired and well into the ripe old age of seventy-two, had begun to lose control of his body. Having thought that his body would forever remain under his control, he was appalled by the fact that he could no longer walk in harmony with his wishes, swallow mouthwatering chunks of samosas, remember the name of his favorite movie, and loudly chant the name of God. Unable to seize the steering wheel and navigate his body, his life, and his soul throughout his remaining years, he often found his old age to be a cruel curse.

At the tender age of eighteen, living in India, Govindbhai had already been endowed in wedding vows. To support his family, he worked as a signal inspector by day and a rickshaw driver by night. He was a very active and energetic man. He was described by many as "the man who could not sit still for even a second." Sitting around bored him. And it seemed that the older he got, the more impatient he became. At many occasions – weddings, family get-togethers, birthdays – he was never the first to come but was always the first to leave.

After moving to America, in his senior, retired life, he would only be seen at the house three times during the day: lunch, evening prayer, and dinner. Early in the morning, after drinking his chai, he would set out and walk five miles to a temple and actively perform puja rituals. Immediately after performing the puja, he would walk the five miles back home for lunch. On his way home, he would often stop by the bank. Despite being a man of faith, he showed more interest and concern in money than one might think. At the bank, he would often withdraw fifteen dollars, which he would take to the grocery store and spend ten dollars on a lottery ticket and the remaining five dollars on food. He would buy food, not because there was a shortage of it in the house, but because he

would have an excuse for being late for lunch. He was an incredibly cunning man. Upon arriving home late, Govindbhai's wife, Ganga, would always probe to find out why he was late. If she had found out that he was gambling away money, Govindbhai would not only incur the fury of Ganga but be left without being able to eat a single morsel of lunch. But, by buying groceries, Govindbhai never needed to mention the lottery tickets and thus always had an excuse for being late.

This was the pattern of most of his retired days for many years. Being an immigrant and living in an isolated community, he was often lonely. Everyone around him, including his wife, family, and friends were engaged in their own responsibilities, so much so that not a single person had the time to talk with him, play board games with him, or even go out on an evening walk with him. Thus, secluded and isolated from the world, he began walking from place to place, an activity that must have provided him with a sense of community and comfort. And so, Govindbhai continued walking until the day he was forced to stop.

Over a series of months, his family had begun noticing changes in Govindbhai's balance and motor abilities. For

example, at one moment he and his grandson would be standing side by side watching a beautiful, fire-red sunset, and just a second later his grandson would hear a loud thud. Very occasionally, Govindbhai, while standing up, in a perfectly normal posture, would begin stumbling backwards, in small, rapid steps, ultimately falling backwards, slamming his butt onto the plywood floor with a loud thump. Additionally, throughout the day, his son-in-law, Vishnu, would note an almost musical vibration of his right hand. When Govindbhai was not actively participating in any movements, his right hand could be seen spontaneously shaking or vibrating, almost rhythmically, as if tuned to some metronome. Because of this tremor, the content of his handwriting had become microscopic, cramped, and squiggly, almost as if written by a kindergartener first learning to draw. He also faced difficulties in conducting regular tasks such as buttoning and unbuttoning his shirts, using forks and spoons to eat a meal, holding a cup of tea without splattering drops, and so on.

After witnessing an array of falls and deficits in motor skills, his daughter, Gita, brought Govindbhai to a neurologist who diagnosed the initial conditions as a form of Parkinsonism. Due to the early stage of the disease, the

neurologist was unable to conclude definitively whether he was suffering from Parkinson's Disease (PD) or atypical Parkinson's. Only time would tell. For now, not much could be done except for prescribing a combinatory medication: Carbidopa/Levodopa. If Govindbhai truly had Parkinson's Disease, an ailment caused by the death of dopaminergic neurons in the substantia nigra, Levodopa, a precursor of dopamine, would lead to sustained improvements in his balance and motor function for many years. If, rather, he had atypical Parkinson's, a condition wherein the cause is not only limited to death of neurons in the substantia nigra but also includes deterioration in areas of the nervous system that hold dopamine receptors, then the medication therapy would not produce a long-term response, and so he would see a rapid, dramatic degeneration in health – in the short span of two-to-five years.

With the diagnosis, Govindbhai's family began to spend more time around him to prevent those risky falls. They distributed the schedule so that nearly at every hour of the day someone – Vishnu, Gita, Ganga, or the grandkids – was with him. However, more than often, the person scheduled would have to leave to take care of urgent responsibility. Just a few

minutes after they left, a deafening thump could be heard, leaving the whole house rattling.

He continued to stumble and fall over in a variety of places and occasions but was always dismissive of his injuries, seemingly unaware of his falls. One would think that a man, upon experiencing repeated falls, with injuries ranging from elbow bruises to scalp lacerations, would come to realize that he should no longer get up by himself, at least not without the aid of others. Yet, it seemed Govindbhai did not realize this. When his family inquired why he continued getting up despite the drastic falls and wounds, he would always retort dismissively, articulating his mantra, "Don't talk about falling!" Even when lesions and abrasions from his falls were presented and shown to him, Govindbhai denied all such injuries, claiming he was just fine.

From the beginning, Govindbhai was known to be a very energetic and active man. Especially after moving to the States, he found walking to arouse a spirit of kinship and community that could remove his deep loneliness. After the diagnosis, despite his family's increased companionship, he would continue to risk falling simply to go on a walk. He had

grown too fond of them. Could it be that by not being able to walk, he had fallen into a deep hole of isolation – one that could not be filled with familial comfort? Could it be that he was not ready to lose this wider sense of community, sparked by walking?

Though this could very well be the case, there may be another neurological explanation for why Govindbhai continued getting up despite his greater risk of falling down. Speaking from a clinical perspective, it seemed that he was suffering from a form of PD-related anosognosia – a reduced self-awareness for his motor losses. It was not just plain denial but a neurological phenomenon wherein his brain had fabricated a different narrative to account for his injuries. For him, when he fell down, his chin dripping with crimson blood, it was not because he had gotten up, walked, and collapsed onto the floor but rather because he had nicked himself while shaving. In some cases, it was a story that made partial but incomplete sense. In some cases, upon not being able to contrive a story, it was pure confusion, expressed in silence. Thus, not being able to perceive any impairments of his motor balance, Govindbhai continued getting up, only to fall back down.

Govindbhai was once a man who had control over his body: being able to shower his own self, button his own shirt, tie his own shoes, write his own name, eat with his own hands, and walk to any location in the world with his own two feet. Nothing could stop his will. Nothing could stop his desires. Nothing but change. And for Govindbhai, change was not so welcoming. It robbed him of his freedom. No longer could Govindbhai be in control over his own life. The abode one calls his or her home, the wealth we amass, the materiality we hold dear, and even the bodies we inhabit - all are but ephemeral. To force life to stay submerged under the delusion of permanence is like trying to stop a caterpillar from metamorphosing into a butterfly. One cannot remain a caterpillar forever. Nor would they want to. At the same time, trying to control a natural process is as futile as forcing a caterpillar to become a butterfly. As Ram Dass says, “It's only when caterpillarness is done that one becomes a butterfly. That again is part of this paradox. You cannot rip away caterpillarness. The whole trip occurs in an unfolding process of which we have no control.”

No matter how hard one tries, it is impossible to control change in any such direction. Change, whether good or

bad, is but the inevitable course of existence. All one can do is to flow along with it, one step at a time.

2
Impulse Control Disorder

There was a sitar player, Sona, who was very devoted to the idea of meditation. He was determined to practice it as intensely as possible. He practiced walking meditation with such rigor that the skin of his soles cracked and bled. Seeing that all his efforts had been futile, he went to the Buddha to seek advice.

What happens when you tune your instrument too tightly?" inquired Buddha.

"The strings break," the musician replied.
"And what happens when you string it too loosely?"
"When it's too loose, no sound comes out," the musician answered. "The string that produces a tuneful sound is not too tight and not too loose."
"That," said the Buddha, "is how to practice: not too tight and not too loose."

From the Buddhist Scriptures, Anguttara Nikaya 6.55

Life is like the strings of a sitar or violin: the most harmonious sound appears from the center of the two extremes. Everything in nature revolves around the notion of balance.

In an ecosystem, the predator and prey ratio must be managed to the right number to allow for the sustenance of biodiversity. Too many or too few predators and prey can lead to the collapse of entire ecosystems. Take for example, Yellowstone National Park, wherein the biodiversity of life was dependent on the see-saw balance of wolves and elks. In the former half of the 20th century, all the wolves of Yellowstone were exterminated, leaving the elk population unchecked, and so Yellowstone saw a drastic rise in the number of elks. A larger population of elk meant more feeding and overgrazing, which disrupted the land directly and indirectly, contributing to the loss of the rivers, landscape, and biodiversity. This loss of wolves and excess of elks – an imbalance in the predator and prey ratio – triggered a cataclysmic collapse in the environment of Yellowstone National Park.

In 1995, however, through the reintroduction of grey wolves, the elk population dwindled. The see-saw scale had once again become balanced, and thus the environment of Yellowstone National Park had been salvaged. The rivers had returned, along with trees and beavers, which led to the additional growth of other species such as the songbird, rabbits, amphibians, etc. The message is that the intricate food network is a delicate framework, which when hampered by an imbalance of predator or prey, can cause devastating effects on the biodiversity of an ecosystem.

Balance is also seen more intimately in one's personal life, inside the design of friendship. A desirable companion is one who is balanced in the art of conversing and listening. One who always talks becomes irritating and one who only listens becomes a bore. A partner, friend, or ally must possess the ability to both engage in meaningful conversation as well as lend an open ear.

The last application of balance given here is the most personal of all: it is the balance of neurotransmitters released within one's own dynamic, intricate brain circuits that contributes to stable behavioral functions. Any imbalance in

neurotransmitter action can lead to either a deficit or an excess in function. For instance, Parkinson's patients who suffer from a complete dearth of activity, show a scarcity of dopamine. Here, in this case, the loss of dopamine contributes to the imbalance within certain brain circuits, instigating a deficit of motor function. But does this mean having more dopamine than necessary is good for you? Not necessarily. In fact, patients with Tourette's syndrome show a heightened level of the neurotransmitter. The results being a disease characterized by unwanted tics, violent impulses, and erratic movements. And so, similar to Parkinson's Disease, the overabundance of dopamine also contributes to the imbalance within certain brain circuits; however, the difference is the causal effect, which in Tourette's is an excess of motor function.

It is within this paradigm that doctors acquaint their patients with medicine: a hope to see a restoration in balance. Parkinson's patients receive Levodopa, a drug that directly increases dopamine concentration in the brain, hoping to compensate for the deficit of dopamine. On the other hand, Haldol, a medicine that blocks the dopamine receptors in the brain, is given to patients with Tourette's in hopes that it will lower the effect of excessive dopamine. Overall, it seems that

any imbalance in the neurotransmitter dopamine, be it an excess or deficit, leads to respectively either wild, excited movements or a complete silence of motion—deviations from the anticipated normal.

It should be noted that dopamine is just one of the many neurotransmitters playing a role in our brain but the point is that there is a balancing act even within our very own brain circuits—a design by nature that appears to permeate the core and essence of existence. And so, just as Goldilocks favors the porridge that is neither too hot nor cold but just right, it appears that the *lila*, the cosmic dance, of creation adopts a similar scheme: a nature desiring to be devoid of excesses or deficits, but balanced in all the right ways, even if unapparent to the naked eye.

Anosognosia, when combined with levodopa, could become quite dangerous. Levodopa supplies the brain with supplemental dopamine, a chemical of great significance to the functioning body, but only if delivered at an appropriate level. Patients with Parkinsonism are often given levodopa to raise dopamine levels in the brain to a balanced state; however, if the

dosage of levodopa is too high or too low, the consequent imbalance of dopamine can trigger abnormalities in the reward system, causing a stream of compulsive behaviors from gambling to drug addiction. These types of behaviors are classified under the category impulse control disorder (ICD). In the case of Govindbhai, during the first couple months of levodopa therapy, it seemed as if his impatience and gambling behaviors became aggravated.

In everything he did, it seemed as if he was in a rush to finish the task at hand and move onto another one. For example, he would never watch a movie from start to finish – near intermission, he would become impatient and either change the movie or become engaged in another activity. Another instance of impatience, perhaps better classified as a particular type of impulse control disorder, included his eating habits. At almost every sitting, lunch or dinner, Govindbhai had this habit of stuffing food down his esophagus. Having just put half a paratha flatbread into his mouth, he would proceed to gulp down the second half without even having swallowed the first. At times, he would be choking on the food, coughing it out, and at the same time trying to put another bite into his mouth. It was the most bizarre thing one could witness. He did

not pause. He did not take a break. He just kept on pushing more and more food into his mouth, one second after another. Medically speaking, Govindbhai seemed to suffer from binge eating, one of the many impulse control disorders, wherein, like the flow of water in a waterfall, he could not stop nor control himself to stop eating.

And so, to prevent the likelihood of choking, Govindbhai's family began to sit next to him while he ate and at some points, his family had to restrain him from shoving food into his mouth. It would have been easier to feed Govindbhai rather than having to wrestle with him; however, time spent with the elderly allows one to realize independence as a graceful gift of old age. Hence, though Govindbhai had become dependent on many other activities of daily life, cooking, laundry, showering, and dressing, there were still certain activities such as eating that he could independently manage with a bit of support.

Another type of impulse control disorder that could be subtly seen within Govindbhai was an aggravated level of gambling. Before his diagnosis, Govindbhai would regularly go on his morning journey to the temple first and then to the

grocery store, wherein he would purchase a lotto ticket—usually for ten dollars. However, after his diagnosis, his family members began to stay closer to him, monitoring him as much as possible to avoid potential falls. Because his family was surveilling him nearly the whole day, Govindbhai was not able to leave for his morning journeys. He was not able to gamble. As a retired man who had once led a very vigorous life, he missed the adventurous sensations of existence. He missed the electrifying thrill that embodied the elements of surprise. To him, lotto tickets were a way to recapture that sensation of a thrill; they were the passage to living the adventurous life once again.

As a result, no matter the obstacle, Govindbhai had to get a hold of more lotto tickets. Thus, to avoid his family's surveillance, he began to change up his routine. Though the family was paying greater attention to Govindbhai, there were times, such as the early morning or mid-afternoon, where upon the assumption that he was sleeping, the family would be in different rooms, engaged in their own personal matters. It was at these times—early mornings and mid-afternoons—that Govindbhai would tiptoe out of the house and take with him his lustrous red walker. He had begun gambling more than

fifty dollars every time he went to purchase a lotto ticket. He had begun to lose control, and with every chance he got to gamble, he would increasingly spend more and more money, hoping it would lead to a bigger thrill. Each time he sneaked out by himself, he was awaiting a greater risk to befall.

Upon his family's discovery of Govindbhai's disappearance, a wild goose-chase would erupt. His son-in-law, daughter, and two sons would hop into two separate cars and go from store to store, from bar to bar, from one 7-Eleven to another until they found him. Annoyed, bitter, and enraged are just a few words that could describe his family's emotional state. With each passing day, it became increasingly harder for the family as they had to give up more and more control over their own personal lives to devote themselves to Govindbhai. Couldn't Govindbhai just stop going to buy lottery tickets? Couldn't he get this sensation of thrill from some other activity? His family was going through troubling times because of him. Couldn't he just break out of his gambling habit?

Unfortunately, it was not as simple. The imbalance of neurotransmitters in the brain, particularly dopamine, tended to be the dominating force for Govindbhai's behavior. When

paired with imprecise doses of levodopa, Govindbhai's reward circuit went into disarray, leading to this uncontrollable gambling behavior. Thus, it was not so much his old gambling habits that drove him into this uncontrollable frenzy but more so that he was under the control of specific faulty neural networks – a man imprisoned under the machinery of his brain.

It was a quiet and peaceful autumn mid-day. The sun was bright but not hot. A robust but gentle breeze blew. And yellow, golden leaves slowly fell from nearly barren trees onto piles of parched leaves. Alas, for Govindbhai's family, there was no time to sit around and appreciate the cozy, serene nature of autumn. They were in the midst of a hunt for Mr. Govindbhai, who had once again taken off to buy a lottery ticket. They had rummaged through his several favorite stores: Stater-Bros, Rite-Aid, Vons, Albertsons, 7-Eleven. Nonetheless, there was no Mr. Govindbhai to be found. The family began thinking the worst: "What if he slipped and fell in the middle of a busy street and got run over by a car?" or maybe, "He fell backwards and cracked his skull and is unconscious somewhere," or

perhaps he has been taken to a hospital for a serious trauma, and so on.

After searching for hours, they returned home to file a police report. As they pulled into the driveway, they saw on the sidewalk an old man with white hair, striped button-front shirt, pajamas on the bottom, shuffling with a red walker in their direction. It took less than a split second to identify this old man as Govindbhai. As he got closer and closer, it was apparent that he had sustained injuries, this time far greater than those small cuts and abrasions that had come before. And only when he was a few feet away from his family could they differentiate between the red paint of his walker and the red stain on what should have been white pajamas. He had suffered a leg laceration. And of course, due to his anosognosia, he quickly dismissed and denied any injury by fabricating an alternative narrative to explain the situation. Ultimately, Vishnu took him to be treated by the emergency department with several stitches to seal the laceration.

It was after that day that the family realized the mental and physical pressure of caring for a man with Parkinsonism. They realized that Govindbhai needed greater attention. And

so, on the following day, Vishnu had quit his job to become Govindbhai's primary caretaker – twenty-four hours a day, and seven days a week. His grandkids spent less time with their games, television, and friends and began spending more time with their grandfather. Ganga started sitting down with him at the dining table. And Gita, after work, would spend much more time with her father — talking, watching television, and going on evening walks. With increasing time spent with Govindbhai over the next few years, the family began to realize the more nuanced and subtle problems hidden within this massive, ominous Parkinsonism complex; and thus, they began a journey into the brain and its chemicals and how they shape a Parkinsonian patient's life.

The theme of balance is prevalent all throughout nature. Yet, to be balanced, you still have to entertain imbalance. In the Samkhya philosophical tradition, it is the imbalance of life by which the drama unfolds. This philosophical tradition has two principles: *purusa* (consciousness) and *prakrti* (nature). When *prakrti* is in a balance between its three qualities, *sattva* (purity), *rajas* (passion), and *tamas* (dullness), it is inactive or unconscious. Only when *prakrti* comes into contact with *purusa,* the balance

of the three qualities becomes disturbed, thereby manifesting itself. The simple analogy most used is *pursa* is the observer of *prakrti*, who is a beautiful dancer. When *purusa* observes *prakrti*, it motivates *prakriti* to start dancing, upsetting the equilibrium between the three qualities. It is when *prakriti* starts dancing that the whole drama of existence comes into play. *Purusa,* now engrossed in the dance, forgets its true nature as the observer and becomes an actor alongside *prakriti*. And here is the beauty of imbalance. When you look at life from the perspective of an actor, you see a dualistic position of good and bad. But, when you realize your role as the observer, you see the non-dualistic position that there is neither good nor bad. It is just a dance.

3

Tremors and Handwriting

It is said an Eastern monarch once charged his wise men to invent him a sentence, to be ever in view, and which should be true and appropriate in all times and situations. They presented him the words: 'And this, too, shall pass away.' How much it expresses! How chastening in the hour of pride! -how consoling in the depths of affliction! 'And this, too, shall pass away.'

- Abraham Lincoln

As the years passed, Govindbhai's grip on his physical being dwindled. His body, like a once robust apparatus with rusted gears, began to show tottering defects. Falls became more common and the emergence of new symptoms made it increasingly difficult for him to maintain his independence. Though his loved ones tried to preserve his sense of autonomy,

sometimes, in order for them to prioritize his safety, he would have to forgo some degree of liberty. Small, little things that seemed insignificant to the family may have been consequential for Govindbhai. Nonetheless, slow but surely, he was losing those things.

He cherished his two finger rings — one which was his wedding band and another was a token from his spiritual mentor from forty-five years ago, inscribed with the sacred ॐ symbol. As the course of time advanced, his fingers became naked, with his rings stored away in a drawer. Whether he was in the scorching heat or blistering cold, Govindbhai would don the same beloved outfit style every day: a long-sleeved button-down dress shirt and informal dress pants. The most important part of this ensemble was the front pocket where he held the talisman of his passion, a red ink G2 Pilot pen. As the days of his Parkinson's marched forward, his pen was stolen from him. His cherished attire served no purpose anymore, and was banished to the back of his closet, replaced by the dull and unremarkable plain shirt and plaid shorts or trousers. The golden gleam of his wristwatch, along with his spiritual pedant, his beloved Rudraksha, were removed and stored away. Inch by

inch, like the gradual fading of a sunset, in the name of safety, his independence was being stripped.

Typically, the hallmark sign of Parkinson's Disease is characterized by the resting hand tremor. General practitioners rely on the resting hand tremor as one of the main criterias to diagnose a patient with Parkinson's Disease. In fact, oftentimes, a Parkinson's patient is misdiagnosed with another disease simply because they do not show resting hand tremors early in their pathological development. At first, when Gita and Vishnu took Govindbhai to the doctor for his newly surfacing medical issues, namely, greater recurrence of falling backwards, constipation, nightly delusions, and increased urinary frequency, there was no presentation of tremors. His family doctor, consequently, was muddled as to the underlying medical condition, ultimately asserting that his delusions and frequent falls were simply acts put on by Govindbhai to fulfill his cravings.

And for the family, the doctor's "diagnosis" did not leave them unbelievingly surprised — it made sense. Throughout his life, Govindbhai was a master of manipulation

and illusion, using his wit and charm to bend the rules to make things work in his favor. From sneaking into the Las Vegas casino, snagging a jinxed lottery ticket, to slipping out of tedious tasks, Govindbhai always had a strategy up his sleeve to get what he wanted. He was especially a notorious troublemaker when it came to board games. Whether it was *Monopoly* or *Rummikub*, he would try his hand at sneaky tricks like hiding cards, stealing ace pieces, or making illegal gambits. Despite his mischievous nature, there was something undeniably charming about his antics, as he ultimately lacked the finesse to deceive others. Everyone would catch on right away.

He was as obvious as an elephant in a pet store, making his attempt at trickery all the more comical. With daring confidence, he would try to hide cards in the most blatant of ways, out in the open, pretending as if no one had seen him in his devious act. On the flip side, he was also quite gullible, making him an easy target for scammers. For example, there was a time he got a call from an alleged security personnel in New York who claimed that Govindbhai's passports and social security number were leaked. Govindbhai foolishly followed the scammer's instructions, buying a gift card worth five

hundred dollars and disclosing both the gift card number and PIN code. Overall, the internal care doctor's conclusion that Govindbhai was making up certain symptoms such as frequent falls and nightly delusions had convinced the family for the time being. It was the case of the boy who cried wolf.

However, as time progressed, the falls and delusions not only continued but worsened. Every time he stumbled topsy-turvy, falling backward onto the hard, cemented floor, his wife, following the doctor's suspicion, would comment that he was doing it on purpose. This was frustrating for Govindbhai. Who in their right mind would want to hurt themselves on purpose? Even if Govindbhai wanted to get his hands on something, he would never put himself through that much pain. No one would!

Having nobody on his side was deeply disheartening. His family, friends, and even doctor suspected a pretense when in reality it was chemical haywire in his brain. Govindbhai was fighting alone. Not only was he isolated in his fight but he had no idea what he was fighting against. He was going in blind. His body and physiology were changing and he had no idea why and how. He was unable to control his balance. He was unable to swallow food without throwing it up. He was unable

to control his delusions. He wanted to stop it but could not. Nobody believed him and nobody helped to explain to him his bodily changes.

Nearly six months after his internal care doctor called his falls simple stunts, in August 2020, his family took him to get a second opinion from a neurologist, more specifically, a movement-disorder specialist. It took six months for his family to realize that Govindbhai was not acting and that there must be something wrong with him. Upon entry into the neurologist's office, simple hand-motor tests were performed and his history and symptoms were compiled. Within a few minutes, the neurologist diagnosed Govindbhai with Parkinson's Disease. There was the slight possibility of it being an atypical Parkinsonism case, however, time would tell. To the doctor, it was a no-brainer, a diagnosis as clear as day and night. Working with Parkinsonian patients for most of his life, he was able to easily identify the symptoms, each and every one of them, fitting the checklist for Parkinson's disease. Even without a resting hand tremor, frequent falls due to imbalance, delusions, impulsive behavior, constipation, and urinary problems are expected symptoms of those who suffer from typical and atypical Parkinson's disease.

Diagnoses, while intimidating, heave a sigh of relief for both the medically-ill person and their family members. Knowing the cause of a phenomenon provides humanity to better empathize with the situation. In the early days of psychiatry, the mentally ill were treated abusively due to the inability to understand the cause behind their psychiatric disorders. Those who suffered from depression, post-traumatic stress disorder, bipolar disorder, schizophrenia, etc. were thought to be witches or under demonic possession. Even as the 19th and 20th centuries rolled around, the mentally ill were sent to asylums as a form of punishment. Cruel treatments, ranging from electroshock, and lobotomy, to isolation, were abusive and impractical. Only in the last half-century, since the 1950s, did scientists begin to associate mental health with brain health. They began to see a neural correlate, a specific affected brain region or neurotransmitter pathway, for each of the above-described psychiatric disorders.

Since then, there has been an effort to remove the negative stigma associated with poor mental health and to come up with more humane treatments such as antipsychotics and therapy. Govindbhai's diagnosis was eye-opening, giving his family a different perspective, helping them understand that

there was a different entity that gave rise to many of the peculiar behaviors he carried out. The diagnosis gave his family knowledge. It created a space for empathy. Though Govindbhai could never defeat such an enemy, knowing such allowed him and his family to acknowledge the disease as the cruel instigator of his bodily changes. Being able to blame the disease allowed his family and patient to be accepting and tolerant to his emerging odd behaviors.

While the resting hand tremor is often the diagnosing tool for Parkinson's, it is not the case for each and every individual. As each individual is unique, the disease is manifested in a subsequently unique way. For Govindbhai, the resting hand tremors did not appear till one or two months after the initial diagnosis of Parkinson's disease. With its appearance, his life was not radically changed. The tremor was actually the least impacting problem of his Parkinson's disease journey. The resting hand tremor can be described as an involuntary, rapid movement of his hand back and forth, like a metronome. People often believe that this resting hand tremor is the same tremor that is seen when one is trembling their cup of hot, brewing coffee while holding it. This, however, is not the case. When one is drinking from a cup of coffee, any

quivering or shaking of the hand is considered an action tremor. The resting hand tremor, on the other hand, as announced by its name, only occurs while his hands were not in use, while his muscles were relaxed. In other words, there are various different types of tremors, each one producing different behavioral responses. The hallmark feature of Parkinson's disease is resting tremors that affect the hands, arms, legs, jaw, etc. when not in use, when the muscle is at rest.

A few months prior to his diagnosis, another symptom was his progressing dysgraphia. One of the principal features of his dysgraphia included his micrographia, which was characterized by a reduction in the size of the letters he produced. This led to difficulty in distinguishing letters in a word as they soon developed into squiggly, curvy letters. In addition to his micrographia, many words had letters that were cramped and squished together, making the word entirely unrecognizable. Though his dysgraphia made his overall writing poorer to perceive, certain features were more identifiable than others: numbers, the first letter of any word, and words with only capitalized letters. The cause for this Parkisonian dysgraphia was reported to be his muscle rigidity and bradykinesia (slowed movement), which made it difficult

for him to make clear-cut, precise movements required in the coordinated art of handwriting.

Overtime, his dysgraphia worsened to the point where the small letters simply became a curvy horizontal line. Only a year later, even getting him to produce the curvy horizontal line for signature purposes became difficult: he had a hard time even coordinating the pen to make contact with the paper. A signature entails your wish and desire for a certain action. Govindbhai was no longer capable of signing and with that he had lost one of his last pillars of independence.

"And this, too, shall pass away," a phrase that reflects both the crests and troughs of life. The young man of the old city had succeeded in securing his dream job, a vocation that came with all the abundances and riches ever imagined. A car, a boat, a jet, no matter the amount of money, the young man had more than enough to buy any object of his dreams. He had become quite boastful and prideful in his success to the extent that he neglected the poor, treating them unkindly. One day, as the man was going to work, a beggar had asked for alms, which the man rudely refused. As the man left, the beggar was heard to

say, “And this, too, shall pass away.” A few years later, the man’s business had gone bankrupt and he ended up on the streets. His pride was gone and depression had taken its place. To survive, he ended up begging for food and one day he begged a businessman in a black suit, walking to work. The businessman looked at the young man, opened his wallet and offered a few dollars. Before leaving, he grinned and told the young man, “And this, too, shall pass away.” The young man looked at the businessman more closely, and realized that it was the same beggar he had pushed away a long time ago.

At times of happiness, when one has secured his dream job or bought his dream car, the phrase reminds us this feeling of happiness will soon pass. At times of sadness, when one has lost a close friend or family member, the phrase reminds us that this feeling of sadness will soon pass. Not only will the feeling itself pass, but the object in question will also pass. As we age, the body begins to wear and tear, slowly losing its ability to function appropriately. Each and every part of the body starts deteriorating until we are incapable of performing an act by ourselves. It is our hope that death finds us sooner but in the event it does not, a person becomes dependent on others. And

it is this loss of independence that shall find all of us, sooner or later, for in this lifetime, there is nothing that lasts forever.

4

Swallowing

There was a Zen Master who, while out walking one day, is confronted by a ferocious, man-eating tiger. He slowly backs away from the animal, only to find that he is trapped at the edge of a high cliff; the tiger snarls with hunger, and pursues the Master. His only hope of escape is to suspend himself over the abyss by holding onto a vine that grows at its edge.

As the Master dangles from the cliff, two mice - one white and one black - begin to gnaw on the vine he is clutching on. If he climbs back up, the tiger will surely devour him, if he stays then there is the certain death of a long fall onto the jagged rocks. The slender vine begins to give way, and death is imminent.

Just then the precariously suspended Zen Master notices a lovely ripe wild strawberry growing along the cliff's

edge. He plucks the succulent berry and pops it into his mouth. He is heard to say: "This lovely strawberry, how sweet it tastes."

- A Zen Koan: The Tiger and the Strawberry

As the golden years of old age arrive, a sense of liberation washes over. The daily grind of work and responsibility slowly fades away, replaced by a newfound freedom to explore and pursue one's passions. Time opens its rigid door wide open, ripe for filling with the people and activities they hold dear: playing with grandchildren at the park, gathering for a game of chess with old friends, and watching a movie every night with your beloved. In youth, one must suppress his or her dream to garner enough money to support their family and their eventual retirement. Upon arriving at retirement, each and every one of their long-suppressed dreams, whether it is climbing the peaks of Mount Everest, drinking late into the night with old friends, snorkeling through the Great Barrier Reefs, or from skydiving 12,000 feet above sea level, become available with the hours of the day stretched out before them. There is one problem, however.

In life, there is a constant alternation between the poles of ecstasy and misery — at times, there is great joy and at other times, there is great suffering. As one ages, the burden of duties may ease, but simultaneously, the wear and tear on the body become more pronounced. Broken bones, aching backs, joint pain, and other internal health problems impede the ability to realize one's long-deferred dreams. Old age is the beginning of a slow and steady route toward the ultimate end. And as time passes, troubles may increasingly find their way into one's life. Ananda Coomaraswamy once said, "I would rather die ten years too early than ten minutes too late–too late, and too decrepit or drugged, to seize the opportunity to let myself go." And so, the paradox of life is such: the youth, with healthy bodies, spend much time slaving away their lives to gain monetary success, and upon growing old they are left to spend that hard-earned money to fix their broken bodies. In the eyes of society, a staircase has been built, one that beckons to be climbed from the earliest days of learning in grade school until the final days of labor. This is the norm for many, with the idea of a target, an end-point that must be reached. A lifetime is spent striving towards this goal, strangling young dreams and

hopes. By the time this objective is attained, it is far too late to savor the fruits of the labor.

Alan Watts, a late British philosopher, summarizes this best: "We thought of life by analogy with a journey, a pilgrimage, which had a serious purpose at the end, and the thing was to get to that end, success or whatever it is, maybe heaven after you're dead. But we missed the point the whole way along. It was a musical thing and you were supposed to sing or to dance while the music was being played." Each and every step of life should be enjoyed with no expectation that life will get any better than it is now. Waiting to enjoy life at old age is like saving a fine bottle of wine for a special occasion, only to find out that the cork has dried out and the wine has gone bad when you finally open it. Just like a fine wine, life is meant to be savored and enjoyed in the present, not kept for a future that may never come.

Govindbhai, though coming from an older generation, carried modern millennial ideals: a work-life balance that allowed him to enjoy his life. Unfortunately, he was punished for carrying such an ideal. From his first salary at the age of eighteen,

Govindbhai spent five rupees on a soda-pop to drink with friends. Upon discovering that his son had wasted money on a drink, his father slapped Govindbhai across the face, in front of his newlywed wife, a humiliating start to his married life. Most traditional people of Indian heritage work hard to make money, only to store most of it so as to give it to their future generation. This is the ideal of traditional Indian folks: save up, don't spend. There is virtually no work-life balance. Govindbhai had to thus balance his own ideals with the traditional ideals imposed onto him by the older generation. He spent a good chunk of his youth working hard, day and night, to support his wife and children. On the side, every now and then, he would spend some of his hard-earned rupees to watch movies, drink sodas with friends, and go on hiking trips in the Himalayas. He tried his best to enjoy the present moment throughout his life, given the surrounding circumstances he was forced to deal with.

Even after growing old, Govindbhai still tried his best to live fully in his retirement. Until he could no longer, he walked miles on end to various parts of the city, worshiped both the gods and the lottery tickets, and engaged in all sorts of new activities from hiking the steep, rocky slopes of Yosemite

to reading about the various scientific and religious systems of the world. Even after the age of 65, he would go back to India every four years or so to embark on the Ambaji trail, a 500-mile hike over a span of a few weeks. Two years prior to his Parkinson's diagnosis, when he went to Ambaji, he sustained multiple injuries from various falls, some as serious as the blood rushing down his face due to hitting his head as he fell down the stairs. Thereafter, his daughters in India had to continue to accompany him to the end of the trail.

"Papa, after you finish this time, don't do this trail again" his daughters cried, with great concern.

Govindbhai, always having a counter ready, retorted, "Until the day I die, every time I come to India, I will continue to walk to 'Ambaji'".

"No one will keep coming with you Papa," his daughters responded, hoping to convince him otherwise, "I have to take the whole week off work to escort you."

"No one needs to come with me. I will be just fine on my own," he confidently replied, even as blood streamed down his face. For Govindbhai, it was not merely an activity, but a

sacrament. Though his body was failing him, he had a strong determination to continue this pilgrimage till the day of his death.

Slowly and steadily, as his walking ability deteriorated, he turned to his second favorite hobby: eating. One of the best joys in life is the ability to taste delicious foods. To put a morsel of food on their dinner table, humans labor for hours during the day. The tongue perceives five sensations: sour, sweet, spicy, bitter, and umami. Each of these tastes gives us a rush of pleasure — a brief dopamine hit that hinges our memory on that delicacy, urging our mortal bodies to continuously engage in that very taste whenever hunger arises.

An hour before the food was made, Govindbhai would be downstairs, bothering his wife, Ganga, about how much longer it would be before the food was done. Unlike the millennial male, he was more of a traditional Indian male when it came to sharing the responsibility to cook food: he would not help his wife cook the food nor did he care enough to learn how. This created some friction between him and his wife, who demanded Govindbhai to remain patient for his meals.

Though on the outside, appearing rigid, distant, and inattentive to his wife, Govindbhai deeply cared for her. The one biggest flaw, nonetheless, was his impatience. He had very little patience when it came to not only waiting for his food but also devouring it. From a young age, Govindbhai was known for his speedy consumption, shoving one mouthful after another without properly chewing before swallowing. He ate as if he were in a speed-eating competition. As he ate, his cheeks puffed out like a balloon, overstuffing his esophagus. In his later years, his binge-eating caused food to get lodged in his oropharynx, creating a choking hazard and requiring his lungs to work extra hard to clear it through coughing.

Govindbhai's rambunctious cough was his final line of defense, a mighty exhalation that expelled food particles from his chest and prevented choking. Coughing is a reflex generated automatically by the body in times of need. It is what protected Govindbhai from the many different risks of his developing dysphagia, a medical term that refers to generalized difficulty in swallowing. The feeling of food being stuck to his throat or entering his airways, coughing after swallowing, and regurgitations were all characteristic hallmarks of dysphagia.

What was even more interesting was that while coughing, he would drink water, possibly in hopes to relieve the discomfort. But anyone who has ever attempted to drink water while coughing, talking, or laughing knows that water could accidentally enter the air pipe and flood the lungs, creating further discomfort.

During these coughing bouts, if the obstruction was not resolved, Govindbhai would rise from his seat in a hurry and bolt over to the sink, with his food still partially unfinished. The sounds of his coughing and regurgitating became the brass section, loudly blaring in the background. His melodious howls, acting as the violas that wove together various elements of the orchestra, added a touch of sentiment to the performance. The overall effect was chaotic, yet somehow melodic as if an experimental jazz piece was being played out in real-time. This bizarre musical performance went on until the food obstruction was finally expelled. If one ever wondered why he remained so skinny given that his main hobby was eating, the answer was blatantly obvious.

Over the five years leading up to his Parkinson's diagnosis, he was able to manage these episodes of

regurgitation. He would be able to get up and walk over to the sink to relieve himself. However, as Govindbhai began to lose his balance, Vishnu would usually hold onto his waist as they made their trek to the sink, acting as a crutch in the event that Govindbhai tipped over. Being around Govindbhai more often allowed his family to understand how his dysphagia was worsening. As his Parkinson's progressed, his ability to swallow worsened. Five years ago, it might have been one regurgitation episode every three days; now, it seemed that at almost every single meal, he had a regurgitation event. The chaos and unpredictability of mealtime took a toll on both Govindbhai and his family, as they all struggled to manage the increasing difficulties of dysphagia.

In the beginning, Vishnu was able to rapidly escort Govindbhai to the sink before he regurgitated; however, as Govindbhai became slower in mobility, he was neither able to walk over to the sink nor able to control his regurgitation. The family had to discover a way to detect an imminent regurgitation before he vomited onto the hardwood table. Soon enough, the signs became clear: a hacking cough, a strained hum from his throat, puffed cheeks. The best course of action was to rush over to the kitchen, grab a large plastic

bowl, and bring it over to Govindbhai at once. This new normal added more stress for the family, as they would have to be more attentive: it became progressively difficult to eat at the same time that Govindbhai ate, there was more cleaning that was required due to the fact that the regurgitations were now uncontrollable, and one had to be careful to moderate the amount of food he ate at a certain time so as to prevent binge eating episodes.

It was not only his family that was troubled. Govindbhai was also troubled as his body was changing at an uncontrollable pace. Changes in our health can be very scary as we take our autonomic bodily processes — breathing, knowing the position of our arms and legs, swallowing and digesting, urinating, and pooping — for granted. Before he could understand the changes in one part of his body, another part of his body would start deteriorating. And it did not help that the confusion that he felt was often trivialized and ignored.

Most of his family were under the impression that his binge eating tendencies and regurgitations were due to his personal choice — habits he had developed and could change at will. Maybe it was, to a certain extent, but maybe the

neurodegenerative disease was slowly and subtly making its effect present on his ability to swallow. Nature and nurture, two phenomena that scientists to this day debate in regards as to which impacts our behavior more. Nature refers to our genetic predisposition, our natural bodily tendencies, and diseases that penetrate and impact our systems. Nurture refers to our environmental influence, the way our parents raised us, and the impact of our surrounding friends and family on our mood and health. And so, the question becomes is any habit truly a form of nurture alone, or could it also be associated with nature?

For Govindbhai, most neurologists would argue that it was the intertwining of nature and nurture that led to such behaviors, and maybe more so of nature than nurture. They would claim nature to play a big role in his manifestation of binge eating because, in many patients with Parkinson's disease, this symptom of impulsive eating is exhibited. Not every patient of Parkinon's disease undergoes similar environmental circumstances, thus while their nurture is different they still exhibit similar binge eating tendencies, which means nature (the biological disease itself) plays a big role. Nevertheless, his family was convinced that his binge

eating habits derived entirely from nurture. Govindbhai, since he was a young man, around the age of 20 had always had the tendency to consume meals quickly. Due to impending work, or other family-related tasks, there was always a need to finish eating as quickly as possible. He carried this habit from his former days into retirement and would eat very fast; however, his aging body could not keep up with his fast eating habits. The older he got, the more he experienced symptoms such as vomiting out the food and excessive coughing from binge eating. Though nurture may have played a role in his up-and-coming binge eating tendencies and regurgitations, it was not the sole player.

His family, however, could not, in their wildest imagination, fathom that Parkinson's disease, a neurodegenerative disease, could wreak havoc on Govindbhai's body. Hence, they clung to the conviction that all his troubles were of his own making. His regurgitations could all be prevented if Govindbhai ate slower. At the same time, whenever his cheeks were filled with regurgitated food, he did not need to spit it out; he could easily swallow it just like everyone else swallows their acid reflux. This was the way they thought: a classically-defined free-will ideology.

Couldn't Govindbhai just start eating slower? It would definitely help prevent some, not all, regurgitations. However, asking him to take control of the wheel and start eating slower was futile. He was no longer in the condition to be able to exert control over his brain chemistry: his sharp dopamine fluctuations resulted in his binge-eating episodes. He could not override them. But maybe, there was a trick or mechanism to help him better control his binge eating. A timer! Every 30-45 seconds was the suggested time in between each bite. However, without a visual interface wherein Govindbhai could see the countdown timer, he would wait less than five seconds and resume binge eating (representative of impulsive behavioral symptomatology). However, when actually shown a timer, he would wait the whole 30 seconds or at least most of it. However, no matter how many times his family repeated these instructions, the minute his wife, son-in-law, or daughter stepped away from the table, he would instantly disregard these instructions. Someone had to be present at the table to remind him to follow the countdown timer.

It was found that slower eating was definitely helpful in preventing a higher frequency of regurgitation as slower eating attenuated with his dangerous binge eating tendencies.

However, even if his family carefully monitored him so that he would eat very slowly, there would still be episodes of regurgitation. There was something else, something hidden from the naked eye, something that could not be commanded or governed, something without jurisdiction. His regurgitation episodes were due to a bodily disease process that could not be fully controlled by any such mechanism or trick. As each day passed, his family was slowly beginning to understand this.

Since 2015, Govindbhai has been diagnosed with dysphagia. However, with the diagnosis of Parkinson's five years later, his doctors soon became aware that it was a specific swallowing disorder known as achalasia. While the cause of achalasia remains unclear, one of the ongoing theories states that patients with this disease experience degeneration of nerve cells located in esophageal muscles. The esophagus is the long tube that pushes food from the mouth to the stomach. Imagine if the muscles in the esophagus stopped working. Every time one would swallow, the food would get stuck to the esophagus and would not be able to descend the long tube into the stomach. That is what happened to Govindbhai. His Parkinson's disease, being a neurodegenerative disease specific

to motility, negatively impacted many of the nerve cells throughout his body.

Nerves are specific wires that connect the brain and the body. If the nerves are damaged, the signals from the brain to the body are impaired. While the brain was sending signals to the esophageal nerve cells to push down the food, the nerve cells in his esophagus were dying. So, the signal was unable to be transmitted and as a result the function of muscle contraction (or pushing down the food) was disrupted. Thus, for Govindbhai, as much as he wanted to swallow all of his food and bring it into his stomach, he was unable to. The signal was cut short. Diseases of the nervous system really make one double-check your concept of free will.

It should be noted, however, achalasia is a two-part problem: 1) due to nerve cell damage, there are issues of improperly operating esophageal muscles, and 2) at the bottom of the esophagus, the lower esophageal sphincter (LES), functioning as a door, does not open to let food into the stomach. So, even if the food does get to the bottom of the esophagus pipe, the door will not open. So the food remained stuck in the esophagus, causing a build-up of macerated food

to the point where one would have no other option but to regurgitate. This was the biological mechanism behind Govindhbai's bizarre swallowing behavior. And it made sense. His family noticed that many times, he would not have a regurgitation episode during the meal; however, four to five hours after the meal, he would regurgitate. Also, if one examined his regurgitation, one would find not only recently ingested food but food that had been stuck for some time in the esophagus.

Over time adjustments were made to better suit his inability to swallow rigid, large morsels of food. Much of his food was presented to him as a liquid diet, with a watery consistency. A liquid diet allowed for finely-grained food particles, small enough that they would not interfere with his swallowing. Along with the liquid diet, solid food was also given but it was cut very finely and placed in the liquid so as to mitigate any complications from the food itself. However, no matter what diet he was changed to, he was not immune to regurgitations and intense coughs. Even with the liquid diet, he would still face difficulties in swallowing, although now less.

His family, even after hearing the explanation from doctors, failed to understand Govindbhai's reality. They tried their best, being accommodating by creating a new diet, placing a timer, and watching him closely so as to avoid binge-eating episodes. But no matter, the achalasia was there in the background, and so nothing could impede the regurgitations. They still believed it was a problem that could be overcome. It seems that true understanding requires experience in and of itself; experience of an external body, picked up by your senses, might only lead to partial understanding, but never to full understanding.

The Zen master clings to a slender vine, hemmed in by a snarling tiger and jagged rocks, both threatening death. There is no way out. Knowing such, the master, instead of worrying uselessly, embraces the present moment and savors the sweet, luscious red strawberry within reach, relishing each juicy bite to the fullest. Like Govindbhai, many individuals are faced with the challenge of balancing their dreams and responsibilities, often sacrificing one for the other. A vast share of people relinquish their dreams and hobbies in their youth to

better support their families. They then grow old and are unable to enjoy their long-sought-after activities due to poor health. Like the Zen master, there is no way out of the conditional dilemma of existence. The best we can do is enjoy each and every moment, whether we are young or old, doing laborious work or fun activities, eating gourmet foods, or eating from a bland, liquid diet. Govindbhai, in his youth, enjoyed the moments he went to work, laughing and talking with his colleagues. Even as he aged and his health began to deteriorate, he refused to let it dampen his spirit. He continued to pursue his interests and revel in life's simple pleasures, such as a rich and flavorful meal or a heartfelt conversation with his grandchildren. Even when Parkinson's disease limited his physical abilities, Govindbhai never lost his zest for life. He found joy in the simple things: watching movies with loved ones, savoring each spoonful of a bland liquid diet, and feeling the cold, evening breeze on his bare face as he sat outside watching the beautiful sunset with his grandkids. He knew there was no way out and so he took each and every moment and lived it fully.

5
Urinary Challenges

A wandering monk moved about preaching. He owned only the clothing on his back and, strangely, a golden begging bowl, gifted to him by a benefactor who was also his disciple. One night as he was about to lie down among the ruins of an ancient monastery he spied a thief, lurking among the columns. "Here, take this," he said, handing the golden begging bowl to the thief. "That way you won't disturb me once I have fallen asleep." The thief eagerly took the bowl and ran off. But the next morning he returned, saying, "You have made me feel poor, giving me the bowl so freely. Teach me to acquire the riches that make this sort of lighthearted detachment possible."

- Popular Buddhist Anecdote: Nagarjuna and the Thief

Everyone often takes for granted their ability to not only know but control when they are to urinate. The process of urination is a complex system of muscle coordination that is composed of sensation and expulsion.

The bladder is the main headquarters wherein the process of urination is conducted. Imagine the bladder to be a water balloon, which is filled with urine waiting to be expelled from the body. As the bladder fills up, it starts to stretch against the fine linings of the wall. When it is full enough, the bladder sends a message to the brain. Your brain sends a response to a certain muscle located within the walls of the bladder called the detrusor muscle. It is this very muscle that acts as a small, powerful pump, pushing against the walls of the bladder, creating pressure. This contraction of the detrusor muscle contributes to a tension, wherein our bodies feel a great urge or sensation to urinate.

But, just because one feels an urge to urinate does not make it right to urinate at any place at any time. If one is on a romantic date and suddenly their detrusor muscles start to contract, are they going to start urinating everywhere simply because they feel the urge to pee? Not at all. Another component of the bladder, the external sphincter muscle, which is like a gatekeeper located at the opening of the urethra, relaxes to allow the urine to pass through. It is under our conscious control. In other words, one controls when the gates open. After the date, one will go to the bathroom and open our

gate, or relax the external sphincter muscle, allowing for urine to flow out. The internal sphincter muscle, which is like a second layer of protection located deeper inside the urethra, also relaxes to allow the urine to flow out of the body. It, however, is not under our conscious control but still works in conjunction with the detrusor and external sphincter muscle. In summary, as the detrusor muscle continues to contract and the sphincter muscles remain relaxed, the urine is squeezed out of the bladder and through the urethra like water being squirted out of a water balloon.

This is the coordinated system of urination: a sequence of carefully synchronized muscle and brain activities that allow one to know and control the sensation and expulsion of when and where to pee. Govindbhai though, due to his Parkinsonian disease, had trouble controlling his urination. In medical terminology, one would say he was incontinent, or unable to control when and where he should pee. It was not the case, however, that he became incontinent overnight; rather, it was over a series of years that he developed urinary challenges. His family started to take notice a few months prior to his Parkinson's diagnosis. His grandson reported consistently that the amount of toilet paper being used was ridiculous. In one

sitting, a third of the roll would be used to the point where the toilet would get clogged. Nonetheless, this was a problem: it was the beginning of the COVID-19 pandemic. Eventually, the family began to suspect that he must have some sort of urinary challenge and so they took him to a urologist.

The diagnosis was simple: benign prostatic hyperplasia (BPH). BPH is a common condition that affects many men as they age, and while it is not cancerous, it can cause significant discomfort and disrupt daily life. It is a condition that occurs when the prostate gland, a small organ located below the bladder in men, becomes enlarged. Imagine a small gland tucked underneath the bladder and wrapped around the urethra (the tube that carries the urine to excrete). In a healthy prostate, this gland is the size of a walnut; however, in a prostate with BPH, the gland has grown larger, swelling to the size of a lemon or even a grapefruit. What's the problem with a grapefruit? Well, since the prostate wraps around the urethra, the larger it gets, the more it pinches the urethra, a tube through which urine flows out of the body. This can cause the urine to flow more slowly, or even become blocked, making it difficult or impossible to fully empty the bladder.

For Govindbhai, his enlarged prostate prevented the bladder from being completely emptied, retaining some of the urine. This is what may have accounted for his strange behavior of using a third of the paper roll. Because the urine was obstructed in the urethra by the prostate, he was not able to relieve his bladder fully. Rather, he may have felt the continuous urge of urinating without any more pee coming out. At the same time, Govindbhai was a Parkinsonian patient. This meant that the effect of Parkinson's on disrupting coordination between the brain and the muscles of the bladder also contributed to his urinary challenges. It is important to remember that Parkinson's affects the muscles of the body in various ways: making them work excessively or stiffening them up. There was a real possibility that his Parkinson's was specifically impacting his detrusor and sphincter muscles. Specifically, the external sphincter muscle, which is under conscious control, may not relax when they want to urinate, leading to difficulty actually urinating. On the other hand, the detrusor muscle, which contracts to expel urine from the bladder, may become overactive, causing overly frequent and strong contractions, leading to incontinence and the feeling that one has to urinate urgently.

Before Govindbhai was diagnosed with Parkinson's disease, his family spent only some hours of the day with him. After the diagnosis, nearly all his waking and sleeping hours were monitored and observed, giving us insight into his eccentric urinary behavior. It began with frequent visits to the bathroom, especially at night. Normally, during the daytime, every two or three hours, he would visit the bathroom for urination. However, at night, it would seem that his mind was constantly agitated by the thought of having to urinate. He consistently had a strong urge and so he would get up nearly six to eight times throughout the night. When he visited the bathroom, however, no urine would come out. Seeing this multiple times throughout the months, the family came to believe that this was all in his head.

And it was. It was the brain getting signals from the overactive bladder (e.g. overactive detrusor muscle) when in fact there was little-to-no urine in the bladder, to begin with. And so, he only felt this urge, without having any urine to excrete. This coupled with his benign prostatic hyperplasia diagnosis contributed to further urinary urges and excretion difficulties.

There was only a single solution that came to mind: diapers. This word is one of the most frightening words in an adult's dictionary. It is this word that conjures up terrible memories of changing your child's diapers but more petrifying is the thought of losing your independence and autonomy. Knowing that you require a diaper means that you are slowly and steadily aging, reaching a point in your life where you will not be able to take care of yourself. This is a concept that is difficult for seniors to grasp: it is hard to think of yourself reaching a point in life where you will become dependent on others, especially after living a mostly independent life. In addition to the fear of losing one's social independence, there remains a societal taboo wherein many adults fear embarrassment from wearing a diaper. So, when the family bought diapers for Govindbhai a month after being diagnosed with Parkinson's, it is not entirely unexpected that he was not open to the idea of wearing one. He rejected them flat out and continued wearing his boxer briefs.

Due to his urinary incontinence, he would have to change his boxers nearly three to four times a day, increasing the daily laundry load. Despite this, he adamantly dismissed diapers in a last resort to maintain his sense of pride and

dignity. There had to be another way to make his nocturnal urinary urges safer: if not diapers, then maybe a commode. So, his family bought him a small, gray commode and put it next to his bed. Rather than walking thirty steps to the bathroom, the commode allowed Govindbhai to walk only one or two steps to reach his own personal commode. Each and every step was risky: an imbalance or tilt in any direction could lead to a sudden, perhaps fatal fall. Thus, the purchase of the commode minimized the risk of falling, creating a safer space for Govindbhai to carry onward his nocturnal urinary urges, but soon enough the family would realize that every silver lining has a cloud.

As time went on, Govindbhai's nocturnal urges became more and more frequent. Upon taking him to bed around 10 PM, for the next three to four hours, he would continue to get up every fifteen to twenty minutes from his bed to sit down on the commode. This behavior carried on for a whole year. In the beginning, besides the detriment to his sleep quality, getting up every twenty minutes did not pose any serious fall risk; however, as his Parkinson's disease progressed, even the act of getting out of bed and taking a step or two to sit on the commode posed greater and greater fall risk. Once,

Govindbhai, just having finished urinating in the commode, got up and while pulling his underwear up, stumbled and fell backward, thumping his head against the wall. There was no fall that left him unharmed; each and every tumble left a lasting scar. That fall from the commode left a large hole in the wall, one that seemingly could only be created by a hammer-like object.

Even though one of his family members would sleep with him, either Vishnu or Mohan, his grandson, both were tired due to their daytime work or schooling. Thus, weary, both fell asleep, waking up only periodically throughout the night to check on and help out Govindbhai. But no matter how hard they tried, to stay awake fully till two in the morning to ensure Govindbhai used the commode safely was a daunting task. Maybe, it would have been easier to stay up late into the night if Govindbhai woke up later around nine or ten in the morning; however, he always woke up at 6 AM, come hell or high water. This meant the person sleeping with him had to also wake up early at six and assist him to the bathroom for a bath and brush. His son-in-law and grandson, thus, grabbed as much sleep as possible throughout the night.

Eventually, the family thought of a solution to minimize the risk of injury from falls. They padded the walls and floor with a plushy, foam-based gym mattress so that all the surfaces were cushioned. Now, anytime that Govindbhai fell down, he did not suffer any recoil injury from the wall or hard carpet floor. And given that he was skinny, weighing around 115 pounds, a fall onto a padded area would not cause any major musculoskeletal injury. However, as time progressed, even with the commode, Govindbhai was ultimately talked into wearing a diaper for additional safety measures. Even then, he treated the diaper as a boxer, continuing wanting to use the commode. In one way, this was a wise decision. Usually, the first time a person starts wearing a diaper, he or she progressively declines in health due to inactivity, reaching a point where he or she becomes bed-bound completely. It becomes hard to break this cycle of inactivity. Fortunately, Govindbhai was not the type of person to become inactive, even when wearing diapers.

For him, diapers were equivalent to boxers, with the sole purpose of catching any excess urine from any incontinence. Thus, even after having begun diapers, he continued performing all sorts of activities, including using the

commode. He would continue getting out of bed, removing his diaper, and sitting on the commode to urinate. However, nearly a year after his diagnosis, muscle stiffness was no longer a surmountable force. It now posed a serious threat: he was no longer able to stand up from bed by himself. He was able to move his body from a lying position into a sitting position on the bed, but once the time came to stand, he could not muster enough strength or energy to overcome the muscle stiffness, preventing him from transferring himself from the bed to the commode. Here began the real struggle for Vishnu and Mohan. Normally, here one would see the impact of the diaper on beginning the perpetual cycle of inactivity. When muscle stiffness becomes an unconquerable force, one would just start to urinate in their diapers instead of using the commode.

Govindbhai, on the other hand, was a special case. Even though he could no longer get out of bed and transfer himself to the commode, he did not give up. For many minutes, he would continue mustering every drop of energy to stand himself up. Unfortunately, he was not able to stand up completely; at most, he could only rise a few inches and thereafter collapse backward onto his bed. Other times, he would try his best to slide himself from the bed onto the

commode inch by inch. Ultimately, when all failed, he would call out to the person sleeping with him to help assist him.

"Vishnukumar, come get me up."

As nightfall approached, those who were to sleep with Govindbhai trembled at the thought of the unknown horrors that awaited them. Sleep had become a mere afterthought, cast aside like an old rag. Govindbhai's continuous nocturnal urges commanded the help of his family late into the night. One might think, "Given that Govindbhai could not get out of bed alone, if no one helped him sit on the commode, he would have learned to urinate in his diaper." That would have been the dream scenario. But no, no matter how much his family told Govindbhai to urinate in his diaper, he would continue to attempt to get himself up to use the commode, regardless of high fall risks. And thus, those who slept with him maintained key alertness, sleeping less and less, to ensure that Govindbhai was being safely transferred onto the commode.

Most of the time that Govindbhai sat on the commode, it was to relieve this progressively growing "urge." It would be rare to actually hear urine flowing out. However, he expected urine to flow out and when it did not, it got him worried. He would sit, waiting on the commode, mustering all

his energy to force urine to exit; none would come out. He did not give up, however. He would ask the person sleeping with him to give him some water — not because he was thirsty, but because he wanted to expel his urine.

"What? Why?" Being able to give water to someone is a blessing. It's a gift. However, when it came to giving water to Govindbhai, Mohan always panicked. The main reason he was asking for water was not that he was thirsty. No, it was because he had wanted urine to be expelled. He believed that if he drank water, it would push out the urine currently being stored in his bladder. What he failed to realize was that the water he would consume would take the place of the urine that would be expelled. No matter how many times his grandson would explain this to him, he did not care. He wanted his water. And thus, a cycle was set in motion: the urge to urinate, followed by drinking water, then expulsion of urine, only to be repeated every twenty minutes till about two in the morning.

The Buddha is known to have said in his sermon of the Four Noble Truths that attachment is the root of all suffering. When one becomes attached to any one material object, he suffers,

because all material objects are conditioned to death. Neither clothes, cars, nor golden pieces of jewelry last an eternity. Nor does knowledge or ideas claim their permanence in this impermanent world. All ideas from all scriptures either perish or evolve eventually so that nothing of the original idea is left. One may fight hard for a certain idea only to see that it passes away a generation or two later. Even history cannot remember entities in their original form forever. Civilizations are lost and forgotten. Though technologically advanced, our modern civilization will also one day be lost — it might not be tomorrow but a thousand years later, a faithful memory of it will perish. Eternity, an unfathomable infinite, conditions all within its bound to paradoxically remain finite. Maybe the idea of eternity itself is an illusion that perishes upon death, upon exiting the bounds of material condition. Ultimately, this world and all its moving wheels are ever-changing. When humans attempt to cling onto something within his grasp, they suffer for they realize that what they try to keep will never stay the same — it continuously devolves, even if in the false guise of progress.

Attachment leads to suffering. Regardless, it is hard to let go of the idea that our bodies are suddenly, maybe

permanently not functioning properly. Even if we can come to understand the concept that our bodies are limited in time, acknowledging that they will deteriorate in their capacities is not enough. Until one experiences those sudden limitations directly, one cannot come to realize the impermanence of existence. No words can describe such physical and mental hardships of forcefully being detached from one's own body.

6

Difficulty Sleeping

You have a right to perform your prescribed duties, but you are not entitled to the fruits of your actions. Never consider yourself to be the cause of the results of your activities, nor be attached to inaction. Be steadfast in the performance of your duty, O Arjun, abandoning attachment to success and failure. Such equanimity is called Yog. (Bhagavad Gita 2.48-49)

One whose mind remains undisturbed amidst misery, who does not crave for pleasure, and who is free from attachment, fear, and anger, is called a sage of steady wisdom. One who remains unattached under all conditions, and is neither delighted by good fortune nor dejected by tribulation, he is a sage with perfect knowledge. (Bhagavad Gita 2.56-57)

Govindbhai had never truly rested. Since his youth, he worked laboriously from dawn to dusk and then beyond. His good night's rest had shrunk into small naps, as he was called to his night post as a signal inspector. If not at work, his mind was troubled by the constant worry of how he would support his five children and wife. Needless to say, this constant pressure on his mind made it quite burdensome for him to find peace in his sleep. Upon moving to America in his fifties, though relieved of his financial responsibilities for his fully-grown children, his poor sleeping habits followed. He would randomly wake up in the middle of the night to get a midnight snack, take a bath, or find another activity to fill the silence of the night. Even if he had not received a solid six hours of sleep, he would get out of bed, sure to finish his morning prayers before the sun rose up into the sky. He had difficulty falling asleep and staying asleep. And those difficulties were only further intensified in his later life with the onset of his Parkinsonism.

In general, you see many old people having difficulty sleeping throughout the night. With Parkinson's, these sleep disturbances are exacerbated. Urinary difficulties, delusions, anxiety, and the side effects of medication all conspire to make

sleep a precious and elusive experience. Add to that the myriad symptoms directly related to the disease itself, and it is no wonder that rest comes hard for those affected by Parkinson's.

Govindbhai's urinary challenges (*Chapter 5*) and delusions (*Chapter 7*) made it difficult for him to either fall asleep or maintain sleep for a long consecutive time window. Another prominent symptom that seemed to seep deep into the very essence of Govindbhai's soul included a relentless, gnawing anxiety, a shadowy presence that seemed to haunt him every moment. He did well to hide his anxiety, so subtle was it that only a trained mental health professional could truly identify it. The anxiety should not be a surprise to anyone — it was a product of the cruel machinations of his Parkinson's disease. The fear of being consumed by a progressive illness that has no cure, one that will relentlessly attack every aspect of one's being, until you lose your sense of who you are, is enough to strike terror into the hearts of even the bravest of souls. Add on top of that the fact that everyone around him, from his family to his doctors, talked about his Parkinson's disease and what it would entail. He wanted the truth. No, he needed the truth. Nonetheless, it frightened him, and rightly so. Parkinson's leads to the eventual loss of all functions, a total

loss of independence, and a quality of life that would have one begging for the mercy of death.

Slowly and steadily, all these things were becoming a reality for Govindbhai. He was slowly losing his balance and ability to urinate properly, his swallowing was worsening, and his behaviors were insensible, even to himself. Govindbhai was slowly but surely being transformed into a stranger in his own body. As the disease progressed, he found himself becoming someone he no longer recognized. And to make matters worse, his family, while well-intentioned, were ill-equipped to help him cope with the many challenges he faced. They would ask him why he was behaving in such strange ways, not understanding that he himself had no control over his actions. Under such circumstances, it was no wonder that Govindbhai was plagued by anxiety.

His anxiety was especially manifest at night, though subtle. He did not give out any direct indications that he was suffering from anxiety. However, upon retrograde examination of common behaviors, it is apparent that there was something bothering Govindbhai. He did not want to be left alone and wanted to be sure that someone was responsive to him at all times. As the night wore on, Govindbhai would pester the

sleeping family member at his bedside, typically either Vishnu or Mohan, repeatedly requesting changes to the fan setting or the number of blankets. If it was too hot for him, he would not hesitate to shout out and wake his sleeping buddy to turn the fan to its highest setting. At first, his sleeping buddy did not mind helping: they turned the fan setting to the maximum level, helped remove a few layers of blankets so as to allow air to circulate, and even produced a few jokes that put a smile on his face and that of the sleeping buddy.

However, Govindbhai continued to report temperature changes every fifteen minutes, prompting his sleeping buddy to continuously get up from their sleep to change the blanket layer number and adjust the fan setting. As the nights faded further into darkness, both of their smiles did too. His bedmate, getting called out of bed every so often, would get frustrated. It is hard to imagine how Govindbhai's sleeping partner felt throughout the night: even after lying back down in bed after having changed a few things around, there was a dark, crawling fear that lurked, making his co-sleeper worry that he would have to wake up again at any moment. Some days, when his sleeping buddy was exhausted from the daytime labor, he would ignore Govindbhai's

repeated requests for adjusting fan settings, allowing themselves to catch up on their lost sleep. But Govindbhai was not yelling simply to make his body more comfortable to the right temperature. No, Govindbhai just wanted a response. Though unsafe for Govindbhai due to his high fall risk, he was the type of person to get up and change things himself if no one helped. So, to Govindbhai, it was never about changing the fan setting or the blanket layers but rather just to hear the voices of his son-in-law or grandson — voices that kept the anxiety away and allowed him to fall asleep.

It was as if he couldn't bear the thought of being left alone in the quiet darkness of the night. But what was it that really troubled him? Was he afraid of death, of the unknown mysteries that lay beyond? Or was it something else, something that lurked beneath the shadows, something more insidious? Perhaps it was the fear of his disease overwhelming him, of losing all sense of self as his Parkinson's ravaged his body and mind.

In order to avoid the quiet, lonely darkness of the night, Govindbhai turned to his trusty iPad. From its glowing screen, he would play soft bhajans and chant soothing mantras, seeking comfort and companionship in the familiar sounds.

And if by some mischance his iPad charger went missing, he would badger and cajole his family members until they retrieved it for him. For they knew that without his beloved device, the night would be filled with laborious misadventure. For Govindbhai, the iPad was more than just a source of entertainment. It was a lifeline, a way to keep the fears and anxieties of the night at bay. With its help, he could check the time, reassuring himself that the dawn was drawing near. And so he clung to it like a liferaft in a stormy sea.

It was problematic, however. At first glance, Govindbhai's use of the iPad for these activities may have seemed harmless. However, when done in excess, even the most innocent of activities become destructive. Govindbhai would drag the use of the iPad late into the night and maybe it was the blue light or some other feature but something prevented him from falling asleep soon after he had put away the iPad. It seemed the iPad intensified his trouble falling asleep. And added to that was his constant urge to check the time, afraid that the night would never end and the morning sun would never ascend.

Govindbhai had several other eccentric nocturnal behaviors, which may or may not be attributable to his anxiety.

Around 1 AM, he frequently requested his family members to take him to the bathroom to defecate. Typically, he only used the commode for urination. If he asked to defecate, his family would take him to the toilet in the bathroom. Almost unfailingly, however, he could not or would not defecate. So it led them to wonder whether or not he had any intention to defecate from the start. Was it his anxiety that called for Vishnu or Mohan in the dead of the night? Or was it his constipation that prevented him from defecating? Govindbhai was prone to some rather unusual behaviors, including the sudden desire to take a shower, shave, or visit his wife in the middle of the night, whether it was the stroke of midnight or the wee hours of the early morning.

He would wake up his sleeping buddy and he would suddenly insist on going downstairs to see Ganga, his wife. And everyone knew that once he made up his mind, there was little you could do to change that. Either you helped him downstairs to see his wife or he snuck out by himself. To solve this problem, they even applied tight resistance bands locking the two adjacent doors from the outside. Govindbhai and his sleeping buddy were trapped in the room for the night, supposedly. But Govindbhai was smart. He was a problem

solver. Unfortunately, though, that was a problem. He would sneak into the bathroom, find his razor blades, and silently cut through the resistance bands, all while Mohan or Vishnu were deep asleep. He would then go down and wake up Ganga, just to say hello, nothing more. After waking his wife up, she would start shouting, waking Mohan or Vishnu from their slumber, and letting them know to come to pick up Govindbhai from downstairs. Though it was not the response Govindbhai probably wanted to hear from his wife, at the very least it was an activity that filled the silence of the dark night.

These sudden urges seemed to come upon him out of nowhere, and he would become agitated and restless until they were satisfied. It was as if he couldn't bear the thought of being alone with his thoughts and fears in the quiet darkness of the night, and sought out any distraction he could find to keep them at bay. This often left the caregiver of the night in fear for what was to come.

Govindbhai, appearing as though he did not like to sleep, was always desperate for a few precious hours of sleep. Habitually waking at dawn, he forced himself out of bed and was often sleep-deprived the rest of the day. As a result, he would spend much of his days dozing on the couch, seeking

any opportunity he could to catch a few precious winks. Govindbhai, thus, embarked upon a crusade to find a solution. He scoured the land in search of every sleeping pill he could lay his hands on, from modern melatonin to ancient ayurvedic remedies. But no matter what he tried, it seemed that sleep remained elusive, a tantalizing promise always just out of reach. As time went on, Govindbhai became increasingly obsessed with finding the perfect sleeping pill and would stop at nothing to get his hands on one, even if it meant waking his family in the middle of the night to search for it.

At times, he would become so consumed by this desire for sleep that he would attempt to take multiple doses of the same sleeping pill all at once, hoping that the increased dosage would finally be enough to force his body into slumber. But his family knew that this reckless behavior was not without its risks. They were terrified at the prospect of Govindbhai overdosing on the powerful medications he was taking, and they did everything in their power to talk him out of it. They pleaded with him, censured him, and even begged him to see reason, determined to keep him safe and sound.

It was also quite frustrating that he chose to get these sleeping medicines during the middle of the night, the most

inconvenient time. If he got up, that meant the family member who was sleeping with him that night would have to get up, leading to a night of unrest. Sometimes to prevent overdosing on one sleeping medicine, his family would trick him into taking vitamins instead of sleeping pills. But even this was not always enough, as Govindbhai would sometimes become fixated on the idea of taking some ancient, expired ayurvedic medicine he had had sitting in his closet for the past decade. In these moments, he seemed almost possessed, driven by a single-minded determination to get his hands on the precious pills. His family would have to hold him down in his bed, hugging him tightly to keep him from getting his hands on the expired medication. If he had already reached his closet, his family would have to hug him from behind, locking his arms to his side, and gently, forcefully walk him back to bed. It was always tearful to have to pin him down, but it was the only option. No amount of words could sway his terrible decisions. Even as he raged and threatened them with his cane, promising to strike them if they didn't let him go, they knew that he would never follow through on his threats. And so they held on, night after night, determined to keep him safe and sound no matter what the cost.

Govindbhai's struggles with Parkinson's disease were compounded by a cruel and vexing affliction known as restless leg syndrome. This insidious condition added to his ongoing sleeping difficulties. His legs would twitch and churn throughout the night, restless and agitated as if they had a mind of their own. For Govindbhai, this was a source of endless misery. No matter how tired he was, he could not escape the constant movement of his legs, and he would lay awake for hours on end, writhing in discomfort. And while his family did what they could to help, it was clear that the true burden of this affliction fell on Govindbhai himself.

Govindbhai's fitful, hard-earned sleep was a thing of legend, a strange and rare creature that seemed to elude him no matter how hard he pursued it. For years, he was plagued by a host of Parkinson's-related symptoms that made it nearly impossible for him to find any rest or comfort. His restless legs kept him up all hours of the night, and his anxiety and delusions made it hard for him to relax and let go. It was a never-ending cycle of exhaustion and frustration for himself, one that seemed to have no end in sight.

His two alternating bedmates began this journey with great misery, but as each day passed they found themselves in

the same situation but with a different attitude. In the beginning, it was hard because either his son-in-law or grandson had wanted to maintain some autonomy or control over certain things such as their own sleep. Their attachment to wanting to control how their own time was spent created pangs of desire. When their cravings remained unfulfilled, it was a breeding ground for sorrow. It was also difficult initially for the sleeping buddies to sacrifice their control over their own time as Govindbhai never showed appreciation for their help. Rather, he always complained that they were no use to him as they would typically deny him his erratic, late-night shenanigans. Regardless, they took care of Govindbhai the best they could, not because they expected thanks but because they deeply cared for him and loved him. Love is often the great "dissociator" that allows one to perform their rightful duty without being attached to the outcomes. True love no longer requires but gives freely without exception. It is no longer selfish but selfless.

Each day, they learned what it meant to take care of Govindbhai. Many times it felt that it was Govindbhai against his family, but as time went on, they tried their best to remind themselves that it was Parkinsonism against both Govindbhai

and his family. They could not let Parkinsonism win, and so for the sake of selflessness, they became more and more detached from their sense of time and control, adopting a positive attitude towards each and every situation. This was the best way, no, the *only* way for Govindbhai and his sleeping buddies to battle the undefeatable Parkinsonism. Their duty alone, undertaken without attachment, allowed them to best help Govindbhai and keep their own mental health robust.

After what seemed like an eternity of sleepless nights, almost a year and a half after his diagnosis, Govindbhai finally began to find some rest and peace. And so too, his sleep mates. In due time, the long, endless nights of tossing and turning gave way to a sense of calm and contentment, as he started to sleep through the hours of darkness for longer and longer stretches. At first, this seemed like a cause for celebration, a sign that Govindbhai was finally finding some respite from the endless cycle of sleeplessness that had plagued him for so long. But as the months went by and his sleep grew deeper and more restful, it became clear that something was amiss. For this newfound quality of sleep was not a gift, but a curse, a warning

sign of the advancing dementia that had taken hold of Govindbhai's mind. And so it was that the family struggled to find a way to balance the joy of seeing Govindbhai finally find some rest with the sorrow of knowing that this rest was not a sign of healing, but a harbinger of the end.

7

Delusions

"Every human being relies on and is bounded by his knowledge and experience to live. This is what we call "reality". However, knowledge and experience are ambiguous, thus reality can become illusion. Is it not possible to think that, all human beings are living in their assumptions?"

— *Masashi Kishimoto*

Whether one is a physician, educator, musician, businessman, engineer, lawyer, computer programmer, everyone comes to a point in their life where they ask: Who am I? Am I even in charge of this abstract idea called "I"?

Throughout life, we have a strange confidence that we are in control over our personality, behavior, emotions, sensations, and perceptions. I am a well-behaved male who engages in community welfare activities and feels great

happiness when surrounded by my family. Would you be surprised to hear that each and everyone one of those words in the previous sentence may be beyond our control? Let's begin with the word "well-behaved." Society has defined "well-behaved" as one who engages in rational thinking and ethical decision-making, inhibiting inappropriate behaviors, acting in accordance with social norms, and evaluating the consequences of our actions. But could we lose access to that locus of control in an instant.

On a fateful day in 1848, Phineas Gage, a railroad construction foreman, was struck by a sudden and unfortunate disaster. As he toiled alongside his crew, a powerful explosion erupted, launching a fourteen-pound iron rod into the sky with the ferocity of a cannon. The rod pierced through Gage's skull, spearing through his prefrontal lobe and leaving a devastating path of destruction. It burst through the bottom of his left cheekbone, shattering bone and flesh, before soaring through the air and finally coming to rest almost 100 feet away. Despite the catastrophic nature of this event, Gage somehow managed to survive..

Gage's body survived but his previous inner self did not. He was once regarded "as the most efficient and capable

foreman" by his colleagues; however, as a result of penetration into the prefrontal lobe, his personality changed for the worst, tainting his reputation and causing him to behave in ways that were egregiously socially inappropriate. He was no longer able to control his impulses, lashing out with tantrums and expressing his primal desires with animalistic fervor. His once-refined speech devolved into a torrent of profanity, and he was reduced to a mere shadow of his former self. This is the power of the brain, its areas, and the interaction between these components. As can be seen in Gage's case, the specific component for the social context of "well-behaved" is the prefrontal cortex: an area of the brain that is involved in a wide range of cognitive and emotional processes, including decision-making, impulse control, and social behavior.

To argue that the basis of the next word is a brain-derived phenomenon might become controversial. What if I was to say that the word "male" is not so much a set-defined event based on biological components (testes versus ovaries) but rather an expression that is partially influenced by one's brain? According to the Cleveland Clinic, as the embryo develops, the body diverges into either male or female; however, that is not to say that the brain will follow the same

path. It should be noted that male and female brains have different structural and functional characteristics. Many of us look at the transgender community and accuse them of *choosing* to switch to another gender. However, it is not so much so that they are *choosing* as it is an inclined perception created by their brains. For example, let's say that Timothy is a person born as a male. Timothy deep down has an inward feeling that he is not actually a male but a female. And if we put Timothy under an MRI machine and scan his brain, we will see that Timothy's brain shares common characteristics of the female brain. It's the brain that does the choosing, not even your sex organs! Psychiatrist Murat Altinay beautifully summarizes this idea: "When we look at the transgender brain, we see that the brain resembles the gender that the person identifies as."

The deeper one traverses the field of neuroscience, the more one will come to understand that he or she is simply a product of your brain, forced to behave and perceive life in a certain way, all under the guise of free will. The next phrase, "feels great happiness when surrounded by my family" will help to solidify this idea. The realm of feelings and emotion is governed by the interaction of multiple components: the

amygdala, hippocampus, thalamus, hypothalamus, basal ganglia, and cingulate gyrus. All of these individual components together comprise the limbic system, a structure that interacts to regulate emotional stimuli and reinforce behavior.

In 1966, from the top of the University of Texas Tower, an armed gunman fired indiscriminately, killing 16 individuals and injuring 31 others, stopping only when he was himself killed by two police officers. The gunman's name reverberated throughout the world for the upcoming years: Charles Whitman.

Soon after the school shooting, police went to explore Whitman's home, after which the situation became even more grim. Two cold bodies were found. Before Whitman assaulted the university, he began his day by stabbing his mother and wife to death. In his suicide note, he writes, "It was after much thought that I decided to kill my wife, Kathy...I love her dearly, and she has been as fine a wife to me as any man could ever hope to have. I cannot rationally pinpoint any specific reason for doing this." Usually premeditated murder is motivated by some reason, no matter how perverse, but in Whitman's case there was no known motivation. His daily life seemed average:

he was a former Eagle Scout and Marine, worked at a bank, and was fairly intelligent with an IQ of 138. All of America wanted to know why Whitman fired on the school. They wanted a cause, a reason, a motivation. A man who kills for no reason is a monster, and it is this monster which scares humanity to its core.

In his suicide note, Whitman had requested that an autopsy of his entire body be performed to find out why he had these violent impulses. His stomach, kidney, brain, and liver were all examined. First, a thorough drug test was performed to see if Whitman was taking any drugs that motivated his violent impulses. It was negative. The coroner then took his brain and examined it, finding a tumor the size of a ping-pong ball impinging onto the amygdala, the part of the limbic system involved in emotional regulation. More specifically, the amygdala functions to process fear and aggression, and so damage to the amygdala had been the triggering factor for his violent impulses. This finding struck the hearts of the American public: a brain malfunction had caused this mass shooting. It was unfathomable. The reason you, right now, can exercise free will is because your brain is

healthy; those with brain diseases lose their capacity for free will and *they* become mere puppets of their brains.

Govindbhai, a year before being diagnosed with Parkinson's disease, insistently asserted with his piercing gaze fantastical falsehoods that seemed too real to be fake, captivating even the most skeptical of minds. Before his eyes, the world would transform into a surrealist landscape, where everyone, instead of being asleep in their rooms, had gone out to the temple. These episodes of disorienting delusion would almost always occur at the worst times: late in the dead of night or very early in the stillness of dawn. During these episodes, he would be lost in a world that only he could see, his own mind becoming a playground of illusions and distorted truths. The first episode of this strange behavior had taken place a few days after he had returned to California from his trip to India, where he had embarked on a journey to the holy site of Ambaji.

Before the world had even stirred from its slumber, Govindbhai had already slipped out of his room, his two suitcases waiting obediently by the door. He had just zipped up his traveling jacket and pocketed his passport. Before he walked downstairs, lugging with him his cases, he turned on the radiant central lights, penetrating all the room's darkness. He

walked downstairs silently, his two bags in tow, and just as he was about to step out into the crisp morning air, Meena, his daughter, emerged from the adjoining room.

"Where are you going?" Meena asked, her voice laced with surprise.

"Ahmedabad Central Bank. I need to withdraw some money and sign a few documents," replied Govindbhai, without batting an eye.

Meena stood there silently for a few moments. Her mind raced as she tried to grasp what she had just heard. Did her dad actually mean the Bank of America? No, it seemed that Govindbhai had meant exactly what he said. Why else would he have two suitcases and be trying to leave in the middle of the night? Meena thought that her dad was simply confused due to jet lag from his recent travels.

She then replied to her dad, "Papa, right now, it is 4 AM in the morning. No bank is open in the middle of the night. And, how are you going to get to India? You don't have any airline tickets!"

Govindbhai tried defending his actions but the more he tried to defend himself, the more he felt that something was

amiss. He had a clear, confident motive for going to the Ahmedabad Central Bank, and yet his daughter's point made some sense as well. Govindbhai's conviction wavered for a moment, his brow furrowed in confusion. Had he made a mistake? Was he really supposed to be boarding a flight to India that morning? Ultimately, he gave up insisting and walked back upstairs, now unsure if he was supposed to board a flight to India that morning. The suitcases were left downstairs and the intention to go to the bank was also left. The only thing he brought upstairs was his confusion. He pondered his actions as he took off his traveling jacket, put away his passport, and removed his watch. Preparing to go back to sleep, he wondered why his intention to board a nonexistent flight to go to the Ahmedabad Central Bank was so strong.

For the first time, he felt as if he was commanded by a completely different entity. Every now and then, over that year, he would lose himself to that entity and would either believe or engage in actions devoid of logic or reason. There were times he would wake up in the middle of the night, and wake Mohan to help him make tea because it was time for his evening cup. Other times, he would be completely disoriented, claiming that he was still living in India, wanting to go to a certain location in

India. A few times, Govindbhai reported that his mother was with him during the night. This was always surprising because his mother had been deceased for nearly forty years. This also followed a similar theme to when often during the evening, Govindbhai strongly urged others to take him to a certain room within the house because his mother was there. He remained restless till his family abided. When they finally brought him to the room, they would ask, "Here we are. Where do you see her?" He would give a quiet reply, "She's here." He was not hallucinating. He did not actually see her but it seemed he had calmed down after basking in "her" presence — wherever she was. There was a quaint smile on his face, with a sense of peace enveloping him. These episodes of disorientation would occur so randomly and sporadically that his doctor and family dismissed these episodes as mere theatrics.

A year had passed by since his initial delusion, but he was still a few months away from being diagnosed with Parkinson's disease. It was the beginning of the coronavirus lockdown and so Govindbhai's family was closer to him than ever before. One night, as Mohan was studying late past midnight, he heard an eerie creaking sound. He went outside

his room to find that the front door was opened up. He quickly rushed downstairs to close and lock the door before the chilly wind could enter the home. Why would the door be open in the middle of the dark night? Panic surged through his mind as he tried to find a reasonable explanation. As he was walking towards the stairs, he saw a bright light emanating from the laundry room. He ran into the room to find his grandfather, dressed in his white night tank top, his favorite striped brown-and-cream beanie, and one half-on shoe, clutching a set of keys.

"Dada, what are you doing?" hesitated Mohan, afraid to hear the answer, his eyes brimming with confusion. Govindbhai had not driven a car in ten years, since the car accident with Mohan. "Why do you have keys in your hands?"

"I am going to the park to take a shower," he answered, casually, as if it was a routine thing to do.

Almost nothing in that sentence made sense. Why would he go to the park in the middle of the night, and that with only one shoe on? Besides, which park has a shower? Likewise, why did he suddenly get the idea that he could drive again? Mohan was convinced he was disoriented or having

some type of delusion. It couldn't have been a simple stunt. No, it was too disorganized and too chaotic — it had to be a delusion.

At first, no matter how much Mohan tried convincing him with logic, he did not budge from his position that he was to drive to the park. As they stood there arguing, Mohan's grandmother suddenly appeared, standing right in front of them with a stern look on her face. Without trying to understand the situation, she just started yelling at both of them to quit the ruckus and go upstairs so she could sleep.

But even she couldn't convince Govindbhai to give up his strange obsession with going to the park. Govindbhai insisted, "I have to go take a shower at the park right now." His face and eyebrows scrunched up, as he was frustrated that no one understood him.

His wife, Ganga, replied, "Is that right? YOU CANNOT EVEN DRIVE! Stop this acting and go back upstairs."

Mohan quickly added, "Come on dada. I have to study for my midterm tomorrow. Let's go to sleep."

Govindbhai must have heard their pleas. Only after a few minutes of persuasion, he finally relented and retired to bed. He overturned the commanding ideas and gave up his insistent, irrational demands. Mohan helped him back into his room where he fell back asleep after a few minutes. It was a little surprising. Typically, in a delusion, the person's belief in a false reality is so powerful that nothing you can say can convince him otherwise. However, it seemed Govindbhai still had some control over his beliefs and decisions during that episode. Despite this temporary moment of lucidity, it was clear that as the months went by, the commanding entity, namely, his faltering brain, took full throttle over Govindbhai, such that whenever Govindbhai had an episode of delusion, it would be impossible to turn him around.

Several months later, after he was diagnosed with Parkinson's disease, his family was given a reason as to why Govindbhai would randomly try to sneak out in the middle of the night. They found solace in the fact that his behavior wasn't of his own volition. But it didn't make things any easier for the family as they grappled with the consequences of the commanding entity's actions. Once, when Govindbhai was staying at Meena's apartment for a few days, there were times

he would sneak out in the middle of the night, stark naked, to go "take a shower" at a nearby park. Unsurprisingly, the police were called and the family had to become involved in order to resolve the report. Though the family knew that these behaviors were not Govindbhai, they became frustrated with his delusions. Each time he had a delusion, he wanted to go somewhere: the problem was that each step he took was one step away from a massive injury. In fact, only a few days after the first delusion at Meena's house, he had another one: this time, however, as he tried to get out of bed with his silver cane, he stumbled forward and slid his lip through the rough edge of the cane, piercing his lip completely. A torrent of crimson blood, with a bold metallic taste, flooded down his face and through his mouth, serving as a jarring reminder to his family of the fragility of his condition and the unpredictable nature of the commanding entity that held him in its grasp.

The family had to slowly shift into monitoring Govindbhai around the clock. At first, they thought they could talk Govindbhai out of these delusions. He was already stubborn, but these delusions made him as unmoving as a brick wall. All they could do was sit next to him on the edge of his bed and *try* talking him out of it, although knowing fairly

certainly the efforts were futile. All one was hoping to do was stall until two or three in the morning, outwaiting Govindbhai's delusions till he fell asleep.

To carry out his delusions, he needed the energy to get up and go somewhere, resist all sorts of push-backs, and make up plans to escape. At the beginning of his time after being diagnosed with Parkinson's disease, he still had vigorous energy. If he had a delusion, the family would only hope that he would want to travel to a different room within the house, not somewhere outside the house. Though frustrated, they would walk him to his desired location for as long as he desired till he finally wanted to sleep. However, if he had a delusion that compelled him to go outside in the middle of the night, the family would have to wrestle with Govindbhai and continue diverting his mind by conversing with him about completely random topics. No matter how much you tried to divert his mind, however, the commanding entity did not falter in its target, and so it became a struggle any night those delusions sneaked in. Though many medical professionals recommended utilizing soft restraints during the night, his family never had the heart to bind him; rather, they decided to endure these episodes together. And so, oftentimes, the best

course of action was to hold him down in his bed until he dozed off, preventing him from getting up and injuring himself.

Fortunately, however, after the first couple months after his diagnosis, his delusions slowly waned. Whether it was the medication or something else, there were very few delusions. During this time, though the delusions were absent, other issues prevented him from sleeping during the night such as his frequent urge to use the bathroom and his excessive saliva flow, sialorrhea, which would sometimes find its way into the wrong pipe, forcing him to wake up coughing. Nonetheless, his family was enthusiastic about the fact that Govindbhai's delusions were slowly going away — a sign that the commanding entity was retreating and Govindbhai was reclaiming his body and decisions.

Unfortunately, this period of limited delusions lasted only a few months. Almost a year after his diagnosis, he started developing complex and heightened delusions on a scale not seen before. Maybe it was a decreasing sensitivity to the medicine or it was the advancement to the next stage of his progressive disease. By this time, Govindbhai's gait was becoming more unstable and unsteady, and thus, each delusion

had to be monitored closely, or else it could result in a severe fall and injury. The delusions throughout that spring and summer almost always followed the same theme and time: around 11 PM, he would start getting ready to go to work as a railroad signal inspector in the town of Kalupur.

It was 11 PM. Govindbhai and Mohan had just finished watching some television.

"Are you ready to go to sleep?" Mohan asked.

"Sleep?" Govindbhai slowly turned his head to face Mohan. He pinched his face, squinting his eyebrows, "No, I have to go to work right now!"

"Work? Right now? It's the middle of the night. What work are you talking about?

"I have to get to the train station right now."

"In the middle of the night? Where is your train station?"

"Yes! My shift is beginning in one hour and I am going to be late? Let's get going."

"Where is your work though."

"Kalupur! The railway station in Kalupur."

"Kalupur? In India?"

"Yes! Let's go!" At that moment, he tried getting up out of his chair. Mohan had to stop him. He had fallen down countless times already due to his imbalance. Why did he not yet understand this?

"Wait, dada!" Mohan sat him down again. "Where do you live right now?" He tried to reason with Govindbhai, hoping that it would make a difference.

He replied, "Orange County, California!"

"How do you expect to go from California to Kalupur in just one hour?"

"We will go in the car. Can you hurry up and get in the car? I will be late," he retorted.

"You do know there is a body of water between California and India, right?" Mohan asked humbly.

"Yes! Get in the car!"

Several logic obstacles were thrown at him but none were able to change his perception, his truth. He was convinced that he had to attend work in Kalupur in an hour. So for the next few hours, until he would tire out, Mohan would sit by his side to prevent him from getting up. Sometimes, Vishnu, Govindbhai's son-in-law, would also engage in benevolent lying by which Vishnu would lie to him, telling him that his boss

rescheduled him to the morning shift. “Sleep early right now so we can get up early and head to work,” Vishnu would say. There was some success in convincing Govindbhai to go to sleep using this tactic, but it was never guaranteed to work each time.

Govindbhai, in his youth, was the railroad signal inspector of Kalupur. It seemed as his Parkinson’s disease progressed, he was slowly returning to his town. Maybe for him, it was something that gave him comfort, a sense of purpose at a time when he could no longer even manage to walk stably by himself. Having lost all his independence, maybe his delusions about going back to work in Kalupur provided him a beautiful dream in which he could reclaim the life he once lived — a life of action and meaning, one dedicated to helping support his poor family.

These types of delusions continued for the remainder of the spring and summer seasons. A little over a year after his diagnosis, though his delusions slowly started fading, other signs of deterioration were becoming blatantly apparent. Govindbhai’s health was worsening as each day passed: he was slowly approaching the point where he could not even take a few consecutive steps, even with someone holding his

shoulders from the back. He was reaching the point of becoming completely wheelchair-bound. Beyond that, his mind was slowing down at an incalculable rate, approaching a dreadful dementia-like state. It seemed that the curse of Parkinson's disease was a treacherous, downward spiral. Though his delusions were gradually retreating, many more problems, arguably, more severe issues were arising.

8

A Physical Deterioration

The master Joshu said to Nansen, "What is the Tao?"
Nansen replied, "Your everyday mind is the Tao."
Joshu asked, "How do you get into accord with it?"
Nansen replied, "When you try to accord, you deviate."

- Zen Story (adapted from Alan Watts)

A year had passed since the fateful day he was diagnosed. Despite the family believing that Govindbhai was on the path to recovery, something sinister was brewing beneath the surface. They were under the false impression that Govindbhai was showing signs of improvement as he had a declining number of delusions. But something was amiss.

Govindbhai's once lively and energetic persona had begun to fade, as if his soul was slowly being drained out of him. His mind was dying: it was no longer strong enough to manifest the energy of a delusion. With that, his brain could no longer bear the burden of maintaining his body, and so began a downward spiral of progressive physical deterioration. Over the next six months, every process, from his gait, facial expression, and eye dryness to his speech, had taken a turn for the worse.

The first thing to deteriorate was his gait. Before, Govindbhai was able to initiate and maintain his gait, with the now-and-then shuffles and frozen knees, which led to his falls. But in no way did Govindbhai or his family consider his unstable gait to be the worst part of his Parkinson's disease. However, the time had finally arrived to rob Govindbhai of his feet. This once minor problem had escalated into a debilitating inability to move his legs as if they were being anchored by lead weights. Moving from one room to another had become a herculean task. His family watched as Govindbhai clung to his walker, desperate to move forward but unable to budge. Vishnu tried to help by demonstrating how to lift a leg and take a step forward but no matter how hard Govindbhai tried, his feet remained glued to the floor. The best he could do was

to lift his heels, teetering on his tippy-toes. But instead of taking a step forward, his body would simply lean forward. Without Vishnu's support, in which he held onto Govindbhai's shoulders from the back, Govindbhai would have fallen face-first onto the ground.

In Parkinson's disease, the specific area of the brain affected, the basal ganglia, is actually responsible for the initiation of appropriate movement and inhibition of unwanted movements. Specifically, inside the basal ganglia, there is another smaller structure called the substantia nigra, which is central in the act of inhibiting unwanted movements. However, if someone wants to move their legs, the inhibition generated by the substantia nigra must be removed. To do this, dopamine, a key neurotransmitter, has to bind to the receptors in the substantia nigra, which initiates the act of moving one's leg. In Parkinson's disease, the neurons that release dopamine into the substantia nigra begin to die, which is the physiological cause for pathological inhibition as seen in Govindbhai's inability to initiate movement, his freezing episodes.

The only way to get Govindbhai moving was by standing behind him, grabbing his shoulders, lifting one side, and pushing him forward manually. When one lifted

Govindbhai's shoulder, his feet would come off the ground for a moment, giving you the opportunity to move him forward. Once that foot was forward, you would repeat with the other shoulder and foot. Sometimes, after doing this action a couple of times or visually demonstrating how to lift one's leg and move forward, an instantaneous chain reaction in his brain-leg coordination would be catalyzed, allowing him to continue walking forward with no manual intervention. The only thing that would stop him then was an episode in which his knee joints would freeze randomly, gluing his feet onto the ground, leading to an unexpected, heavy fall. Govindbhai, even while knowing the risk, would occasionally get up when no one was looking, miraculously initiating his brain-leg coordination; however, after walking a few steps forward, he would suddenly plummet face forward onto the heavy, tiled floor, breaking his front tooth or lacerating his tongue.

Nonetheless, certain exceptions did exist and it was only a matter of time before they were discovered. The first exception involved the use of a treadmill. When Mohan first brought Govindbhai onto the treadmill, there was concern that his feet would remain pasted to the rotating board, sending him hurtling off the back of the machine. But as soon as they

started the treadmill, something breathtaking happened. Initially, it seemed that Govindbhai's legs were being passively dragged along by the machine, his feet barely lifting off the ground. But then, as if by some divine intervention, his legs began to take flight. He was able to initiate spontaneous walking, his feet lifting and landing with a newfound sense of freedom. For as long as the treadmill belt continued to move, Govindbhai was able to maintain his newfound stride. And, perhaps even more remarkably, he experienced virtually zero episodes of freezing. Could it be that the moving belt sent a sensory signal into the spinal cord, which activated a network of neurons known as the central pattern generator (CPG)? The unique thing about the CPG is that it is located within the spinal cord and can operate independently of brain activity. The implications then are that the CPG can maintain rhythmic firing outputs as long as they are being activated by some sensory feedback mechanism, namely here the constantly rotating treadmill belt. As such, Govindbhai's initiation and maintenance of gait were not due to brain-derived activity but a more basic, instinctive activity from his spinal cord.

As Mohan continued exploring the possibilities with the treadmill, he learned that placing the treadmill on an uphill

incline significantly improved Govindbhai's initiation and maintenance of gait. This was not a unique, isolated finding. It was typical for Govindbhai to find greater hardship in initiating movement on a flat surface. Even when taken to the park, where the fresh air and open space should have invigorated him, he often found himself immobilized, his feet rooted to the ground as if by invisible chains. After trying for almost thirty minutes, his family gave up, and had to ask Govindbhai to sit on the walker's seat, wherein they could wheel him back to the car. On the way back, Gita, his daughter, would offer some words of encouragement, saying, "Don't worry Papa. We will come back tomorrow and try to walk five rounds. Is that okay, Papa?" He looked away in silence, feeling embarrassed that he had to be wheeled back to the car by his son-in-law, Vishnu. He was angry. He resented his failing body but had nowhere to channel that resentment. He closed his eyes and turned his head to the distant horizon, his look of disappointment ever so strong that it saddened the heart of his family.

However, when on an uphill incline at the park or climbing a set of stairs, walking became much easier. He was able to instinctively initiate his movement and maintain that

chain of coordination. There was something going on in his mind that stimulated the motor reaction for walking when he was placed on an incline or was walking upstairs. The question, then, was how could Govindbhai stimulate that same motor reaction on a flat surface? The revolutionary breakthrough occurred nearly a month and a half after Govindbhi started showing his debilitating inability to initiate movement. Vishnu and Govindbhai were upstairs in Govindbhai's room watching some afternoon television. Ganga had called them down for some evening chai and so Mohan had gone upstairs to help bring Govindbhai downstairs to the kitchen. Vishnu helped Govindbhai out of his seat, and slowly moved him forward, manually, one shoulder at a time. They were halfway across the room when suddenly & automatically Govindbhai lifted his leg up and moved forward, initiating a chain reaction that allowed him to continue walking all the way to the staircase. But what stimulated that movement?

Mohan noticed that halfway across the room laya long, red iPhone charging wire on the ground, and it seemed to have served as a visual stimulus that forcefully activated his neurons, telling Govindbhai to step over the wire, which initiated his walking. Though his brain was not able to spontaneously

activate neurons to initiate the movement by itself, maybe the visual stimuli of the environment could trigger neuronal firing that would jumpstart movement. Mohan suddenly got an idea and ran downstairs, well ahead of Govindbhai and Vishnu, pulled out some black duct tape from the cabinet, started ripping small pieces, and attached them to the ground. A pathway was created from the staircase to the dining chair. The minute Govindbhai reached the ground floor, suspense brewed in the air, waiting to see if he would respond to the tape. Lo and behold, it was clockwork: Govindbhai was initiating movement by himself, taking one step from one black tape to another, each serving as visual stimuli to tell his brain where to move his foot. Eventually, following this visual-stimulated brain-leg coordination, he reached the dining hall —Vishnu had let go of him halfway through.

Mohan and Vishnu both beamed with excitement that they had discovered a way to help Govindbhai walk on flat grounds. They would no longer have to spend several minutes forcefully pushing Govindbhai from one place to another. No, now, Govindbhai's own body would once again reclaim its control and direction. Vishnu and Mohan both rushed to plaster the black tape throughout the tiled floors downstairs,

creating multiple pathways from one room to another. It was a revolution.

Other than his walking issues, Govindbhai was slowly robbed of his ability to express his emotions. Specifically, throughout the day, Govindbhai's facial expression would spontaneously crunch up. His eyebrows furrowed, creating deep creases on his forehead, while his eyes narrowed to mere slits. His nose wrinkled, and his mouth twisted into a scowl as if he was forever caught in a state of simmering anger. This phenomenon, called facial masking, was a cruel side effect of his condition. His once lively and animated face had become frozen and unresponsive, robbed of the ability to express his inner feelings.

Facial masking occurs when muscles responsible for blinking or smiling become rigid and less mobile due to a reduction in dopamine levels, creating a flat or expressionless facial appearance. For Govindbhai, specifically, the facial expressions often took the form of an angered appearance. The best way to help Govindbhai was to have him close his eyes and take a deep breath, through which he could relax the tension of the facial muscles. If this did not work, it would only be a

matter of time before his face resumed normal facial expression.

Another major obstacle that was slowly worsening was his sialorrhea, or excessive salivation. The main reason Govindbhai had this condition was that his ability to swallow had been reduced, which would mean that he was keeping more and more saliva in his mouth, which led to several other problems. One of the most significant problems noticeable by Mohan and Vishnu was that sialorrhea negatively impacted his sleep. At times, in the middle of the night, he would suddenly wake up, brutally coughing as if he was choking on something. It was as if the saliva had silently slipped down from his mouth into the wrong pipe while he was fast asleep. However, the problem was not just limited to the nighttime. Throughout the day, randomly, Govindbhai would demand a paper towel or a cup to empty the globs of spit from his mouth. Every one of his daughters and his wife would get frustrated, thinking that Govindbhai was just purposely spitting out the saliva for no reason whatsoever. They did not, however, understand that the reason his body was spitting out the saliva was that it was a physiological safeguard: due to his compromised ability to

swallow, it was better to spit out the saliva than accidentally send it down the wrong pipe into the lungs.

Upon bringing Govindbhai to his neurologist, the appointment treatment was to initiate a therapy of botox injections every three months. In Parkinson's disease, the degeneration of the basal ganglia leads to a hyperactivated state of the cholinergic system, which is responsible for releasing the neurotransmitter acetylcholine (ACh). And it is this specific neurotransmitter, ACh, which stimulates salivary glands. Thus, in Parkinson's disease, patients produce too much ACh, which overstimulates the salivary glands, leading to the condition of sialorrhea. Botox is a specific neurotoxic protein that blocks the release of acetylcholine, thereby reducing excess saliva production.

The family noticed, however, that the effects of Botox were slow to come on and quick to end. It would take nearly one or two weeks for the excess salivation and drooling to subside. Till then, endless cups would be used to fill Govindbhai's globs of spit. Once the Botox settled in, however, it was a magnificent change in which for the next two months there would be no worries about Govindbhai drooling or choking in his sleep. However, soon before the three-month

mark was up, Govindbhai's salivary gland, like a dormant force awakening, resumed its unrelenting production of saliva. Once again, to capture each and every droplet of saliva, the family armed themselves with an endless supply cups and papers.

In medicine, the worst diseases are conquered through the human concept of hope. It is hope which gives patients and doctors the strength to endure, the belief in the potential for improvement, and the courage to face adversity. At the same time, though hope is the seed through which comes great disappointment, it is also simply an experience of human nature — there is no meaning without hope. It is the gateway through which one can perceive the intrinsic value of life, even in the face of grave illness. And yet, as Nansen said, "When you try to accord, you deviate," therein suggesting that striving too forcefully for specific outcomes can lead to sorrow. One must recognize that there is an intricate balance between the pursuit of healing and the surrendering to the natural unfolding of life's affairs. True healing often entails finding meaning in the midst of profound challenges and cultivating an aura of hope that transcends particular outcomes.

9

A Mental Deterioration

Two monks were walking along a river when they came across a woman who was unable to cross. The older monk offered to carry her across, and she gratefully accepted. After crossing the river, the woman thanked the monk and went on her way.

The younger monk was surprised that the older monk had broken the rule of their order, which was to avoid contact with women. He stewed in his frustration for hours, until finally he couldn't take it anymore and blurted out, "Why did you carry that woman? You know we're not supposed to have contact with women!"

The older monk turned to him and said, "I left that woman at the river. Why are you still carrying her?"

- A Zen Buddhist Tale

The Buddha, upon attaining Nirvana, came to the realization that the belief in an unchanging, permanent soul was a fundamental misunderstanding of reality. He went on to state that it is this illusory belief in an everlasting atman that is the cause for our suffering. Through the idea of an atman, humans become attached to their sense of self and identity, clinging to their desires, fears, and beliefs. As the illusory veil of the self begins to dissolve, whether it occurs throughout a life or in the final moments of the dying process, great and profound suffering befalls humankind as they are faced with the impermanence of their own existence.

Amidst the gradual deterioration of his physical form, the ravages of Parkinson's disease showed evident signs in Govindbhai's mental faculties. A mere year after his diagnosis of Parkinson's disease, signs of dementia began to make their insidious appearance. There were times during the day where it seemed Govindbhai would enter a state of complete blankness. His focus, his alertness, and his mind were vanishing like wisps of smoke. These ephemeral episodes of blankness came and went with no perceivable pattern, varying not only from day to day but moment to moment. There were the occasional "lucid" moments when he had crystal clear focus, reading a

couple of paragraphs of a book in one sitting, holding meaningful conversations with his grandsons, or watching a movie with rapt attention. However, there were also “dim” moments when Govindbhai would stare off into space instead of focusing on a book or movie, take an eternity to respond to even the simplest of questions, if at all, and engage in meaningless and repetitive tasks with no goal in mind.

However, the dementia was not a sudden onset. At first, its presence was imperceptible, overshadowed by moments of clarity that shone like beacons in the darkness. But as time went by, the dimmed mind began to assert itself, gradually stealing the spotlight from its lucid counterpart. At the beginning of his Parkinson's journey, shortly after receiving the diagnosis, subtle indications of dementia's looming presence began to make themselves known. For example, Govindbhai, when given the TV remote to find and select a channel, would continue pressing the down button at a rapid pace, without ever selecting a channel. It was clear that at that moment, a darkened mind had taken over, and so the goal had become lost and he continued to engage in meaningless activity. When one of his grandkids tried to help him, he stubbornly rejected their help and persisted for a full minute or

two of this meaningless activity. But eventually, like a ray of sunshine piercing through the clouds, his lucidity would return, giving up this fruitless activity and allowing his two grandchildren to turn on a show for him to watch.

Another sign of early dementia was present in his responses. There were a few times, where when given a binary choice, Govindbhai would always pick the latter option without thought or reason.

"Do you want to watch Barsaat Ki Ek Raat or Saudagar?"

"Let's watch Saudagar."

"Do you want to go downstairs and outside for a walk or sit here?"

"I want to sit here."

Suddenly, reversing the question, Mohan would ask, "Do you want to sit here or go for a walk?

"I want to go for a walk."

Perhaps it was because his "dim" mind struggled to hold onto the memory of the first option, particularly if the choices were complex. If his “lucid” mind was present, however, given a binary choice, he would select, with clear intention, what he truly wanted. In fact, during his states of lucidity, a binary choice was not needed: one could give him a open-ended question, “What do you want to eat?” or “Where do you want to go?” and he would provide a clear answer, a testament to the fading but still present strength of his "lucid" mind. It was only when the “dim” mind took over that binary choice became necessary. As the progression of his Parkinson’s continued, Govindbhai’s growing “dim” mind, along with speech challenges, forced his family to solely communicate with Govindbhai through binary choices. The chasm between true communication and its hollow emulation grew wider, as the constraints of binary choices strangled his ability to express himself freely. The once-dynamic spirit that had animated his every word and gesture was slowly being suffocated by the insidious grip of Parkinson's, leaving behind only a shell of the man he once was.

A year had passed since Govindbhai’s diagnosis. His “dim” mind had grown into a formidable force that now

shared the stage with his "lucid" mind. His mind was getting slower, moving at a snail's pace. Besides the inability to focus with greater clarity on the present moment, Govindbhai was showing signs of difficulty storing new memories (anterograde amnesia) and retaining old memories (retrograde amnesia).

However, in the beginning, it would appear that he was suffering from anterograde amnesia more so than retrograde amnesia. After Govindbhai would watch a new Bollywood movie, Mohan would ask general questions, such as "What was the movie about?" but Govindbhai would enter a blank, comatose state. He tried retrieving any semblance of a memory that he had formed of the movie, but no matter how hard he looked, he found nothing. It was as though his mind had drifted into reverie, a place where nothing was received, nothing was kept, and all was forgotten. The "dim" mind had taken over and had made it impossible for Govindbhai to focus and thereby store memory of new, incoming information. Without the capacity to concentrate while watching the movie, the moments he spent watching the movie may have felt like a dream. Govindbhai had become a man like the one Chuang-tzu had described, ''The perfect man employs his

mind as a mirror; it grasps nothing; it refuses nothing; it receives, but does not keep."

Newer movies, with their fast-paced action and unfamiliar characters, seemed to slip away from Govindbhai's grasp like sand through an open sieve. But when it came to Bollywood classics or religious shows, something peculiar happened. It was as though a flicker of recognition was ignited deep within his mind, and suddenly the elusive creatures of memory would appear, beckoned forth from the depths. In fact, if Mohan asked him about the movie, he would be able to talk about it a little. It seemed that he was able to better exert focus and attention on objects that provided some semblance of his past.

In his youth, Govindbhai used to love going to the theater and watching movies with his railway buddies. He was also a very religiously-oriented person who watched and read many Hindu works. Thus, both olden Bollywood classics and religious shows brought back his old memories from the shadows of his mind, promoting greater attention. And so, with this newfound clarity of focus, he was able to store some of the content he was experiencing. It was a peculiar yet divine

phenomenon, this fusion of past and present, of memory and experience. Perhaps it was a testament to the capacity of the human mind to find support and solace in the familiar, to draw strength from the threads of our past that weave themselves into the tapestry of our present.

However, as Govindbhai's dementia progressed, the threads of his life's tapestry began to unravel. In the beginning, it was evident that his anterograde amnesia was far worse than his retrograde amnesia. It was not till the very end, when his dementia was far advanced when the “dim” mind had taken over the stage, that he showed equally worse retrograde amnesia. Memories slipped through his mind and vanished, lost to the ravine. The once-flamboyant colors of his past slowly faded to gray, leaving only a monotone present. Though he continued to recognize his current close-knit family, including his kids, wife, in-laws, grandkids, and siblings, he was slowly forgetting the rest of the world. The childhood friends, the laughter, the heartaches, and the triumphs, all of them faded into nothingness, irrecoverable by no one, like a dream upon waking.

Another effect of Govindbhai's progressing dementia was his deteriorating speech. His once strong and commanding voice became a mere whisper. It was not only his slowing mind that was responsible for his worsening communication but his stiffening muscles. Due to his Parkinson's, his dopaminergic neurons had died, meaning there was no dopamine to initiate movement. Thus, the body's muscles, including the vocal cords, became stiff. It was as if his vocal cords were wrapped in thick wool, muffling his words and making them hard to discern. The staccato and sharp distinction between each and every word that he used to speak faded into a hushed, slurred mumble. At first, his words, like water being squeezed out of a pipe all at once, would run together but they were clear and loud. Later, as the disease progressed, his words remained slurred but each with decreasing tenacity and preciseness.

It became so hard to hear him that Mohan would place his ear centimeters away from Govindbhai's mouth and still was not able to decipher what Govindbhai was trying to say. Mohan would ask him to repeat what he said another additional five times before being able to make a guess of what Govindbhai was trying to say. There were several times when Govindbhai would give up trying to communicate with his

family, seeing that each attempt was futile. Failing to transmit his wishes, he would sink into a deep silence. His body had become a prison, and his once lively voice was now trapped within it.

Dementia further exacerbated his speech difficulty as Govindbhai struggled to find the right words and often had no words he could think of to communicate with his family. His ability to express his desires dwindled like a dying flame. When he thirsted for water, he could no longer call out for it. When he wanted to use the bathroom, he could no longer ask to go. His capacity to communicate had faded and so too did his desires. One by one, each and every bodily desire was drifting away like a ship drifting away from the shore. If he had urinated or defecated in his diaper, he would not tell his family for he did not notice himself. And he could go on several hours without requesting water, only drinking when his family brought it to his attention. Govindbhai was slowly detaching himself from his body, which was becoming a distant memory, only to serve as a mere vessel to carry his fading consciousness.

One of the great difficulties associated with Parkinson's disease dementia is one's declining ability to multitask. In their

youth, their multitasking capacity is great because they are able to divide their attention effectively between multiple tasks: scrolling through social media all while walking and navigating towards the nearest convenience store. The sensory relay and processing regions of the brain are able to differentiate between high-importance stimuli and low-importance stimuli, thereby attending to the stimuli of greater importance. However, it seemed that in Govindbhai's case, due to his Parkinson's disease dementia, his brain's processing regions had lost their discriminatory power, causing every sound, smell, sight, and taste to enter his mind with equal intensity, overwhelming him with a flood of sensations. Even the simplest of tasks, like sitting in the living room, became an arduous endeavor, as he heard the whirring of the blending machine, his wife and son's chatter, his grandsons' joyful giggles, the savory aroma of cooking, the sweetness of the berries he was offered, and the TV blaring in the background, all competing for his attention. He was stranded in the midst of a whirlpool of sensory input, unable to focus and frozen in a sea of unfiltered stimuli.

Someone without dementia would be able to tune out kitchen noises, kids running around the house, the taste and smell of various foods, and focus on the television — that is the

idea of multitasking. However, for Govindbhai, all of these intruding stimuli were considered equally important in his brain and thus it was overwhelming. It was no wonder that he could not multitask, let alone focus on a singular task. The chaos that ensued in his brain was too much to bear, and he sought refuge in the mandir (temple) room. He would often ask Mohan to take him to the mandir, a place that offered him solace amidst the overwhelming storm of stimuli in his brain. It was his sanctuary, a place where he could find peace and respite from the overwhelming chaos of the outside world. The mandir would offer him and his brain some quiet, the only stimulus being the sight of God.

However, there were times when Mohan was not at home; thus, he could not help Govindbhai escape from the thousands of intruding stimuli. Thus, he believed that the best way to help his grandfather to find greater focus and peace was to provide him with headphones. Headphones would greatly diminish the number of stimuli that fluxed into Govindbhai's brain. With the headphones on, the clattering sounds of the kitchen would no longer intrude upon his senses, nor would the giggles of his grandsons. The only sound that could be

heard was that of the television, and for Govindbhai, that was just perfect.

The transformation was clear to Mohan. It was as if a veil had been lifted, and he was finally able to fully engage with the world around him. Govindbhai's face would show a change in expression while he watched the television. He would laugh when the characters were acting funny. He would frown during sad moments. He was no longer watching the television with a blank mind. The headphones allowed Govindbhai to experience life more fully, reducing the overwhelming stimuli that previously held him back. There was a greater response and awareness in his mind and therefore increased focus. Though the intervention would never restore his ability to focus or multitask, it helped a little. More than allowing him to focus on singular stimuli, the headphones were important to him because they turned off the chaos that ensued from the influx of stimuli, thereby granting him a small measure of peace.

The Monk carried the woman from one end of the river to the other end. After bringing her to the other side, he

did not keep her in his mind. What seemed to be an "unholy" action (interacting with the woman) was not an action at all, given that the monk was fully unattached. His mind, like a mirror, was emptied the moment he dropped her off at the other side, neither retaining her image nor thinking about her. The other monk on the other hand appeared to do a holy action by overlooking the woman, and yet he was completely attached to her. He continued carrying her in his mind long after she had left. Being strict on the path to nirvana is itself an inborn misunderstanding, for there is attachment in that itself. Oftentimes, one becomes so attached to the methods, as did the "holy" monk, that they forget the ultimate goal.

The Zen poem speaks on a similar subject related to flying geese over a lake: "The wild geese do not intend to cast their reflection, and the water has no mind to retain their image." The story of a famous Zen master who when offered a smoke, accepted. His students, angered, thinking their master had abandoned the path of Buddha, asked, "Why did you abandon the path and accept the smoke?" The Zen master replied, "It is you who is on the wrong path. Drift like a cloud and flow like water. Accept what comes but do not cling. You continue clinging to ideals and methods of 'holiness' and for

that, you remain attached and stuck in this cycle of life and death. ”

Govindbhai’s dementia was forced upon him. He was slowly losing his focus, ability to perform the most basic tasks, his personality, and memories. Dementia was kind enough to remove all his terrible, painful, scarring memories but its unfortunate curse also took out his lovely, happy memories. He was forced to practice the art of non-attachment, retaining neither the good nor the bad, letting go of his attachments to all memories and bodily sensations. All ideas slowly faded, desires melted, delusions vanished, and all that was left was the moment in front of him. He became a drifting cloud, who like flowing water, accepted everything and clung to nothing. Like a leaf caught in a swift current, he surrendered to the flow of life, watching as desires and delusions melted away like ice on a warm day. And though his sense of being was eroding, he was forced to come to terms with a strange level of non-attachment. He had begun his final pilgrimage towards complete non-attachment, in which he was slowly removing himself from the world, one day at a time, till he reached death.

10
Things Fall Apart

"We resist change. We fear the unknown. But everything is changing all the time – the waves, the clouds, and us. If we are quiet and still in the moment, we can witness change and accept it as inevitable."

"My guru said that when he suffers, it brings him closer to God."

"It's freeing. Aging is freeing. Fewer attachments. I used to comb my hair, concerned about my baldness. Now I comb my hair with levity. Who cares about baldness!"

– Ram Dass

The black tape effect lasted only three months. The visual stimuli that were used to activate the "automatic" walking systems in his brain no longer responded to the black tape. It was as if those areas of the brain had gotten worn out from the strenuous reliance Govindbhai had on those black tapes. His ability to walk had vanished — when he stood up, he remained frozen in place. Govindbhai had now become completely dependent on the wheelchair as the sole form of transportation from one room to another. Moreover, for the past few months, Mohan and Vishnu had been using each and every ounce of energy to push Govindbhai's frail body up the stairs and into his room — an impractical task. It was well overdue, but finally, Govindbhai was relocated downstairs: the problem of not having an extra room was overcome by converting the temple room into a makeshift hybrid bedroom. His wife and daughters, being very religious, tried avoiding this very scenario, thinking that changing diapers filled with urine and feces would defile the purity in the house of God. Over time, they were forced to see that in this world of dualities, purity and impurity are both two sides of the same coin, both illusory in their one-sidedness, inexistent without the other.

Astime passed, Govindbhai's mental exhaustion reached a new limit. His cognitive decline rapidly accelerated. His speech had diminished into a mere whisper. He had started to ignore many questions, remaining in silence, especially those that asked him to explain a rationale for his choices. One would have to repeat the question several times, present it slowly, and ask only binary or at least very simple questions in order to get a response from Govindbhai. The convoluted machinery that drove his inner thoughts and emotions had been dismantled and left to rust. Overall, it was concluded that his thinking and information processing centers had been greatly impaired in the span of just a few months.

Physically, too, Govindbhai had become a shadow of the vigorous and spirited man he once was. Once able to thrive on only four to five hours of sleep, he now spent most of the normal waking hours slumbering in his chair, his body reeking of exhaustion. In addition to sleeping heavily on the chair, he started sleeping more and more consistently throughout the night, with almost zero interruptions, for upwards of ten hours. The once-familiar rhythm of his life had been rewritten, replaced by his body's inflexible desire for rest that engrossed him day and night. As his disease progressed, he continued

suffering from extreme tiredness, requiring more and more sleep, reaching upwards of twelve to fourteen hours a day, to help support his body. Behaviorally, he no longer showed the urges he once had, to go from one room to another, to retrieve his favorite toothpick, or find certain lost documents. Lost in a world that was rapidly slipping away from him, he had entered his own private realm, a state of withdrawal and apathy, that only expanded as his physical and mental symptoms continually deteriorated.

Normally, the average human blinks their eyes about sixteen to eighteen times every minute. In a span of one minute, Govindbhai would blink zero times, his eyelids fixed and immobile.. After a sustained period of exposure to the air, Govindbhai's eyes would fill with moisture – a telltale sign of the incurring dryness caused by his neglectful lids. When he finally blinked, tears would cascade down his cheeks in an unrelenting stream. It was not his body that produced the tears. It was his soul. The body was just a vessel through which the soul could cry. And yet, his stubborn body remained unresponsive and unwilling to acknowledge his soul's anguish.

Mohan often tried to induce blinking by waving his hands in front of Govindbhai's eyes or touching his forehead.

His family added eye drops morning, noon, and night to prevent any adverse effects of eye dryness. Every few hours, for twenty minutes, Mohan would wrap a wet towel around Govindbhai's eyes, acting as a blindfold that would force his eyelids shut, moistening the area around his eyes. Similar to the headphones, Mohan saw that the application of the blindfold allowed Govindbhai to drift into his own peaceful realm, secluded from the outside world. Each crease and etched line of his tense face relaxed and was gradually replaced with smoothed-out furrows. The maelstrom of sensory stimuli could no longer overwhelm Govindbhai as his attention, like a sharp blade slicing through the chaos, narrowed into a steady focus. His eyes were the beacon through which he was forced to witness the pandemonium that surrounded him. He watched his two-year-old grandson darting away from his mother, his wife jostling various kitchen machines, and the television flashing a cascade of rapidly-moving images. His eyes had become a source of agitation and anxiety, like ripples spreading out from a rock thrown into a lake, warping and obscuring his vision until he could see nothing clearly. But now, after donning the blindfolds, Govindbhai's eyes were

forcibly closed, and the waters of his mind began to settle, growing still and calm.

His dementia and growing physical limitations brought forth a time of inertia for both himself and his family. As Govindbhai was having greater difficulties walking, his family would mostly transfer him from one place to another in a wheelchair. From his bedroom to the shower, from the shower to the dining table, and from the dining table to the couch in the living room. Thus, he would be mostly sitting for the entirety of the day; the only times he would stand would be when transferring him from the wheelchair onto the shower chair or the couch. At the same time, Govindbhai felt a state of profound lethargy, permeating each and every cell of his body. He had no urge to move. He just wanted to rest. And for the first time, his family could also take a break. Inertia, however, comes two-fold: an object at rest stays at rest, and an object in motion stays in motion. As the months went by, when changing his diaper, Govindbhai's family began to notice gray marks etched into the skin between the dividing buttocks. At first, his family suspected that the skin discoloration may have been caused by a diaper rash. They started applying certain

creams and powders, but no matter what they did the gray marks continued darkening.

On a fateful day, as Govindbhai's daughter was changing the diaper, she noticed that the gray marks on his skin had been replaced by a more ominous red, jelly-like skin. His daughter was alarmed as just the day before, the skin showed gray marks. What exactly was this new discoloration pattern? And how did it change so quickly? The tides of inertia were changing. The stone of chaos had begun its downhill descent and would stay rolling down for many months: his family's break was over. The next morning, upon examining his butt, what they had dreaded had become a reality. The skin emerging from the grooves between his buttocks had torn open, like an erupting volcano, no longer gelatinous, but bright red in color with the form of a tiny crater. All within a span of forty-eight hours, severe, rapid changes were occurring and the family was clueless as to what exactly was happening. As his family tried to grapple with the situation, they were reminded that the red crater was not their only concern. For exactly ten days, Govindbhai had not defecated.

Govindbhai had constipation problems long before being diagnosed with Parkinson's disease. However, the

progression of his constipation severely worsened during the course of the disease. Because of his Parkinson's, the muscles used in the process of defecation, such as the pelvic floor and anal sphincter, were impaired, not contracting normally, and thus added to Govindbhai's difficulty in passing stool. At the beginning, oftentimes, because his muscles were not pushing the stool out, he had to reach into his butt and pull out the stool with his own finger. As the disease got more and more severe, an enema was introduced and had initial success. The enema was a long tube with a nozzle that would be inserted in through his butt, into the rectum, where it would squirt out water into the intestines. The intention of introducing fluid into the intestines was to loosen the impacted stool. Govindbhai found the enema very helpful at first as it allowed him to relieve his stool without dirtying his fingers. However, over time, it seemed to have lost its effectiveness. Additionally, the frequency of which Govindbhai would defecate began to decrease over time. Initially, he would defecate at least every two days. However, as months and years passed, Govindbhai found it harder and harder.. If he could defecate every four days, the family would be ecstatic.

That week, however, no matter how many times the family tried to take him to the bathroom, Govindbhai would not defecate. Even after ten days, Govindbhai still could not empty his bowels. Becoming worried about the emerging two-fold problem, severe constipation and the skin tearing, his family ultimately decided to take Govindbhai to the emergency room. The emergency doctor diagnosed Govindbhai with fecal impaction and a stage two ulcer.

The fecal impaction was not something new for Govindbhai. It was an ongoing problem, just without a name, in which clumps of stool hardened and became stuck to his colon and rectum. It was then that the enema was used to loosen the stool and push it out from his rectum. However, because Govindbhai had become too reliant on the enema, even in cases when there was no fecal impaction, his muscles started getting lazy as they did not have to work as hard. And so, over time, the effects of the enema dwindled. Thus, in order to remove the current case of fecal impaction, the doctor had to break up and remove the stool with his own two hands. He demonstrated how to do it and thereafter instructed Govindbhai's son-in-law, Vishnu, to continue removing the hardened stool. Hours passed as Vishnu used his hands to

scoop out each and every clump of stool that had been hardening and growing in Govindbhai's rectum for the previous ten days.

After bringing Govindbhai home, his family developed a new strategy to prevent the possibility of having another fecal impaction. Before, they would give Govindbhai MiraLAX, a laxative, and prune juice on the day he was supposed to defecate. Now, they changed their strategy so as to give him miralax and prune juice every day so that he could get enough fiber to help prevent hardening of the stool. They also reached out to Govindbhai's neurologist who prescribed a pill for constipation; however, the medicine was discontinued as it worked too well, leading to severe diarrhea. This newly developed strategy entailed great success, allowing Govindbhai to defecate every three to four days. If four days passed and he could not defecate, a suppository would be inserted into his rectum, to which he would be able to successfully defecate half-an-hour to an hour later.

In regards to his stage two pressure ulcer, there was no immediate treatment. Only time would help heal his wounds. The pressure ulcer had formed because Govindbhai was sitting down for too long a period of time without any movement.

The reason why the family noticed gray discoloration on the skin of his buttocks was because the tissue was dying. Because he would sit for a long period of time, his blood vessels would become compressed, causing a lack of blood flow to the area, resulting in death of surrounding tissues. As a result, the pinkish color of the blood-rich skin slowly faded and was replaced by a dull gray color. The family realized that in order to relieve this compression or pressure, they would have to stand Govindbhai up every two hours, for at least two to three minutes, even if Govindbhai did not want to. By standing him up, the compression would be relieved, allowing for blood to flow into the previously-compressed area, bringing the tissue its much-needed oxygen.

His family even attempted to restart walking practice. After four months, they reapplied the black tapes on the ground, with no prior indication as to whether or not it would work. Miracuously, however, Govindbhai was able to move and coordinate his feet so that each foot would be subsequently placed on the black tape, one step at a time. It seemed that the once-exhausted neural pathway that integrated his visual stimuli to coordinate his walking reflex seemed to have gotten enough rest and thus had restarted. It should be

noted, nevertheless, that his walking was not like before where upon seeing the tape he could individually walk forward in rapid succession. Now, though he was able to move, the movements were slow, which increased the risk of loss of balance. And thus, when walking, Govindbhai needed someone to hold onto him to make sure he wouldn't lose his balance. The tape had once again been a miracle by which Govindbhai was no longer helplessly frozen. Over time, however, just as before, the effect of the tape dwindled and as Govindbhai's disease worsened, he showed decreasing ability to walk, with or without the tape.

Another approach taken to treat the pressure ulcer more directly involved applying a silicone foam dressing every few days. Because the ulcer was located on both sides of the skin inside the gluteal crease, applying the dressing became tricky as one of the sticky ends would end up covering the anus. To circumvent this problem, Govindbhai's family used a butterfly dressing instead of a square dressing, allowing them to target the ulcerous areas. Furthermore, the family had noticed that Govindbhai would sleep on his back the whole night, without a single toss or turn. This highly increased the chances of him developing another ulcer on his spinal bony

areas. To prevent this from happening, an alternating air pressure mattress was introduced. This allowed pressure on his back to move around: a previously inflated, high pressure area would be deflated to relieve pressure on that area, while introducing pressure elsewhere. This alternation occurred every fifteen minutes so as to minimize chances of compressing blood flow in any one region. In the same way, during the day, when he now sat on the chair, he was not sitting on the tough fabric of the chair for multiple hours but rather on a inflatable cushion, specifically designed to remove high intensity pressure in any one region of the bony areas of the butt. These methods of prevention were successful as Govindbhai did not develop another pressure ulcer.

Usually an ulcer takes many months to heal fully, but the basic fragments of the skin started recovering quite quickly. The first few weeks of the ulcer, however, were seen with unusual, positive cognitive changes. Typically, by this time in the progression of the disease, Govindbhai's consciousness and awareness for the external world were diminishing. Now, he would mostly be sitting on his couch, ignoring many external cues, lost in his own world, one without any desires. His cognitive abilities, ones that used to reflect his wants, needs,

and opinions, had come to a stagnant point, where he could no longer express himself as he once did.

However, something changed in the second week of his ulcer's progression. For some inexplicable reason, Govindbhai seemed more alert than usual. He was extremely aware of his surroundings, his wants and desires had returned, and his ability to express himself in communication was almost normal. It was a period of vivid lucidity. Govindbhai, when asked for the date and time, did not guess but answered with the precise date and time. He was also able to recall a distant relationship, his wife's cousin who lived in Maryland, and responded well to questions asked of him with definitive answers. His physical control of muscles had also seemed to improve. His diminishing voice was due to an inability to control the muscles of the vocal cord. However, in that period of vivid lucidity, his family would no longer have to lean over, their ears bordering his mouth as he whispered incomprehensible words. Govindbhai's voice, though remaining slurred, was now loud enough that one could hear it standing a few feet away.

He even was able to demonstrate compassion, something that the disease had robbed. Govindbhai was always

a little selfish in that in order to achieve his own personal desires, he would not think about other people's time; but, when it came to his grandchildren's studies, he prioritized them over his own needs. In the early stages of the disease, before his dementia had settled in, Govindbhai would want Mohan to stay with him at all times. Mohan had a tender approach to care and devoted considerable attention to Govindbhai, providing him with the love and engagement he so desperately needed. Unlike other family members who were absorbed in work, Mohan was present both physically and mentally, his body and consciousness both being in the same space as Govindbhai. As the disease progressed, Govindbhai's dependence on Mohan became more intense. This became problematic at times, especially when Mohan had to focus on a task or his studies but could not because Govindbhai would not let go of him. He would cling to Mohan's hand, unwilling to let go, and would interrupt Mohan's work or studies to be near him. Govindbhai felt vulnerable with the progression of the disease, losing his independence slowly, and felt Mohan's love and compassion. He had become very attached to Mohan, who for him had become a source of comfort and protection.

For the first time, however, during the second week of the ulcer, Govindbhai stopped holding onto Mohan and let him go. Mohan had just come back from school in the late afternoon and had gone into Govindbhai's room to check on him. Instead of finding Govindbhai asleep, as he usually was in the afternoons, he was wide awake. But more than awake, he was alert and responsive. After a few minutes of checking in, Govindbhai told Mohan, "Go wash up and eat first, then come back." Though it seems like a normal thing that grandparents say, Mohan was surprised to hear that because Govindbhai had been unable to bear being apart from Mohan, even at the cost of disrupting his grandson's studies and obligations. It felt like a sudden transformation: moving from vulnerable selfishness to confident selflessness. Could it be that in this period of lucidity, he felt more confident, seeing that some of his cognitive abilities had returned?

During the previous months of his growing dementia, he had lost his craving for certain comforts and sensations. He wouldn't care to let his family know if he had urinated or defecated in his diaper, nor would he let them know if he was hungry or thirsty, cold or hot, and so on. His family would have to take their best guess at evaluating Govindbhai's untold

conditions and desires and then making decisions for him. The period of lucidity, however, marked a return in his desire for sensation and certain comforts. One morning, as Vishnu was feeding Govindbhai chai and bread, Govindbhai moved his neck and eyes to make direct contact with Vishnu and spoke with clarity which belied his usual confusion: "This chai is too hot. And it needs more sugar." He wanted to taste something sweeter. Vishnu was startled by Govindbhai's awareness as he had become used to complacency. It was almost as if Govindbhai's resistant self had returned — the one that would battle with the world to attain his wants and desires.

He even told Vishnu that he wanted to eat by himself. For many months now, other people had started feeding Govindbhai after his hand-motor coordination had become so weak that he could no longer use his hands to lift the spoon to eat. However, during that period of lucidity, it seemed that not only did his strength and motor coordination skills return but so did his old habits of binge eating. There were also times in that period of lucidity when Govindbhai asked Mohan or Vishnu to take him to the bathroom to urinate. He did not feel comfortable urinating in his diaper, which was what he had been doing for the past several months without complaint.

Govindbhai had awakened, albeit for a short while. He was as alert as the time before his dementia had kicked in. He wanted certain things to satisfy his taste buds, his ears, and his eyes. He wanted other things that could keep him feeling comfortable. He kept bothering his wife, constantly asking if the food was done, made witty counter-remarks, chuckled at Vishnu's amusing remarks, and even corrected his grandchildren when misbehaving. Could it be that the unfortunate and intolerable pain of the ulcer had brought back a week of clear lucidity within Govindbhai? The duality was too great. The ulcer imposed great physical pain onto Govindbhai's body, wherein any pressure on the ulcer, including sitting, would be as unbearable as being poked with a hot iron. And yet, the ulcer brought back the Govindbhai of the material realm, one filled with sensations, bodily desires, and higher consciousness — the one who could engage in a meaningful conversation with his family. Was it a blessing or a curse?

Throughout Govindbhai's journey, especially beginning with his dementia, the ebb and flow of Govindbhai's cognitive state were akin to the everlasting fluctuations of waves crashing on a shore. It was an unbroken yet dynamic

rhythm of highs and lows. His dementia, like the tide, was characterized by the gradual retreat of his lucid mind into the murky fog. Yet there were moments when his lucid mind would surge forth through the fog, allowing glimpses of his former self to gleam through. In the early days of his dementia, the peaks and troughs were more evenly balanced, but as time dragged on, the trough began widening whereas the crest began narrowing. So, during the time of the ulcer, seeing Govindbhai as lucid as he was for an entire week was a beautiful surprise to his family. It was another rare opportunity for his family to reconnect with the man they had lost to the sea of dementia.

These chances of connecting with Govindbhai's lucid mind after that ulcer episode were, however, slim-to-none. Govindbhai had returned to his own self, separating himself from the external world, lost in his own personal, private mind. His energy continued being sapped by his progressing disease and he continued feeling increasingly lethargic, sleeping more and more throughout the day. He had returned to being Govindbhai of the nonmaterial realm, not being able to express his desires with his once again diminished voice. Like a lighthouse, standing steadfast and immovable, he basked under

the artificial house lights, seeing the world continue moving around him.

Many months had passed and Govindbhai's disease only brought on newer, unthinkable limitations. The newest emerging symptom began to give hints that Govindbhai may not actually be suffering from Parkinson's disease but something exponentially rare: an atypical Parkinsonism called Progressive Supranuclear Palsy (PSP). In the neurotypical brain, the substantia nigra neurons release dopamine to initiate movement. In Parkinson's disease, these substantia nigra neurons begin to wither, leading to a lack of dopamine release, which causes stiffness, rigidity, and inability to move the muscles of the body. In PSP, however, the substantia nigra neurons are relatively spared and so the dopamine-producing end is not the main concern; rather, it is the dopamine-receiving end that begins to wither. In PSP, a protein called tau accumulates and can lead to damage and degeneration of several dopamine-receiving structures such as the cerebral cortex (cognitive functions), basal ganglia (motor capacity), and brainstem (control eye movement).

The hallmark symptom of PSP is characterized by difficulty moving one's eye, in addition to their growing

inability to blink. Given these unique symptoms come relatively late in the progression of the disease, so too came the late realization that Govindbhai had been truly suffering from PSP this whole time, not Parkinson's disease. Seeing that PSP has no definitive treatment, unlike Levodopa in Parkinson's, this helped explain why his symptoms had progressed so rapidly, from walking to wheelchair-bound in a span of just two years. Govindbhai found great difficulty in moving his eyes up and down. Many times at the dinner table, when given a book to read, he would open the book and hold it open, but his eyes were not pointed at the book but were glued to a frame on the wall. Once his eyes got glued to a certain object or person, he would have difficulty refocusing his eyes on something else. If he was looking in the leftward direction and one was calling his name from the rightward direction, he would remain stuck in gaze in the leftward direction. The only way to have him refocus his eyes would be to close his eyes and then call out his name, to which he would sometimes be able to move his neck and eyes in another direction.

Simultaneous to the stiffening of his eye muscles limiting their movement, his neck muscles were also becoming rigid. At first, when he was seated in the living room, his eyes

were always pointed in the kitchen at his wife, whereas when seated at the dining table, his eyes were always pointed at the framed image of Krisha. His family assumed he stared off into those directions because he wanted to see what his wife was doing or he enjoyed looking at the portrait. Only after a few months did they realize that Govindbhai's neck would get stuck in the leftward direction for some obscure reason. It was not only in the kitchen or living room, but in the temple, outside in the park, and even on simple walks. His head would always be turned in the leftward direction, and when his family asked for him to turn it in the rightward direction, he would face great difficulty.

This created a disconnect between Govindbhai and the people who tried to talk to him as his eyes were always affixed in a certain direction. His gaze was unyielding, unmoored from his body and silently drifting away from the world around him. Even in the presence of his beloved family, his neck and eyes would be stiffened in the opposite direction, and his facial expression blank. Their chatter and laughter were mere echoes to him. He had become an empty vessel — no longer a part of this world nor able to exit. The cruel grip of PSP had finally claimed his eyes, the window to his soul, now lost in an endless

expanse beyond the physical realm. PSP was gradually forcing Govindbhai to disconnect his material presence, mind, and ego from this impermanent world.

Ram Dass used to say, "The art of life is to stay wide open and be vulnerable, yet at the same time to sit with the mystery and the awe and with the unbearable pain – to just be with it all." And that is all Govindbhai could do: sit in silence, vulnerable, surrendering to the dreadful changes occurring within his own body as nature slowly did its part, bringing Govindbhai back home.

11
Freedom

Alexander the Great was standing on the bank of the Indus, talking to a sannyasi (monk) in the forest. The naked old man he was talking to, sitting upon a block of stone, and the emperor, astonished at his wisdom, tempted him with gold and honor to come over to Greece. And this man smiles at his gold, and smiles at his temptations, and refuses. Then the emperor, standing on his authority as an emperor, says, "I will kill you if you do not come," and the man bursts into a laugh and says: "You never told such a falsehood in your life as you tell just now" Who can kill me? Me you kill, emperor of the material world! Never! For I am Spirit, unborn and undecaying. Never was I born and never do I die. I am the Infinite, the Omnipresent, the Omniscient. And you kill me, child that you are!

- Story from Vedantic Literature (as told by Swami Vivekananda)

Govindbhai died three days before the end of the year.

Two years had now passed since his diagnosis. It was a red, blazing summer and Govindbhai's son, Kanu, had finally arrived from Canada to take care of his father. He had come a few times previously, but could only care for his father temporarily before having to return to Canada; this time, however, he came as an immigrant to stay: his visa file for American citizenship had finally opened. Unfortunately, by the time Kanu had arrived, Govindbhai's PSP had only worsened.

And now with Kanu with him, Govindbhai's inertia grew to new heights. His daily routine was a grim reminder of the repetitious and mundane existence that had overtaken his life. Each day, he was woken up past midday, long past the point when most people started going about their day. After being given a shower and having a lonely lunch at the dining table, Govindbhai was left to sit there for another hour before being transported to the living room sofa. Soon after, he would be brought back to his room where he would take a late afternoon nap. When the orange glow of the sun was setting, Govindbhai would be woken up again and be brought back to the dining table. Here, dinner would be presented, an ephemeral distraction, before he was sat down in front of the

television. As the night drew on, he would stare sluggishly at the flickering screen past midnight, when he was finally permitted to retire to his room and embrace the empty solace of sleep. There was no variability. No change in scenery. A sense of ennui had overtaken his life — one without purpose, joy, or hope.

The only enjoyable thing that he could physically and independently carry out was eating his wife's delicious food. But with his achalasia and dysphagia, even a simple task such as eating was mired in difficulty. It should be noted though that in the few months leading up to the summer, Govindbhai had very few swallowing problems. Whereas before, he would have multiple regurgitation events in one sitting, in those few months before the summer, Govindbhai had had very limited number of regurgitations — at the very most, maybe one or two every week. His physical capacity to walk, carry out motor tasks, and even his mental state had diminished, and yet his ability to swallow had seemed to improve. This was most likely due to a change in his dietary approach. At the beginning of his dysphagia and achalasia diagnosis, his doctors recommended a liquid diet. However, as the dysphagia and achalasia continued, the year after, the diet recommendation was changed to a

thickened-liquid diet — a consistency similar to or a bit thicker than applesauce. A pure food diet had a high risk of choking and a pure liquid diet had a high risk of aspiration; thus, his family decided to make all his meals with a medium "apple-sauce" consistency.

Even drinking plain water became dangerous: the liquid fluidity rushed e from his mouth to the back of his throat. Typically, as food or liquid moves into the back of your throat, a muscle called the epiglottis bends and fully covers the entrance to the lungs like a flap, allowing the food or liquid to move only into the food pipe (esophagus). For Govindbhai, however, the PSP had slowed down his muscle movement, which meant that, when Govindbhai drank pure liquid water, it had the possibility of moving down his throat before his epiglottis had the chance to close. This could lead to silent aspiration, in which water could be entering his lungs "silently" (without a bodily reaction), a potential source of developing pneumonia. Even though he was drinking the water one spoon at a time, it still posed risks. Thus, to his thin liquid drinks such as water, a powder would be added that would thicken the consistency of the drink to prevent any possible risk of aspiration. However, in doing so, water was no longer water. It

had lost its invigorating, natural flow — one that required no force. Of its own nature, water moves through the mouth and into the stomach, coolly and lightly. The water Govindbhai now drank, however, had become an unpleasant, heavy mush, without any taste, that sat uncomfortably in his mouth as he slowly swallowed it.

As the spring was drawing to a close and the summer months dawned, Govindbhai's swallowing ability had finally begun to fail, especially when it came to ingesting his pills. Before, he would be able to pick up the pills with his fingers, plop them into his mouth, ingest a spoon full of thickened water, and gulp down both. However, as the disease progressed, he would only gulp down the thickened mush and leave the pill inside his mouth, chewing on it discreetly. This was not an ideal way for medication to be delivered as much of the medication's potential effect would be lost, as it would get stuck on the teeth or on the walls of the food pipe. As the summer months progressed, Kanu tried multiple methods of helping Govindbhai swallow his pills most effectively: he tried blending the pills into the thickened-water mix of his food and tricking him into believing he was just gulping down water or food. This strategy was initially successful but as the summer

drew to a close, these strategies worked randomly, at best, failing many times.

On Govindbhai's "bad" days, Kanu would spend more than an hour trying to help him swallow his pills, but to no avail. Govindbhai would always find the pill, gulp down the other content, and then begin chewing on the pill. For some reason, his body did not want him to swallow the pill: maybe it was because his body subconsciously knew that the small pill posed a risk of choking. If all else failed, Kanu would have to resort to dissolving the pill in regular, fluid water and then slowly, spoon by spoon, help Govindbhai ingest the dissolved drink. This was obviously an aspiration risk as it was not thickened water, but his family was trying their best to make sure Govindbhai could continue getting his medications into his bodily systems.

Pills that were covered in a capsule coat were split open, the powder dropped and mixed into his thickened water. As the fall drew to a close, his achalasia and dysphagia had once again peaked, wherein even as he swallowed the thickened water, including the powdered content of the capsulated pill, none of it was actually getting to the stomach. For example, Govindbhai, around the end of the fall season, developed a

urinary tract infection (UTI), probably from his constant wear of diapers. The capsulated pills prescribed to treat the UTI were given to Govindbhai by mixing the black-colored powder into the thickened water. Govindbhai would initially swallow it successfully. However, an hour after, it was always found that his whole mouth and throat were black, due to the regurgitations of his achalasia.

His family went through all sorts of things to get Govindbhai to swallow the whole pill and yet the treatment course was very inconsistent. The UTI-pill swallowing dilemma was barely solved and his UTI was gone — a bare stroke of luck. But what if next time, there was no luck, there was no possibility of solving the problem? What then? Govindbhai's family became fearful of what the future would bring. Nonetheless, they tried to maintain their optimistic attitude, ready to solve any problem that would come their way.

The winter was at its zenith. Mohan had returned home from school on a sunny Saturday morning for his long winter break. After giving Govindbhai a shower, as Mohan was dressing him, he noticed that Govindbhai had lost a lot of weight. It had only

been two weeks since the last time they saw each other. Mohan brought Govindbhai to the dining table for his lunch meal, where Kanu began feeding him a soft, sweet Indian pudding called seero. At first, everything seemed fine and well. However, as time went on, something felt strange. After a few spoons, it was found that Govindbhai was keeping the seero inside his mouth, chewing but not swallowing it. He must have grown tired of the seero since for the last few weeks it was one of the main meals he was being given. So, Mohan decided to change up the meal and give him something new, something that might appeal to his taste: small morsels of a soft burrito. After a couple of morsels, when Govindbhai opened his mouth, Mohan saw that none of the food had actually been swallowed. Like the seero, he had chewed it up but did not swallow it. Mohan took out the pulverized food from his mouth into a small plastic cup and threw it away. Why was he not swallowing? Again, they tried to give him his medication by mixing it into the thickened water. But it was the same result; he would not swallow them.

No matter how many times Mohan or Kanu tried or how long they sat feeding him, he would not swallow. They tried again in the evening with various foods. But it was the

same result. He went without food on Saturday. Mohan thought it was just a peculiarity due to his PSP and that he would eat again starting the next day — it was just one of his bad days.

Sunday came but Govindbhai had not swallowed. However, one of his daughters, Gita, had decided to take a look at the back of his throat using a phone camera. To the family's surprise, they saw white, blotchy patches covering the back of his throat. A fungal infection. Obviously, that's why he could not eat. Who could eat with that many white patches? How painful it must have been. The fungus must have come from his poor oral hygiene: though his family helped to brush his teeth after his meals, two to three times a day, the back of his mouth remained unclean. Because Govindbhai could not initiate gurgling, he could not gulp down a cup of water and rinse the back of his throat. And so being unable to cleanse the food completely from his throat, a fungus infection was subtly growing in the background.

His family rushed Govindbhai to the urgent care where the doctors diagnosed him with thrush (candidiasis) and said that he would have to go to the ER so that they could start the IV antifungal treatment. Regular antifungals for the mouth

would require a rinse-and-spit mechanism which Govindbhai lacked; thus, Govindbhai was taken to the ER where he was admitted overnight for antifungal treatment. The horizon was brimming with hope. In a few days, his fungal infection would clear and he would be able to resume his diet.

Monday arrived. In the morning, the speech therapist had come in to evaluate Govindbhai's swallowing ability as part of a routine checkup. She gave him a couple of ice chips which he chewed but was still having a hard time swallowing. Was it still the fungus? Vishnu, with his phone, flashed a light onto Govindbhai's open mouth. The speech therapist, Vishnu, and Mohan were looking into his mouth to evaluate if the fungus was getting worse or if it was getting better. They even started questioning whether it was the fungus in the first place.

Suddenly, with none of them aware, a booming voice projected from the foot-side of the bed, "Yep, that is Candidiasis!" All three of them turned around. "Hi, my name is Dr. Pheng." The doctor had entered the room.

After introductions, Vishnu asked, "So doctor, after the IV antifungal treatment, he will be able to eat again, right?"

The doctor, patient but frank, responded, "Look, I think there are two different issues at play. The secondary issue

is candidiasis. That's not a worry. I can easily fix that. What I may not be able to fix is the primary issue: his inability to swallow."

Mohan and Vishnu were confused. If the candidiasis was gone, why would Govindbhai still be unable to swallow? What did he mean by saying candidiasis was a secondary issue? Slowly but steadily, the reality was beginning to seep in.

Dr. Pheng continued, "This inability to swallow is not caused by fungal problems. No. It is the growing progressive nature of PSP. The way I see it, you and your family have two choices: a feeding tube or hospice. The family must decide this."

His family's fears had become reality. Govindbhai had lost his ability to eat. The muscle that allowed him to swallow gave up on him while the rest of the body functioned superbly. The lungs were excellent. The heart was incredible. Even his ability to recognize close family members, given that he had not eaten in the last several days, was still prominent. Every part of the body was online. Only the muscles responsible for swallowing were lost. And that was everything. If a man cannot swallow food or water, what hope is there left for such a man? It was the final frontier for Govindbhai. He had begun his PSP

by losing his ability to walk. Two years later, his ability to engage in conversation with others was lost. And now, in his final year, he was not able to eat. His body had failed him.

After some time to grasp the situation, there were two questions his family had to answer: Is it better to keep someone you love artificially alive, knowing the quality of life will be poor and the suffering will only be prolonged? Or is it better to watch them become a skeleton, eating nothing, drinking nothing — a slow but necessary death? He had written no advanced directive nor was he communicative of what he desired, and so the decision had fallen into the hands of the family.

As the days progressed, Govindbhai's ribs slowly jabbed out of his skin, a bony silhouette of a skeleton slowly forming. And without having the ability to take his Parkinsonism medication, his limbs, hands, and legs were all contorted. It was very challenging to see him in such a state. But, was it better seeing him live the way he was living now?

What exactly defines quality of life? Did Govindbhai have an acceptable quality of life? The myriad problems his body had from a brain disease rendered him without any independence. Who was Govindbhai exactly? Who was he

before his disease? It had become hard to remember his old self, the self with no disease, the self which was very independent. The self which ran 10 miles in each and every direction every morning. The self that could not sit still for even a second. Would prolonging his current state of life really have been what he wanted?

To live is to desire. When he stopped walking, he was not able to fulfill his desires by himself. He had become dependent on others to fulfill them. When he stopped being able to engage in conversation with others, he then lost his ability to express his desires. And as such, his desires remained unfulfilled. Now, he had stopped eating. Maybe this was the final desire that he was forced to let go of. Maybe it was not that his body had failed him but that this was nature's way of helping him pass. All worldly attachments relinquished. This was the nature of death. And if seen in a non-dualistic way, there could be beauty even in death. Unfortunately, Govindbhai had no capacity to make this decision anymore. His wife and his five children would have to make that call. And they leaned toward the feeding tube.

When Govindbhai was in his twenties, he wanted to become a *sannyasi* (or ascetic, monk). He wanted to endure

such a rigorous path so as to become devoid of attachments, desires, and other vices. He was a very religious and spiritual man. He wanted to seek what many others seek: an understanding of what life really *meant*. His father, however, forbade him to become a *sannyasi*, forcing him to become a family man. Now, at the time of his death, without eating any food or drinking any water, he had taken the vow of a *sannyasi*. The question was: would his children now also forbid him to enter his final phase of life as a *sannyasi*?

It is hard to let someone you love die. After all, death is the black void, the enemy of life. If possible, one would do everything in their power to give them a fighting chance to live. That was the consideration of his five children. His lungs were strong. His heart was strong. He was also able to recognize his family members. How could they give up on Govindbhai? How could they not even try to save him, to help him live? It is only human nature to prolong life as much as possible. And

ne feels enormous guilt if they do not help to prolong someone else's life when the means are possible.

Over the next week, the family spent rigorous time thinking about Govindbhai's life, the meaning behind a good quality of life, and the potential outcomes of a feeding tube.

Govindbhai's children tried to entertain all sorts of hopeful thoughts: "Maybe with the feeding tube, once the medication starts going in, he will be able to recover, maybe even walk. He might improve his life. We can even take him to all sorts of places. We can even take him to Europe." They were still, understandably, in denial. His family had to truly perceive Govindbhai's current quality of life, which was no life — it was a life with no purpose, joy, or hope. His life was no longer his own. No, it was now controlled by others, from the moment he could wake up, what he could eat, where he could go, and what he could do. Everything was under someone else's control. He was forced to relinquish the illusion of control. So, what exactly was their goal with the feeding tube? Was it really a treatment for the patient or a treatment for the family?

Even the hospital doctor, Dr. Kim, who came on Wednesday, recommended against the feeding tube. He claimed that while modern medicine offers certain machines and artificial means to prolong one's life, it does not necessarily mean that it is the right thing to do. Typically, doctors are held in a tight position when it comes to discussing death. By definition, the social role of a doctor is a healer, someone who is supposed to help you live. Thus, his recommendation against

the feeding tube spoke volumes: sometimes the best treatment for the patient is no treatment at all. Sometimes, leaving nature alone to do its job may be the best solution.

Dr. Kim, looking deep into the hearts of Govindbhai's children, clearly communicated that the only reason why one would even think about a feeding tube in the first place for such a patient is because one was not ready to let go of their own attachment. To keep him imprisoned in such a body simply because the family is not ready to let go could never be a proper form of care.

Besides attachment, his family feared incurring bad karma from not doing anything to save Govindbhai's life: a fear of guilt. Over the next few days, Mohan stressed the importance of thinking about Govindbhai when coming to a decision. He asked them to wonder what they would do in his position. If Govindbhai could talk, what decision would he make? Govindbhai was the type of person who hated sitting still for even a few minutes. The disease imprisoned him and kept him from pursuing his true human nature.

When the Indian Buddhist sage, Bodhidharma, arrived in China, the famous Emperor Wu called him forth into his palace and asked him, "I have helped to build many Buddhist

temples and pagodas, ordained many monks and nuns, and even translated the Buddhist scriptures for my people. What is my merit?" Bodhidharma replied, "Sir, you have gained no merit whatsoever." When positive action is done for selfish intent, there is no "good" karma. Extending Govindbhai's life forcibly, prolonging his struggles only to satisfy the purpose of feeling no guilt and having "done no harm" is like the Emperor's actions — on the surface, it may appear to be a good deed, but in reality, it is motivated by self-interest, lacking true merit.

On top of that, inserting a feeding tube was not to say that his problems would be solved. In fact, a feeding tube would be a temporary solution for growing problems that would bring Govindbhai more pain and suffering.

A feeding tube, inserted and attached through surgical means directly into the stomach, would allow liquid-food to enter his stomach directly, bypassing the mouth, throat, and esophagus, which in turn would dry up. As the skin's protective layers would eventually tear apart from the parched environment, feelings of terrible anguish, discomfort, and unease would come. Besides that, inserting a feeding tube was only a spell for furthering his inertia, which could potentiate

into more bright red, painful ulcers. In fact, within two days of bringing Govindbhai to the hospital, wherein he was stuck in bed without any movement, a new stage 1 ulcer had formed. Furthermore, considering Govindbhai's nature, on his "good" days, when he was more physically energetic, even if given a protective device to secure the feeding tube such as a belt, there was no doubt that Govindbhai would pull out the feeding tube if he wanted to. Thus, his family would have to be alert day and night to ensure that Govindbhai would not pull out the feeding tube.

Even if his family decided to prolong Govindbhai's life through artificial feeding, even then, Govindbhai could not live forever. He would have to die at some point: either through aspiration pneumonia or another opportunistic infection such as his recurring UTI. Inserting a feeding tube increased his risks of aspiration, from food going in a reversed direction, from his stomach, and into his lungs. If so, aspiration of such vomitus would lead to the development of pneumonia. Pneumonia is the most common cause of death in patients with Parkinson's and PSP. Dying from pneumonia is described as gasping for air to breathe as your lungs drown — a much more painful way to die.

For Govindbhai, his current state of not eating or drinking was an innate process of nature — a compassionate means to receive death. This was a critical point of understanding for Govindbhai's family as they were severely worried about his experience of pain from starvation. As one reaches their final days of life, his or her metabolism slows down exponentially, causing one's appetite to decrease enormously. The dying feels virtually neither hunger nor thirst. What we see as starvation is simply nature's way of providing a means for experiencing as little pain as possible as it shuts down the body.

Overall, without a doubt, the feeding tube was simply delaying an inevitable future, but one possibly worse. After days of parting with their father, husband, and grandfather, the family finally put Govindbhai at the forefront. They put their attachments to the side, strengthened their hearts, and replaced self-interest with true compassion. As Paulo Coehlo remarked, "If you truly love someone, you must be prepared to set them free." And so, the ultimate decision of the family had arrived: to allow him to die peacefully rather than artificially and forcefully prolonging a poor quality of life. Govindbhai could

at last find liberation in death — freedom from his imprisoning body. He had waited long enough.

Govindbhai had not eaten in over nine days. At the hospital, they provided IV saline to keep him hydrated. However, the IV saline was removed as the decision for hospice was made. He was brought back to his home where he would spend the last remaining days of his life, his family at his side.

Unlike the binary Western concept of consciousness, wherein one can be either conscious or unconscious, the Buddhist concept of consciousness lies on a spectrum. There are infinite variations of conscious states divided into three major categories: gross level, subtle level, and very subtle level. In the first two days, after having been brought home, Govindbhai was still alert and had enough energy to move his hands up and down upon command. In fact, he stayed awake almost the entirety of the time, sleeping only three hours throughout the day and night. Govindbhai was never left alone. At each second of his train ride towards the doors of death, one of his family members, either his wife, children, grandchildren, or other visiting family members, sat next to

him, keeping him company and comfort. As he was dying, each day, they read a chapter or so of the *Bhagavad Gita* out loud, to help ease his passing and bring him peace in his final moments.

On the third day, he remained alert and awake, but noticeable changes in his vitals began to emerge: a pulse greater than 110, a temperature higher than 100, and oxygen saturation beginning to decline. It seemed that Govindbhai was using his stomach far more than his intercostal muscles to breathe and so oxygen was given to provide him comfort. On the fourth day, his pulse continued to elevate, and he remained responsive to his surroundings, without showing any signs of pain, hunger, or thirst. He could hear, see, touch, and respond. His family had brought a religious ceremonial garland of flowers and put it around Govindbhai's neck. He automatically lifted his hands up, a sign of transmitting blessings, which is nothing but a greeting to the soul beyond the body.

A blessing, in its truest form, is not an expression of superiority; rather, a blessing entails lifting one's hand up, in the same way, one says "hello" to another, simply to greet and acknowledge the divinity in the other human, hiding behind the impermanent body. Alan Watts used to share a story of

Ramana Maharshi:"People used to come to him and say 'Master, who was I in my last incarnation?' As if that mattered. And he would say 'Who is asking the question?' And he'd look at you and say, get right down to it, 'You're looking at me, you're looking out, and you're unaware of what's behind your eyes. Go back in and find out who you are, where the question comes from, why you ask.' He had a lilting laugh that said, 'Oh come off it. Shiva, I recognize you. When you come to my door and say `I'm so-and-so,' I say `Ha-ha, what a funny way God has come on today.'"

During the first four days, Govindbhai was responsive, alert, and awake to sensory experience, and thus, the Buddhist would classify this state as being at the level of gross consciousness. However, as the fifth day emerged, Govindbhai slowly fell into what the Buddhists would call subtle consciousness. His vitals remained about the same, but it seemed that as the day came to an end, he was slowly becoming less responsive to external stimuli. He had begun the process of fully withdrawing into himself, into his consciousness. He had started to truly let go of the world. He had gotten off the train ride at his final station and had begun walking up the stairs, to the doors of death. Over the next few days, he was in deep

sleep, unresponsive to any external stimuli, and each and every one of his emotional and conceptual mental states slowly dissolved. The nurses could not tell if he was in any pain or not and so they started administering small doses of morphine, a measure of additional caution to help him die comfortably with as little pain as possible. Nine days had passed, and his heart was still beating, his brain not yet dead. The nurses were actually surprised to find Govindbhai still alive — they had thought he would not have made it past the weekend, but here he was, two more days later.

His pulse had begun to increase over the last few days, reaching 130, and by Tuesday, his pulse was unmeasurable. It was still present but rapidly fluctuating, at one point, it would be at 150, and just seconds later it would be above 200. His extremities were getting cold and Govindbhai had also begun showing signs of apnea, which were long pauses in his breath. He was close. He had reached the doorstep and was about to open the door.

Tuesday passed, the night fell, and early morning drew, a small, yellow glow in the dark sky began to show as the sun rose. As his family was sitting next to him, his eldest daughter saw as her father took in one last breath, waiting for him to

breathe out. He never did. Govindbhai had opened the doors of death and had passed onto the other side. He had a habit of waking up early in the morning, and he followed through, even in death. At that moment of his dissolution, Govindbhai's subtle mind fell apart, leading to the manifestation of his clear light mind, a subtler and deer level of awareness. This very subtle mind, manifesting at the moment of death, is best described by Ram Dass: "Clinging of human experience dissolves. It is pure awareness but it is not self-conscious. It is in harmony with everything around it because it is part of everything around it, but it's not busy saying, 'I am part of everything around me.' It does not say I am living in the Dao. It is the Dao. It has gone beyond dualism. That is the ultimate freedom. To enter into awareness which is no longer experiential."

Govindbhai was no more. His ego, his body, his name was gone. His consciousness had merged into a blissful oneness — lost forever from the mortal world and yet ever so present. Ananda Coomaraswamy is believed to have once said, "I pray that death will not come and catch me still unannihilated!" One cannot die if there is no one to die. The gospel of strength begins with acknowledging the presence of death, dissolving

the ego, and coming to grip with the idea that on one can hang on forever. This is the pinnacle from which arises the gospel of strength — an energy so invigorating so as to free one from the terror of death. Govindbhai's PSP had woefully forced upon him this state of reflection, wherein over the years that led up to his final moments, as each and every bodily function faded, his ego had slowly dissolved. He had become a soul imprisoned in an empty vessel, no longer his. And so, when death came, Govindbhai showed no fear; rather, a serene smile had graced over his face. He had been awaiting this moment for a while. And now that it was upon him, a peaceful radiance had suffused Govindbhai's being, like the warm glow of the setting sun.

No longer a caterpillar. No longer a cocoon. A butterfly had emerged. Death is not an end. It is a metamorphosis. It is freedom.

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"Once upon a time, I dreamt I was a butterfly, fluttering hither and thither, to all intents and purposes a butterfly. I was conscious only of my happiness as a butterfly, unaware that I was myself. Soon I awaked, and there I was, veritably myself again. Now I do not know whether I was then a man dreaming I was a butterfly, or whether I am now a butterfly, dreaming I am a man."

— *Zhuangzi*