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Transitions Without Cure: A Journey Through The Neutral Zone

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Submitted to the Program of Organizational Dynamics College of Liberal and Professional Studies in the School of Arts and Sciences in Partial Fulfillment of the Requirements for the Degree of Master of Science in Organizational Dynamics at the University of Pennsylvania
Advisor: Charline S. Russo, Ed.D.

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Transitions Without Cure: A Journey Through The Neutral Zone

Abstract

This capstone recounts a story of two merging paths. The first path is a story of navigating a life-changing medical diagnosis, self-realization, and managing transitions. The second path is a story of personal development via experiences and key learnings from the University of Pennsylvania Master of Science Organizational Dynamics program. The two paths are purposefully intertwined in a story format to reveal the zigs and zags of personal growth, as well as the literature and teachings that shaped me while navigating a new normal. This capstone focuses on topics of introspection, managing transitions, dealing with ambiguity, and organizational leadership. I hope this paper serves as an inspiration for those undergoing a personal transformation or navigating ambiguity as the result of a life-changing event. The paper shows how organizational change and leadership frameworks have tremendous value when used as reflection tools at an individual level.

Keywords

self-realization, managing transitions, personal development, new normal

Comments

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TRANSITIONS WITHOUT CURE:
A JOURNEY THROUGH THE NEUTRAL ZONE

by

Christopher D. Schneider

Submitted to the Program of Organizational Dynamics,
College of Liberal and Professional Studies
in the School of Arts and Sciences
in Partial Fulfillment of the Requirements for the Degree of
Master of Science in Organizational Dynamics at the
University of Pennsylvania

Philadelphia, Pennsylvania

2021

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To my parents: Your unconditional love is a source of strength. Your support is never-ending and a driving force in my life.

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LIST OF FIGURES

FIGURE		Page
1	The Three Phases of Transition	26
2	A Life in Transition	26
3	Overview of Intra- and Extra-Individual Factors	34
4	The Johari Window Model	40
5	Increasing Openness and Lowering the Façade	41
6	Seven Ways of Leading	55

TABLE OF CONTENTS

	Page
ABSTRACT	iii
ACKNOWLEDGMENTS	iv
LIST OF FIGURES	v
CHAPTER	
1 Introduction	1
2 Life as an Only Child: Smothered by Love, Driven to Succeed	3
3 Soccer: The Formation of an Identity	6
4 Room 323: The Diagnosis	14
5 Ignorance Is Bliss	19
6 Back to School, Confronting the Disease	24
7 Early Career: A Cauldron of Development	29
8 Learning to Be Vulnerable	37
9 Becoming an Authentic Leader	47
10 The Importance of Inclusion Safety	51
11 Final Thoughts	56
The Power of Reflection	56
A Healthy Relationship With Positivity to Build Resilience	57
Life Is One Big Cruyff Turn	59
Grit and Leadership	60
Conclusion	63
REFERENCES	65
APPENDIX	
A DiSC Assessment	68

CHAPTER 1

INTRODUCTION

You are about to read a collection of stories that have formed and influenced a journey of personal transformation. This series of stories starts from early childhood and moves to adolescence, being a young professional, and finally, the current state, which is that of a 36-year-old disabled father of three young children who is navigating life's stressors during a global pandemic. From reading this capstone, the reader may be able to see the evolution of self-identify, values, and my life's ups and downs—from both a personal and professional perspective.

The reader is provided with a soul-baring, honest, and firsthand account of a life-changing medical diagnosis and the trickle-down effect into both my personal life and my career life. Because life doesn't happen in a vacuum, the reader can experience lessons learned from the literature and various experiences in the Master of Science in Organizational Dynamics (MSOD) program at the University of Pennsylvania, which I attended from age 25 years to the present day. The reader may be able to understand how the program helped influence my transformation through introspection. This capstone explores how introspection, inspired by the program, led to the unearthing of the trickle-down effects and subsequently, transformational growth and new beginnings. As I was learning about the tools to manage "organizational change," it wasn't until years later when I learned I was also learning tools to master my own "personal change."

My hope is that readers can relate or find my story inspirational as I navigated what Bridges (2009) refers to as the neutral zone for over a decade. Bridges discusses managing transitions in terms of three phases: letting go of old ways or of an existing

identity, navigating the neutral zone where psychological repatternings take place, and the new beginning. In this new beginning, a new sense of purpose or new identity is formed (Bridges 2009). This work spoke to me as I had developed a strong identity, forged in my early years, in which I was reluctant to let go of for many reasons, which is explored throughout this capstone. This journey led to a prolonged trip in the neutral zone. As a society, we constantly seek to make sense of the ambiguous, vast, and at times a scary world. I hope that my story provides hope for individuals and organizations who are attempting to thrive under the weight of constant uncertainty.

CHAPTER 2

LIFE AS AN ONLY CHILD: SMOTHERED BY LOVE, DRIVEN TO SUCCEED

Born as the only child of two very loving parents, I had only one way to feel growing up: a sense of being the center of the universe. As one of the oldest grandchildren of a large family with over a dozen cousins, I had almost too much attention, which correlated to an inability to hide from failure. The large extended family of which I am a part of is the foundation for me to have built my life, a safety net of sorts that is constructed by love, trust, and support. However, I always felt the need to succeed primarily because I did not want the shame of letting my family down.

The attention I received for success—whether in school or through athletics—was a positive reinforcement for behavior that my family cherished. In addition, within my family no one ever talked of their failures. In fact, there is not a single memorable family fable of someone who failed or who acted in a less than desirable manner. In a sense, my childhood and view of my family was Shang-ri-la; I never knew anyone who failed. Mixed with all the positive reinforcement I received for succeeding, a stable home environment with all basic needs met, it is easy to understand my quest for self-actualization and hunger for achievement (Heylighen, 1992, p. 41).

Recognition was my love language; there was nothing better than getting a trophy. It was not about personal satisfaction; it was about showing those I loved an outward symbol of my achievement so they would be proud of me. My parents were never disappointed with me and were always very proud. They never created a pressure to succeed or the idea that failure was unacceptable. They valued me so much that I felt

compelled to keep making them proud, which made me question deeply why I felt the need for outward reward and recognition. I craved positive reinforcement. Consistent with literature and rationale behind positive reinforcement, the more of it I received, the more my hunger for it grew (Piazza et al., 2011, p. 151). In one of my classes we had to write our personal story and about the events that shaped our lives. I had never reflected on some of these events, but I uncovered one key event that shaped my desire to make my parents proud and fed a thirst for achievement.

When I was 9 years old my mom had a miscarriage. This rocked the family. She had three previous miscarriages but this one was different. Each of the previous miscarriages occurred later in the pregnancy so we knew the gender of the babies. However, the last one was so far along the family had let their collective guard down and had names picked out. I have vivid memories of these conversations when the whole family was excited, laughing, and joking. I remember my dad teasing me that the baby girl would take my room and I'd be forced into the smaller room—a suggestion that sent my 9-year-old self into a flurry and eventually led to a father-son wrestling match after dinner while my mom watched and shook her head.

We sat there every night around the square, polished wooden table with rounded corners, laughing, joking, and sharing stories of the day as a family of three—a trident of inseparable bonds, which I knew I was lucky to have. My parents never missed a night at the dinner table, never missed an event in my life, and never took their loving gaze and focus from me. They went above and beyond, and sometimes even without, to support my every need and want.

My parents were meant to have many kids. Their hearts were big enough to handle a dozen children. Sadly, they never got that chance as miscarriage and misfortune led to me being their only child. I knew the weight they both carried. It carried a certain weight that you could feel, or at least that was my perception. This experience led me to feel as if I could take away some of their pain by achieving more and being more. I wanted to achieve enough for many people in a lifetime to fill the void in their lives. This realization through introspection was important because it helped me better understand my identity and why I so fervently held onto it, even as my life changed over time.

CHAPTER 3

SOCCER: THE FORMATION OF AN IDENTITY

My drive to succeed intersected with soccer—a game I grew attached to in my suburban cul-de-sac home. Playing with boys in the neighborhood who were 2 to 4 years older than me helped me sharpen my skills. We used the woodpile in my backyard as one goal and the pillars supporting the elevated deck on my house as the second goal. Our games began after school and lasted until it got dark or neighborhood parents would start yelling “Dinner Time” from their back doors. Bel Air, Maryland, where I grew up, was a true slice of Americana, an almost 1950s way of life.

I remember my dad watching the games; his face would beam with pride as I ran until my face was blood red and my clothes were covered in sweat and grass stains. My dad recognized my talent and love of soccer in the back yard immediately. He enrolled me in the recreational league. He later told me that when I was 5 years old, the 9- and 10-year-olds from the neighborhood would come to the front door asking if I could play soccer after school. At 5 years of age, I played my first recreational game; they had to take me off the field because I dominated the game and would not pass the ball. If you have ever watched a game of young kids playing soccer, there tends to be a swarm of kids surrounding the ball and one child often emerges. I was that child. I was ultra-competitive and relentless in my pursuit to win even the smallest game. If there was a meaningless game, a game that someone made up to pass the time, I would have to win it or else I would be sent into a tailspin. This streak of competitiveness and drive to win

waned in later years as I matured and became a different person. It was something I explored in the MSOD program as I sought to understand why.

When journaling in Dr. Charline Russo's coaching class, I explored many introspective themes in my life. One was why my competitive streak was still around but not as prevalent. It was the fifth of my top five strengths in "Strength Finders" but I would have anticipated it as my number one strength. I had always wanted to be the best at what I was involved in, a feeling that propelled me in soccer as a youth but also as a student in college. I achieved serving as the valedictorian of my major through sacrificing many hours in the library when my friends were having fun.

In the years after college as a young professional as I began the MSOD program, I had this epiphany that people don't need to be the best or have accolades to succeed. In fact, in my organizational politics class a professor said, "Nobody likes the smartest person in the room. You don't want to present yourself as the smartest in the room." This was a bold statement, and it made the proverbial lightbulb go off for me. What I had been seeking was validation or approval from others by presenting my credentials, which I had worked hard to earn. I felt as though without "the trophy" I would not be accepted as credible. I believe this insight fueled my competitiveness; when I had this realization, this trait relaxed significantly.

My competitiveness was also tied to my early childhood of wanting to make my parents proud. As I matured and achieved the goals I set out to accomplish, my parents' approval and pride about my accomplishments were explicitly stated so many times over that I perceived I had filled the need to achieve for them. This perception also allowed me

to relax my relentless pursuit of achieving something, anything, and it allowed me to pursue goals for myself versus anyone else.

As a new leader, I took the DiSC assessment—namely, describing a person’s dominance (D), influence (i), steadiness (S), and conscientiousness (C). DiSC is a personal assessment tool used by many organizations to help improve teamwork, communication, and productivity in the workplace. My results revealed some key developments indicating how much I had matured with regard to my approach to competitiveness. I had gone from an unhealthy form of competitiveness to an almost laissez-faire attitude toward winning. In my DiSC profile, my dominant style was Si. According to my profile feedback,

Like other managers with the Si style you seek the approval of others and are concerned about letting others down. Competitive situations aren’t really your style and you probably find it hard to understand people who are most interested in individual accomplishments. (Everything DiSC Management, <https://www.everythingdisc.com/management>; see Appendix A)

When I explored this report including this paragraph in particular, it sent me further down the path of introspection. I knew I could respond to the notion of seeking the approval of others with a resounding yes and as something I identified strongly with as a leader. I knew the genesis of that character trait in myself. However, competitive situations had always been my style. I was the exact opposite of not being interested in individual achievements. I was obsessed with individual achievements for most of my life. I dug into this and asked myself if I actually was “over” individual achievements, to which the answer was “not completely.” But I certainly had moved closer to the other end of the spectrum in seeking individual achievements and competitiveness.

The “why” behind this shift was two-fold. First, I realized I had fulfilled a promise I had made to myself to make my parents proud, which enabled a shift from

“achieving for others” to “achieving for myself.” It turns out I was a lot easier on myself when I didn’t feel a desire for approval from others. Second, I experienced a life-changing medical diagnosis that changed my perspective on life and what’s important. This realization started a new beginning of self-identity.

When I was 10 years old, athletics stepped into overdrive. I was playing soccer and baseball competitively and, in some cases, a few years above my age level. Coaches in Maryland informed my parents that I had been identified as a player who should try out for the Olympic Development Program, a program for youth who are considered the best players in the state. The program was considered elite and a feeder to the future U.S. Olympic Team and U.S. Men’s National Team.

I’ll never forget pulling up to the tryout on a cold, fall day. My dad and I stepped up to the registration desk where I received a shirt with a three-digit number to identify me to the dozen coaches who were patrolling the fields and scouting the talent. I was a year younger than the other kids at the tryout. Playing “a year up” was something I was used to in recreational leagues, but this was a different level. At least 400 young people were trying out for a team of 23 members. It was my first real taste of competition. I could feel my heart racing on that crisp, cold morning waiting for the drills and scrimmages to start as coaches huddled with their coffees in hand—the steam rising into the air. I remember hearing a parent talk about how they had traveled 4 hours from the western part of the state to get to the tryout. I could sense my dad’s nervousness in anticipation of what was to come. I watched a few players juggle and pass the ball, sizing up the skill level of my competition. The anticipation was the killer. But as soon as the

whistle blew and the games commenced, I knew immediately that I belonged and had the talent to make the team.

The tryouts were all day Saturday and Sunday. After each scrimmage or drill, the players were moved to different fields. You could see the subtle methodology of where the top fields were. The top talent players were moved so players were segmented to groups according to their skill levels. It became apparent by late Saturday afternoon if you were in the talent pool being considered for the team or if you were simply playing out the tryout and not in consideration. If you caught the coach's eye, you moved to the best fields; make a mistake and you moved backwards toward the group that didn't have a chance. By the end of Saturday, I had caught the coach's attention and was on the best field, testing myself against the top players in the state.

It was my first taste of pressure and fear of failure. I knew I needed to perform on Sunday. By the end of the day on Sunday I was still on the best field, and I was elated. I knew I had done enough to make the team but I didn't know if I'd actually be selected. I heard the parents of other kids talking about "politics" and heard quotes such as: "Well, that coach knows him from their club soccer team so I know he will make it."

Looking back on this tryout, I realize it was my first experience with "politics," and it shaped the way I looked at the term. I had a negative connotation for politics that influenced my professional career in pharmaceutical and medical marketing and sales. I wanted to steer clear of politics. I wanted to prove my worth by doing my best and being the best. I wanted to rise above politics, not be seen as someone who got somewhere by cozying up to leadership. I resented people who had not "earned their way" into positions

of power or advancement. When I took John Eldred's class in the MSOD program, my eyes were opened.

Through introspection, I realized my worldview was completely off with regard to the topic of politics. During the first lecture of his class Professor Eldred referenced an article in which he was interviewed for *Fast Company* and was quoted as saying: "Politics is simply how power gets worked out on a practical, day-to-day basis" (Labarre, 1999, para. 1). He cleared the negative connotation of the term, which I had engrained in my mind from such an early age.

This key learning was groundbreaking for me early in my career. I began to lean into "politics" and build networks, like Professor Eldred had taught us. He had us journal in class and list in two different columns what we could help colleagues with and where we needed help. This was a super helpful exercise as it helped me think critically about the skills I had and could develop even further to offer more value to my colleagues. As a salesperson, I recognized a key gap existed in our organization on interpreting sales data. I taught myself how to use Excel and put together a dashboard that helped my sales vice president solve a key issue in measuring performance. As a result, I was put into a developmental role, which led to a permanent role as a sales leader with nine direct sales reports.

John Eldred's politics seminar taught me that "politics" was not a dirty word. It led to a key development in my professional career. The class also reinforced the idea that you did not need to be the best or portray yourself as the best to make an advancement. In many ways, it taught me about power dynamics, including that sometimes being too good at a job or being too much of an expert can lead to negative

political consequences such as getting trapped or pigeonholed in an organization because your skill set becomes a crutch for the organization. This phenomenon is also what I had experienced in my young career. It is amazing how through reflection one can uncover how views and experience with a topic as a child can influence worldview as an adult. The Olympic Development Program experience really had a profound impact on my life.

The decisions on who made the Maryland Olympic Development Program 23-person squad was announced 3 weeks after that impressionable weekend. I waited for what seemed like a decade. Each day after I got off the bus from school, I would check the mail (e-mail didn't exist back then), assured that my letter would be there. My parents would call other parents we knew to see if they had received their son's letter.

One by one my parents heard results from their telephone chains. Letters were starting to be received in the mail; not one of them had been positive. Even Matt, one of the best soccer players on our team, was rejected. He was a year older than me and was someone I looked up to. I thought for sure that I'd be rejected, too. I had already planned to chalk it up to "politics" as I'd heard from eavesdropping on those parent conversations. I didn't know what it meant but I knew it wasn't good so I was already planning how to save face.

I got off the bus on a sunny Thursday. I remember being nervous when my bus turned and hopped over the last speed bump before turning into my cul-de-sac. I wondered if this was to be the day. When I looked out the window, I saw my mom standing at the front door. She tried her best to conceal her emotions, but I could feel her positive vibes. She handed me the letter as we sat at the square, polished table with

rounded corners, a place where life's important conversations happened. The seal on the letter was opened so I knew she and my dad already knew the answer.

When I opened the letter, it said: "CONGRATULATIONS." As soon as I read the word my mom and dad screamed. I can close my eyes to this day and see their joy and pride. From there my soccer journey began to take off. I was leaving school early several times per week to go to practice. Being a top athlete and future soccer prospect became my identity. I received attention from friends, family, girls, high school scouts, coaches, and even an occasional stranger who had stopped to watch our team's games.

From the age of 10 to 14 years, my soccer career took off. I played in a showcase tournament in France, drawing attention from some European scouts representing some of the biggest teams in international football. I won a national championship with my club soccer team and was having a tremendous amount of success individually alongside the team. Ultimately, I was recruited to play soccer at Calvert Hall, an all-boys high school in Baltimore, Maryland, that was a perennial powerhouse. It was always a dream of mine to play there, and it was an honor to be recruited to play there. It fit with the story of how I wanted my life to unfold. It cemented the identity I had been building throughout my young life.

CHAPTER 4

ROOM 323: THE DIAGNOSIS

“It isn’t the changes that do you in, it’s the transitions. Change is situational. Transition is psychological” (Bridges, 2009, p. 3).

As a freshman at Calvert Hall, I realized when the soccer team hit the weight room, I wasn’t getting stronger. Instead, I was getting weaker in certain areas. It was most notable that my right pectoral muscle was wasting away as my left pectoral muscle was getting bigger. I’d wear a t-shirt or sweater, look in the mirror, and notice it. At the advice of my parents (who refused to believe anything was wrong with their only son), I chalked it up to puberty. I was never able to do sit-ups well because my lower abs were weak. I had a four-pack instead of a six-pack and joked about it—in confusion, not knowing anything was wrong and that this was actually a symptom of a disease lurking within that was about to come to center stage in my life.

None of it made sense until my diagnosis a year later.

During the summer of my freshman year, I was prepared to start varsity soccer tryouts by getting the coach’s attention. I aimed to get bigger and stronger, which, according to the coach’s advice, was the only thing holding me back in my freshman year. I hit the weights harder than ever and followed a trainer’s advice. In June I began a cardio training program. My dad helped me monitor my progress, clocking my intervals around the track and my recovery time. By July, my times were significantly slower. But most importantly, I was having trouble running. My right bicep and pectoral muscle were so weak that it was becoming impossible to even hold my arm in the right posture when

running. This was a symptom I could no longer ignore, and my parents agreed that we should seek some medical attention.

I went to no less than five different providers: athletic trainers, primary care physicians, physical therapists, and a sports medicine physician for evaluations. I was poked and prodded but all of them were at a loss due to the asymmetry of my muscles. On one side I was ripped from multiple training sessions per day, and on the other side muscles were atrophied. Several theories were presented but there was no definitive alignment on a diagnosis. At the advice of my primary care doctor, I made my way to a pediatric neurologist at Johns Hopkins Hospital in Baltimore, Maryland.

At Johns Hopkins pediatric neurology department, I was joking with my dad and mom about the Baltimore Ravens. I had just been put through my paces on strength tests, which included a standard 6-minute walk test, jumping, jogging, grip tests, and manual pulling tests. These were tests that I thought anyone could do, and I scoffed at them, thinking it was all a big waste of time. I was used to intense physical training, not some tests that geriatric patients would do. The strength tests were followed by a blood test, which I remember distinctly thinking how unnecessary it was. I laughed at the tests, completely naive and blind to the fact that a proverbial bomb was going to be dropped by the doctor.

The blood test was submitted to a lab, and we were instructed to make a follow-up appointment for a few weeks later. When we arrived at Hopkins for this follow-up appointment, we were escorted to Room 323. At worst, I thought they would give me some growth hormones or some other drug that would develop my asymmetrical

muscles—and that would be it. When the doctor came in, I saw the look on his face. He knew we were not prepared for what he was about to say. The doctor said these words:

Chris, you have FSHD, a form of muscular dystrophy. There are no treatments, no cures, and we are not sure what this means for you in the long term. This disease has a wide spectrum of symptoms-- from people who have the disease and are unaffected to 20% of the people who need wheelchairs and significant accommodations for mobility.

In the movies when an announcement or life-changing diagnosis is made for one of the characters in the film, the music takes on an ominous or haunting tone, the camera pans in slow motion, and sometimes a blur effect is used. This is exactly how I experienced the moment, a cliché as it may seem. I was rocked by the news.

Facioscapulohumeral muscular dystrophy (FSHD) is a genetic disorder that leads to the weakening of skeletal muscles. It's not a fatal disease but it can be severely debilitating. The disease typically begins in the early teenage years with the loss of muscles in the face (facio), shoulders (scapula), upper arms (humerus), legs, or core. FSHD can spread to any muscle. Many people experience debilitating pain and fatigue. FSHD is a rare disease that cuts across all genders, ethnicities, and races. About 30% of the cases arise in families without a prior history of the disease. The disease affects less than a million people worldwide (FSHD Society website at <https://www.fshdsociety.org/what-is-fshd/>).

I looked at my parents first; their faces were unlike anything I had seen before. They were in shock, as was I. They quickly pivoted their expressions when they saw me staring at them. After the usual questions—What can we do? Will I die? What drugs can I take?—I asked the doctor about playing soccer. The doctor said delicately but

intentionally, “Well, there aren’t any professional athletes who have FSHD. I would focus on your academics. You’re a smart guy so develop those talents.”

The doctors and social workers at the clinic told my parents that having a positive outlook on the disease and maintaining optimism were critical. He mentioned how he saw patients “go the wrong direction” by being consumed with the fear of the unknown. Conversely, there were cases in which people lived with hope and had seemingly “normal” lives. Perhaps the doctors and social workers had read theories of Eastern medicine and the mind-body principles. East Asian medicine understands emotions in terms of their relationships with different visceral systems in the body or the idea that emotions can negatively or positively affect health outcomes (Lee et al., 2017). Or perhaps in the absence of a treatment or cure, their suggestion of positivity as a treatment was loosely based on a theory about the placebo effect, which involves the idea that your brain can convince your body a fake treatment is the real thing—the so-called placebo effect—and thus stimulate healing. an idea that has been around for millennia (Harvard Medical School, 2017).

In my case, I was one of the 30% of the people with FSHD whose family didn’t have a prior history of the disease, which added to the disbelief and initial shock of the diagnosis. I also only had part of the total package of symptoms, which is normal for those presenting with the disease for an initial diagnosis to a clinician. But from the patient’s perspective, it comes as a surprise because the symptoms were mild to medium. Had I not been training for soccer so I was in tune with my body, I may have missed the symptoms altogether. Again, this dynamic compounded the disbelief.

I didn't know it at the time but what I had experienced was what Feiler (2020) referred to as lifequake, which is a forceful change in one's life that leads to a period of upheaval, transition, and renewal. However, he states it's not enough to just go through upheaval. Rather, one needs to assign meaning to the event and accept that the change has happened for a transition to occur. I understood the diagnosis, but at 15 years old I didn't know how to accept or assign meaning to what had just happened. It was apparent that I was in the midst of experiencing the patterns of grief identified by Kübler-Ross. First there was shock and then denial. As Kübler-Ross's (2014) stages of grief and loss dictate, denial is nature's way of letting in only as much as one can handle (p. 10).

CHAPTER 5

IGNORANCE IS BLISS

The doctor's words were what my parents latched onto. Maintaining and focusing on positivity became their mantra, then subsequently, my own. Living one day at a time, not looking too far ahead, being present in the moment: These were common themes in my household. The Serenity Prayer helped me: "God grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference" (Reinhold Niebuhr, 1954, as cited in Shapiro, 2014). These themes were all prescribed by my parents to help me, and them, thwart the fact I had a disease that was unpredictable and unknowable.

When I was diagnosed 21 years ago, little was known about FSHD. Scientists didn't know the underlying genetic cause of the disease, no therapies were on the horizon, and little hope existed. There was little understanding of a standard disease progression for FSHD, as well as no biomarkers or signs to look for that could accurately predict its progression. My primary care doctor admittedly didn't even know about the disease. Some people's muscle wasting happened quickly, some progressed very slow, and for some, it never advanced. It led me to adopting this mindset: "The experts don't know what's going to happen, I don't know, no one knows, so who cares? I will deal with this tomorrow." This way of living created positives as this mentality allowed me to compartmentalize my life and thrive in a world of uncertainty by focusing on the present—the controllable. However, it also led me into the depths of denial in never confronting the diagnosis head-on.

A dynamic that enabled the prolongation of disease confrontation was that I wasn't "disabled" the moment I received a diagnosis. I wasn't presented with disconfirmation or a piece of data that said concretely: "This is your future." I wasn't immediately forced to let go of my current identity and transition to the neutral zone and an eventual new beginning. I was in Room 323 at 10 a.m. When I left the room at 12 p.m., I was undeniably changed, but I still existed as a teenager with high athletic ability, not an individual with distinct physical challenges. I may have had some quirky things going on physically, but I could still fully blend into normal life.

I came to learn about Schein's (2010) stages of learning and change in my first MSOD class with Dr. Vanderslice. This immediately resonated with me when I reflected on why I was reluctant to confront my diagnosis. I applied some concepts of organizational change to myself and realized I had been ignoring my diagnosis because of many reasons. Schein talks about unfreezing or creating the motivation to change (Schein, 2010). Disconfirmation is the idea that there needs to be some facts about the current path that lets the individual or organization know the current way of operating isn't sustainable in the future. I always interpreted this as a set of facts that hits a person right between the eyes and tells them, "This isn't going to work; this identity or way of operating isn't sustainable."

For me, the disconfirmation step, or a set of facts that told me I needed to change, never happened. In building the need to change I wasn't presented with enough of what Schein also refers to as survival anxiety, which implies that unless we change something bad will happen to the individual, group, or organization (Schein, 2010). Because my diagnosis didn't follow a prescribed path such as cancer or heart disease, the disease's

enigmatic qualities complicated my acceptance. My physical symptoms were mild enough that I could do everything a so-called normal life required. I could run, I could lift things, and I could be physically capable in all situations, apart from elite athletic competition.

Even if I had known about a prescribed path for the diagnosis, there was nothing I could do about it. I was at the mercy of the disease's will. I chose to keep pushing forward with denial and the identity that had served me well in the past until my symptoms progressed and I could no longer ignore them.

I had no idea about the concept that Schein discusses about survival anxiety until I became a student in the MSOD program. When I read his work and how it applied to organizations, it acted as a mirror for me as an individual. When I read about the hesitancy to change and the normal pains of change, it spoke to me at a deep level. My pages were highlighted extensively. The pages on psychological safety and survival anxiety were starred, folded, and highlighted until the plain unmarked words became the minority. Schein writes: "Survival anxiety does not, by itself, automatically produce a motivation to change because members of the organization can deny its validity or rationalize that it was irrelevant" (Schein, 2010, p. 302). He goes on to talk about how organizations can deny a bad quarter by ignoring underlying causes and explaining away the bad as a circumstance of the uncontrollable. This felt familiar to me.

The major star on the page that spoke to me deeply marked this statement:

What makes this level of denial and repression likely is the fact that the prospect of learning new ways of perceiving, thinking, feeling, and behaving also creates anxiety—what we can think of as *learning anxiety*, a feeling that "I cannot learn new behaviors or adopt new attitudes without losing a feeling of self-esteem or group membership." (Schein, 2010, p. 302)

Wow, this was so eye-opening for me as I reflected on the why behind my lack of confrontation. I had so much fear of the unknown, loss, an anxiety around my future state, and a current state identity that was wrapped in positive self-esteem. I was at an ultra-competitive all-boys school where status revolved around athletic achievement, physical ability, or academic merit. I feared losing friends, or as Schein (2010) puts it: “group membership” (p. 304). I was surrounded by a group of homogenous alpha males, which led to a fear of being different. It also explained to me why I needed a new interim identity to pivot to.

Schein’s work helped me realize as much about organizational denial and repression as it did my own. However, Schein’s help didn’t stop there for me. He provided a solution to this learning and survival anxiety with these words: “The reduction of this learning anxiety is the third and most important component of unfreezing—the creation of psychological safety” (Schein, 2010, p. 302). This concept, as well as this feeling of psychological safety, didn’t come for many years. I pivoted to a new identity without closing out my old one.

I played out my sophomore year of high school on the soccer team. I played nowhere near the level at which I had been. The game became a source of frustration for me. I watched others pass me as my speed and skill levels declined; eventually, it became too much for me—both mentally and physically—to deal with. The game no longer was fun. However, my identity was so wrapped up in “Chris, the soccer player” that I needed something to pivot to. I went to Calvert Hall to play soccer. My friends, my social life, and my world as a 15-year-old were completely intertwined. Through introspection, I realized I needed something to pivot toward that would make sense, erasing the shame I

felt from the diagnosis and providing a way for me to save face. At 15 years old I didn't have the tools or the elevator pitch to tell people about my diagnosis.

My solution on how to save face and pivot my life came from Room 323 on the day of my diagnosis. The doctor said, "You are a smart guy. Develop your academic talents," in response to my question around the future of my soccer career. This suggestion amid the surreal blur of that day stayed with me and led to the entrance of a new identity as "Chris, the scholar." I pivoted to this new identity and used the excuse of wanting to focus on school to explain to people why I stopped playing soccer in my junior year of high school. By and large, this explanation was accepted minus a few skeptics who prodded deeper and questioned how I could just give up on soccer. This new identity was another way for me to avoid confronting my diagnosis directly. It was a distraction that allowed me to shift focus away from a scary, unknown progression of symptoms toward becoming a better version of myself. It allowed me to feel good about myself and provided a purpose. However, alongside this approach was a mentality of ignoring confrontation and pretending everything was okay. After years of this approach, it permeated throughout everything I did.

CHAPTER 6

BACK TO SCHOOL, CONFRONTING THE DISEASE

“The neutral zone is a journey from one identity to another. Most people expect it to move straight from the old to the new, like a simple journey from one side of the street to another” (Bridges, 2009, p. 43).

The rate of progression of my symptoms was thankfully not rapid between the ages of 15 and 25 years. It wasn't until I was 25 years old and beginning the MSOD program when I started to have to physically compensate because of the disease. I made it through the formable college years within the standard deviation of normal, playing intramural sports, running, climbing stairs, and moving furniture in and out of dorm rooms on many occasions. I never had to think ahead about what I might encounter physically. Then when I had class at Fisher-Bennet Hall and began to walk upstairs with a heavy backpack, I noticed how it wasn't easy anymore. At first, I used a railing to help pull myself up; I had never needed to use the railing. By the second semester, I started taking the elevator instead, unconsciously. This is typical of the disease progression. It's not like I couldn't do the steps; it was just a choice to take the easier path. However, these choices are a symptom of progression that isn't easily recognizable. It's not until one stops to reflect that one realizes what has happened.

A year later I was falling sporadically, tripping on uneven pavement when my toe would drop down and catch a raised brick or stone. I would bandage my knees and then kept moving on. I thought I was just unlucky or clumsy. Gradually, it happened enough times in a row that the wounds on my knees weren't healing in between falls. I started to realize I could no longer ignore FSHD. I could no longer pretend this disease wasn't

impacting my life, wanting to believe I would be one of the lucky ones whose symptoms never progressed. I was in the process of experiencing a gradual onset of symptoms.

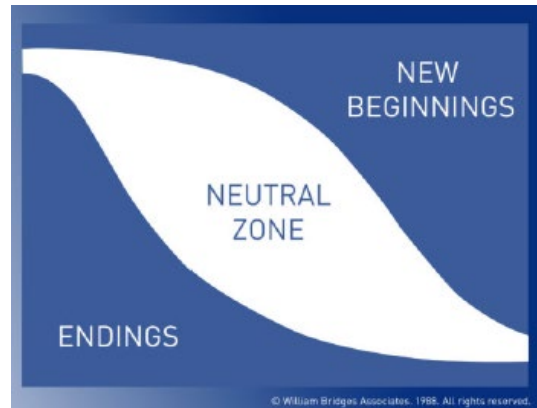
The tough part about FSHD is that the muscles weaken at different rates; it is typically a gradual progression. It's not until you look back and reflect on what you did in prior years when you realize you are no longer physically capable of doing things you used to do. You don't wake up one morning and experience a loss of being able to do something. As your muscles weaken, your body and other muscles compensate, which leads to a lack of realization about its progression. For instance, I didn't realize that over the duration of a year my foot began to drop when I was walking. My body unconsciously compensated by changing my gait. I started lifting my knee when walking to clear the foot that was dropping. It seems like a person would realize this but these micro changes over time conceal the larger change, and it's not until a symptom presents itself when you realize something is different. For me this manifested itself in falling and not being able to wear certain footwear such as sandals. It also shook my confidence when walking on uneven terrain.

I could no longer ignore FSHD, my identity, and what my future would hold after I fell on my honeymoon a total of seven times in a week. I had finally received the disconfirmation—the facts—in the form of symptoms I couldn't overlook. I was scared, and my wife was even more at a loss. Neither of us had experienced this before because the disease had been rather dormant. At a time when there should be high excitement about a future life together, we were both taken aback.

It was at this time when I firmly moved toward navigating the neutral zone (Bridges, 2009, p. 5). Figure 1 depicts the nonlinear fashion of transition that people and

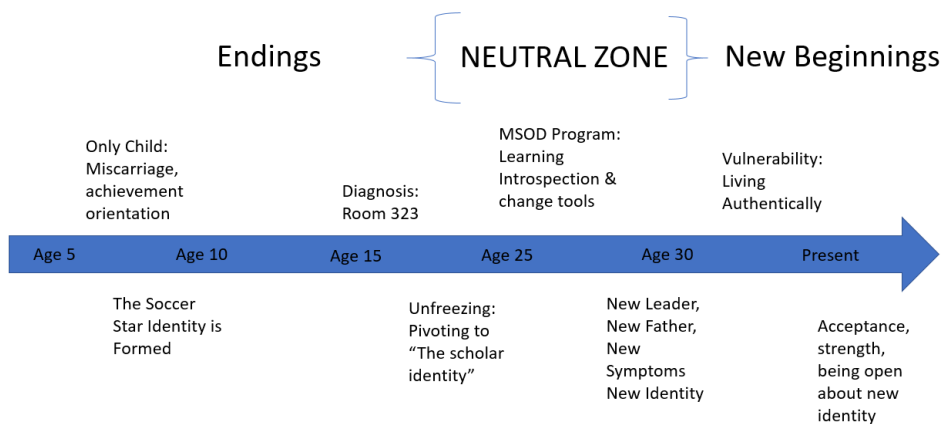
organizations move through as they come to an ending and navigate toward a new beginning.

Figure 1. The Three Phases of Transition (Bridges, 2009, p. 5)



I had finally come to an ending. This ending, bogged down with repressed fears and denial, took a rather long time to come. From age 15 to 25 years (Figure 2), I was coming to grips with my life, its meaning, and an unclear diagnosis. I focused my energy and my identity on scholastic achievement, but it was merely a way for me to escape the reality of what a different future could look like, a future I wasn't ready to deal with. However, the symptoms forced me to deal with my own reality.

Figure 2. A Life in Transition (Created by Christopher D. Schneider)



I wish I would have been brave enough to take the disease on when I was 15 years old, brave enough to not care about what others would think of me, brave enough to look at the worst-case scenario of the disease and think: “I can handle this.” Instead, I exerted so much energy trying to avoid and deny. I have always admired people who could embrace an identity that was unconventional and stand up in front of others boldly while saying, “This is me.” I just wasn’t that person, and my symptoms were a constant evolution. I wasn’t fully sure I would ever experience any life-changing symptoms, but at 26 years old there I was, standing firmly at an ending looking ahead into an unknown neutral zone. Bridges describes the neutral zone as the winter during which spring’s new growth is taking shape. This analogy resonated with me because I was stuck in this neutral zone, reorienting to what my life could potentially look like.

Bridges (2009) makes this comment about navigating the neutral zone: “The outlook, attitudes, values, self-images, and ways of thinking that were functional in the past have to die before people can be ready for life in the present” (p. 43). Personally, my outlook and self-image needed the most help. My outlook was one of toxic positivity that led to denial. My self-image was that of an athlete who was physically strong, capable, and superior to the norm. It took a lot of time (Figure 2), internal strength, and support to begin to let my outlook and self-image die to support a healthy new beginning.

When we got back from our honeymoon, my wife encouraged me to find a doctor who specialized in the disease. I had only been going to a primary care doctor, not keeping up with the latest developments on the disease. Again, part of my denial and lack of confrontation involved avoiding doctors, who I thought couldn’t predict the disease progression and therefore had little merit. As I confronted the disease, I started looking

for a specialist or, as I referred to it at the time, a “muscle coach.” In hindsight, even this language about looking for a “muscle coach” was a subtle denial of my situation. It was a softening of the language, a subtle reframe of the narrative. Even though I was confronting it, I was easing my way into it. I had a long way to go and a lot of hurdles to navigate ahead.

CHAPTER 7

EARLY CAREER: A CAULDRON OF DEVELOPMENT

While all this drama was going on personally, I was pounding the pavement to advance my career as a pharmaceutical sales executive and also deep into the MSOD program at the University of Pennsylvania. I was simultaneously involved in the emerging leaders program at my organization. It was a prestigious position to be involved in the program because only 20 people were selected per year. The high intensity program was both virtual and in-person training geared toward identifying new, high potential leaders. It felt as if my life was swirling. I was confronting my new identity, searching for meaning, and surrounded by professional development.

It truly was a cauldron of development in terms of lots of forced introspection at both work and school. Whether it was journaling, reading articles and reflecting on them, writing papers on abstract concepts, or giving presentations on myself, it was a lot of thinking at a time I needed it the most. It was during this time when I started to realize I was truly a ball of clay. I would read an article and reflect on its meaning, then my thinking would be shaped and reshaped. I'd attend a seminar in which professors would offer a provocative way to think about organizational change or politics, then I would make a fundamental shift in my approach. Sometimes timing is everything; all this learning and reflection opened me up at just the right time as I was searching for a new beginning personally.

I was "ready" to meet with my new doctor, a neuromuscular specialist (aka muscle coach) with my wife by my side. Actually, I was "apprehensively ready."

Admittedly, I was terrified of the appointment. It had been a decade since I had seen a specialist; I was terrified at what the doctor would say or reveal to me about my condition. I was scared if there had been new developments that would allow them to predict my rate of progression. Essentially, I feared the unknown, and this was the first time I was meeting it head-on.

In the week leading up to my Friday appointment, I couldn't focus. I had a lot of windshield time, which many traveling salesmen know all too well. I spent hours driving that week, blankly staring as the trees and lines blurred and wind whooshed past the cracked windows of my company-issued vehicle. My neatly pressed tie—tightly tied around my neck—flapped against the seat belt. I missed many turns and highway exits that week as my mind wandered. Although I had so many things figured out, I realized I was as lost driving as I was with how I would handle my upcoming doctor's appointment.

I had so much anxiety built up around the what-ifs of the appointment. My mind kept going toward the worst-case scenario. For me, that meant the doctor telling me that my progression had advanced and that my future looked bleak or that based on some new scientific data, they could now calculate the exact moment I would need a wheelchair. On Thursday morning I had to pull off the side of the road. I loosened my tie as I broke out into a cold sweat and felt like I couldn't breathe. I was so scared in anticipation of Friday.

On Thursday night I had a night class in the MSOD program at Fisher-Bennet Hall. I took the elevator to Professor Charline Russo's class, which was on the second floor. One of the main goals for the class that night was exploring coaching models. We had a lively discussion and discussed the GROW model, which is an acronym for Goal, Reality, Options, and Will/Way forward (Libri, 2004, p. 1). We received a handout with a

description of each step in the process and a list of sample questions, then we did a live practice coaching session. Professor Russo asked a question of a classmate that literally unlocked the experience I had had earlier that day when I had to pull off of the side of the road. One of my classmates had talked about the fear of something happening if an action was taken and turned out to be the wrong choice. Professor Russo said, “Let’s go to the worst-case scenario. What would that look like?” It completely changed my classmate’s way of thinking as she realized the worst-case scenario was manageable. Professor Russo then pivoted the conversation toward a brighter future and what the possibilities for that student would be if the right action was taken.

It was in this moment when I realized how powerful this technique was. I learned that reflection and asking the right questions of others and oneself were vital. I also remember having this eureka moment of realization when I needed to stare hard at the worst-case scenario and face it, understand it, and then move forward. During the panic-like attack I had had earlier in the day, I also realized I had never even considered the positive side of the appointment scheduled for the next day. What if I had been missing possible augmentations to my diet that could benefit my muscles? What if I learned some new piece of information that could predict my disease severity may be less debilitating in the future? What if there was an ongoing drug trial that was promising that could help me? I had let fear win the day but was determined to face whatever was to come the next day.

It was many small moments in the classroom such as the one I had in Professor Russo’s class that led me to huge personal breakthroughs. A quote here, an article there, a poignant question, or an insight from a classmate’s personal story sparked growth for me.

I was in the neutral zone collecting evidence, artifacts, and data like a detective searching for the ultimate answer or greater truth. The curiosity and thirst for knowledge propelled me in this early career phase.

The next day at the neuromuscular clinic I met with a doctor who was one of the smartest people I had ever met. She specialized in the disease and had treated countless other patients like me who had this rare disease. She was a true key opinion leader in every sense of the word. It was a truly positive experience except for one outcome: She solidified for me the severity of the disease and challenged my self-image and identity. While she painted a positive picture for my life, she also outlined the challenges that could potentially lie ahead. These were challenges I could not ignore anymore. It was also the first time I heard someone really refer to me as an “FSHD patient.” She prescribed me a plan of focus for exercising and diet, while also directing me toward resources and support groups. My doctor played multiple roles in the encounter, helping me take another step in the direction of the neutral zone toward a new beginning.

As noted in Schein’s book, *Helping: How to Offer, Give, and Receive Help*, there are many forms of help, and in personal and organizational life, we may be called on to provide different types of help. My doctor, of course, played the role in helping me navigate a difficult diagnosis. But what made her special was her understanding and experience with the disease. She emanated confidence and helped me feel I had a partner who could help me navigate the future. The most compelling thing she said to me, which changed my outlook was “I am confident in future treatments for FSHD. I will consider my career a failure if we do not find a treatment or cure.” In a sense, she played the role of a blocker, helping a runner to run through the hole (Schein, 2009, pp. 6-7). Using this

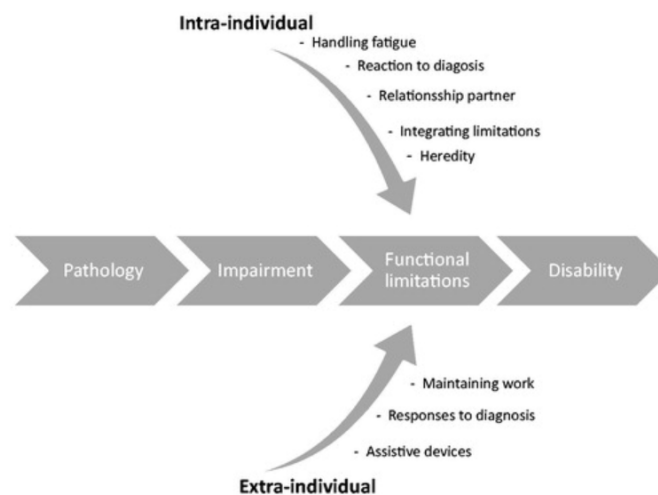
metaphor in which I am the runner, she knocked out some of the blocks I had, which prevented me from running ahead. She showed me how the understanding of the disease had evolved and about potential treatments on the horizon. She also showed me I could be doing something about it, such as eating smaller and more frequent meals, avoiding certain exercises, and doing different stretches she showed me that could help. Most importantly, she removed the main block in my way, which was an idea. She shattered the idea I had that no one knew about the disease and therefore there was nothing I could do to help, or hurt, my situation. My old self-image and outlook were beginning to die as a new one emerged, but I wasn't there yet.

After the meeting an artifact of just how far I had to go presented itself. The next week during my emerging leaders program, I had to do a 5-minute presentation on myself. I had to compose one slide with images that summarized who I was. In what should be an easy task, I spent hours debating what I should depict about my life. It fully illustrated how conflicted I was about my identity and made me reflect on my external reality. I was a member of a group of pharmaceutical representatives, which at the time was quite homogenous and consisted of former athletes, notoriously attractive individuals, and those obsessed with health.

The 2010 movie *Love & Other Drugs*, featuring Jake Gyllenhaal, Anne Hathaway, and Gabriel Macht, was popular at the exact time I was in the industry. This movie played up the stereotype of the handsome-physically-flawless pharmaceutical salesperson; it reflected the perceived culture and in-group of the industry. In-group is the idea in social psychology that people identify with groups they see themselves as being a part of. Furthermore, individuals are biased toward those who they identify with as being

a part of their in-group versus being an out-group. In a study by Molennbergs et al. (2013), participants judged hand actions performed by in-group members as being faster than those of out-group members, even when the two actions were performed at physically identical speeds. My group of pharmaceuticals representatives is a group I once felt cemented in, but with my recent doctor's appointment and newly developing physical challenges, I felt torn. I was disabled but not disabled enough. I was caught in between two ways of living and two identities. This experience is similar to what others with FSHD describe as effects of the disease, including many components that go along with how one feels (Figure 3).

Figure 3. Overview of Intra- and Extra-Individual Factors (Bakker, 2017, p. 981)



As noted by Bakker et al. (2017), not much is known about the experience of how patients experience FSHD. There isn't a playbook for how to deal with the disease. In their clinical study participants pointed out a more social aspect of the disease. People with FSHD felt others would address them differently when using assistive devices such

as a wheelchair or scooter. Being in the external environment where I was, I felt torn as to how others would see me if I were to reveal I was different from them. The clinical study made me feel I wasn't alone in feeling this way. Although I wasn't at the point of needing an assistive device, the idea of being seen as different or weak wasn't appetizing.

My MSOD program was in parallel to the emerging leaders program. We were studying employee engagement and levers to pull as a leader. Rock's work with the SCARF model resonated with me on many levels. It was related to neuroscience and boiled down a complex topic into something understandable. An away response or toward response is generated when either status, certainty, autonomy, relatedness or fairness were affected positively or negatively (Rock, 3). When I read about relatedness and the idea of evaluating whether someone was in tribe or out of tribe, friend or foe, it made me think about my relationship towards others. It made me contemplate whether I should reveal out of group traits, related to FSHD.

I found the SCARF model—the acronym stands for Status, Certainty, Autonomy, Relatedness, and Fairness—as a useful tool for self-reflection. I found myself often reflecting on FSHD and my reluctance to confront the fear it caused in my life. The five domains of SCARF provided some answers and rationalizations. I was scared that letting go of the status I had accumulated from being an athlete as part of the in-group. I was experiencing uncertainty on a daily basis in the form of a disease with an unknown progression. The burden of dealing with this disease on a daily basis led me toward denial which is a self-protection mechanism from the pain of change (Schwartz, 2006). When thinking about autonomy, I didn't have the power to control the disease and the symptoms that would present. However, I did have the ability to control my outlook.

With regard to relatedness, I had a rare disease and didn't know anyone else with the same experience. Regarding fairness, I felt wronged by the universe regularly due to the disease. I realized my threat response was being triggered constantly and that my way to cope was to flee, ignore, deny, or change the focus to something controllable.

When I completed the one-slide assignment for the emerging leaders program, I kept it at a high level. I didn't reveal my identity to preserve a place with the in-group. I wasn't ready to take the leap and reveal any kind of diversity or element. I didn't want to reveal any weakness, whether figuratively or literally physical. I presented the slide and discussed my love of sushi, Liverpool Football Club, some scholastic achievements, and my passion for the intersection between science and business. It was a solid façade that kept me in the in-crowd. It never occurred to me that revealing my diagnosis, its challenges, and how I overcome them could be my biggest strength and inspire others.

CHAPTER 8

LEARNING TO BE VULNERABLE

I completed the emerging leaders program at my company and thought I was ready to take on more responsibility and lead others. I was an ambitious 20-something who was channeling nervous energy into ambition. I had plans to climb the corporate ladder as quickly as possible. As customary with the emerging leaders program's traditions, I received my feedback from the program's completion in the form of a scorecard. The scorecard rated each participant on a number of parameters. We were constantly observed by group leaders who recorded how we acted, how we conducted work in groups, solved problems, and presented arguments on case studies. Minute details about our performances were captured and rolled into the scorecard with specific details. It was intense while I was in the program but the feedback was super valuable. One important metric—what all the feedback rolled up into—was the metric that everyone cared about and really the only one that mattered from a professional standpoint: Not Ready, Ready Soon, Ready Now.

This metric is what determined one's career progression and the speed of rise up the ladder after the emerging leaders program. It was harsh or jubilant to experience that metric as an individual, but for the corporation it crystalized who was ready to fill key vacancies. Underneath the metric was feedback that substantiated the ruling. Waiting to receive the feedback brought me back to my childhood when I was riding the bus home and waiting for the mail in anticipation of the letter from the Olympic Development Program to see if I had made the soccer team.

When I opened the email, I held my breath. I clicked on the attachment and the scorecard within, which read: “Ready Soon.” It was not the metric I was expecting or had hoped for. I closed the attachment and reopened it, thinking it must have been a mistake. When I reopened it, the result was the same: “Ready Soon.” Disgusted, I dug into the details and critical feedback, directly skipping over the positives in search of some sort of justification for the metric. Two areas of critical feedback prevented me from being “Ready Now.” I felt threatened and disengaged immediately, which led me toward reflection. Like Rock’s (2012) dimensions outlined, I felt the feedback wasn’t fair and immediately discredited it.

The first area of feedback was on my platform skills. While we gave presentations our eye contact, posture, tone, and ability to create clear and concise messaging were judged. During the training in the program they discussed at length the power of posture, hand gestures, and eye contact. They talked about having your hands in the ready position and never putting your hands in your pockets because it made the presenter appear as if they were hiding something. I always thought it was ridiculous, especially in studying chief executive officers (CEOs) and executives when they give their keynote addresses. Many of these CEOs and experts routinely put their hands in their pockets or had their hands relaxed by their sides. As hard as I tried, I physically could not keep my hands in the “ready position” due to having weak biceps. I tried as hard as I could but the longest I could sustain the ready position was 45 seconds; by 30 seconds into that time frame I was struggling to focus on the content I actually had to present. It was one of the first times my disability had manifested itself and caused me to be unable to do something physically. The problem was my organization had no idea about my physical struggles;

they just thought I could not be coached or would not listen to their directions. I was not ready and didn't have the tools to reveal why I couldn't put my hands in the ready position.

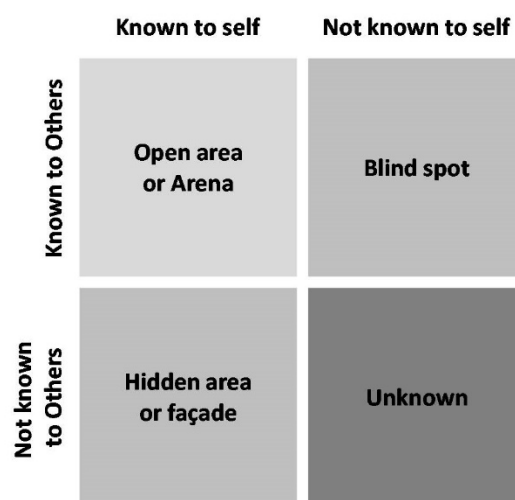
The second piece of critical feedback was about how I seemed withdrawn or disengaged during a few team building events. During the program we had typical corporate team building activities. In one event we collectively had to take a long pipe and physically put it on the ground. The trick was every team member needed to be touching the pipe as the pipe hit the ground at the same time. The event required physical movements I just could not do. It required crouching, and keeping one's biceps flexed and steady in a fixed position. When the instructor read the instructions of the game, everyone was so excited as they were strategizing whereas I was filled with anxiety. My mind was filled with how I could politely withdraw from the event without revealing my physical limitations. I was afraid of being the weak link in the group that would stop the group from being able to complete the assigned task. I thought about revealing my traits to the moderator but was concerned it would awkwardly stop the game everyone was so excited about. Moreover, I didn't want people who were physically able to feel awkward around me or feel guilty or sympathetic toward me. Again, I felt trapped and didn't have the solution. I quietly told my team I wasn't feeling good and left the room for the duration of the activity.

I harbored no ill feelings toward the program for making parts of the program less accessible. In hindsight, perhaps the program's instructional designer should have taken into consideration that some individuals have hidden disabilities or physical challenges. However, I never revealed my challenges or limitations so the program couldn't be

augmented. I did feel an overall sense of sadness driven by thoughts of how unfair the situation was. When I thought critically about the feedback, I thought about how my career was being impacted by not revealing my physical limitations. I was erecting a façade—and erecting it poorly. Those two pieces of critical feedback were directly attributable to my disease symptoms. I told myself, “You would have been Ready Now if it wasn’t for this disease. This is complete bullshit and not fair.” The lack of fairness and sadness turned into anger. Gradually, the anger subsided but not completely.

Fortuitously, I learned about Lufts (2009) construct called The Johari Window Model a week after receiving the feedback, which included a graphic representation of how to examine our own behavior in relation to others (Lufts, 2009, p. 1). The model (Figure 4) depicts four equal quadrants comparing what is known and unknown to oneself and others. I immediately focused on the third quadrant, depicting my avoided or hidden area, and realized how small my first quadrant, depicting my open area, was because of what I was concealing.

Figure 4. The Johari Window Model (Lufts, 2009, p. 1)

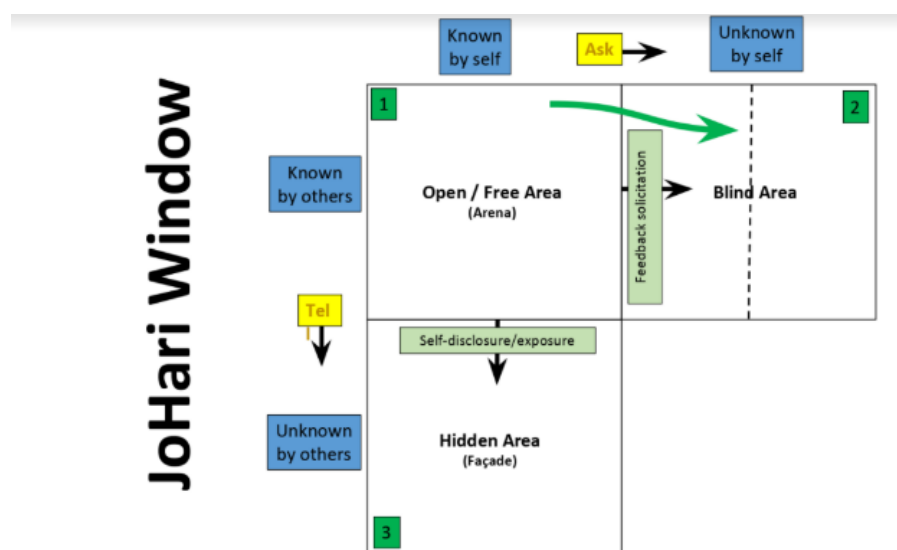


The Johari Window Model

Figure 5 was closely aligned to my current state, and the description by Lufts (2009) revealed what clear actions could be taken to increase the size of one's open quadrant. The answer was simple: Self-disclosure creates commonality between people. I hadn't thought about self-disclosure in this way before. I thought about how perhaps by revealing something about one's self, the other person who is receiving that information can feel more connected and more comfortable sharing something about themselves.

I also highlighted a sentence that resonated with my experience in the emerging leaders program: "It takes energy to hide or deny behavior which is involved in interaction" (Lufts, 2009, p. 4). I reflected on this statement and about how much energy I spent trying to keep my disease hidden to remain in the in-group at work. I reflected on conversations from my MSOD coaching class and the GROW model questions to ask a person when trying to overcome a barrier. I rhetorically asked myself: "Imagine a life in which you don't have to conceal your disease. What would that look like?" I immediately felt a sense of relief. But I also felt an uneasiness about the reactions I would receive.

Figure 5. Increasing Openness and Lowering the Façade



Note: Source: Dr. Charline Russo.

After a month of contemplation I hadn't taken any steps toward expanding my hidden quadrant at work. However, I committed to being more open about my life while taking steps to talk to my close personal friends about my disease. My wife was my biggest supporter and driving force behind being more open. Her encouragement, love, and positive force propelled me forward. I had never found a reason to talk openly about my diagnosis in the past. One night around a fire pit with a few of my closest friends I opened up and started telling them about my situation. My friends unanimously said they were so glad I had confided in them. They mentioned how they didn't want to ask me about it but noticed I had recently had difficulty going up some stairs. My best friend in the group mentioned how it was really brave to open up to them. He then said these words that stuck with me: "You should never feel a sense of shame or fear being different. Your story is inspirational and what you have achieved is super impressive. When you factor in the disease as an obstacle, what you have done is remarkable." When I got home that night, he followed up with this text: "Your ability to be strong in the face of not knowing what will happen with your disease symptoms is amazing. You inspire me. Love you, buddy."

This text message and the support I felt from my friends sitting around the fire pit that night brought many tears when I got home from the gathering. Behind that emotion was an immense sense of relief. I was so happy I was able to share my story. It was a surreal experience to actually verbalize what I was going through. To feel the words leave my mouth and to see the faces of those the words landed on also generated an immense sense of acceptance. Their reactions were so positive and supportive, and I left the conversation feeling a deeper connection to my friends. I received feedback from

their verbal and nonverbal communication that was warm and made me feel as if was okay to share with others at an appropriate time.

I didn't realize it in the moment but how I received their feedback about my self-exposure gave me important data, which is consistent with theories from The Johari Window Model that states every response—verbal and nonverbal—provides data about the you who you allow yourself to be with others (Lufts & Ingham, 2009, p. 3). My friends' acceptance and genuine responses in receiving the information I shared left such a positive impression on me that it gave me the courage to share more. I realized to take the next steps toward being more vulnerable and authentic, I would need to share about my struggle with the disease to my colleagues at work.

Brené Brown's TED Talk (2011) on vulnerability summarized well how I was feeling at the time. She mentioned how as human beings we are in constant search of connectedness. Shame is the fear of disconnection. She asked the rhetorical question, "Is there something about me that if other people know it or see it, that I won't be worthy of connection?" This wording was exactly how I was feeling and the same question I was asking. However, as Brown said in her talk, "In order for connection to happen we need to be seen (TED, 2012)." My friend's encouragement helped me experience what it was like to reveal and be seen.

My wife's support was elemental in the progress I made toward becoming vulnerable. I realized some of my symptoms were no longer hidden as they were before, and that others began noticing subtle changes in how I was moving. My sales partner noticed I had trouble reaching a low shelf in a doctor's sample closet. My boss noticed how, when presenting data, it was more comfortable for me to hold the sales aid in my

left hand. Each person asked me if everything was okay, to which I promptly shut down their inquiries with a short one-word answer: “Yes.”

My wife bought me a book by Sandberg and Grant (2017) entitled *Option B: Facing Adversity, Building Resilience, and Finding Joy*, a book that was literally perfect and timely for what I was going through. The book details Sandberg’s struggle to deal with the unexpected death of her husband. It was one of those books where you can laugh and cry within the same sentence. When I read it, I felt understood. One chapter called “Kicking the Elephant out of the Room” particularly resonated with me in which she discussed the struggle that people experience in having intimate conversations and addressing topics that are sensitive or have the potential to elicit strong emotions (Sandberg & Grant, 2017, p. 31). She identified “non-question asking friends” and those referred to as “openers,” noting the non-question asking friends made her feel isolated and lonely. For me, a “non-question asking friend” had been ideal because I wasn’t ready to be vulnerable. Sheryl Sandberg wrote:

Openers are not always our closest friends. They are people who ask a lot of questions and listen to answers without judging. These individuals can make a big difference in times of crisis, especially for those who are normally reticent. (Sandberg & Grant, 2017, p. 34)

One day my sales partner and I were waiting for what seemed like hours for a doctor to come and talk to us about our product. She asked me, “How are you?” “Fine, why do you ask?” I said, as I could sense there was more behind the question. She then said, “No, really. How are you? I’ve noticed carrying your sales bag looks a little harder.” I was a bit shocked she thought it looked like I was struggling to carry my sales bag and hadn’t realized the symptom had presented itself as visible to others. My sales partner was a true “opener” in every sense of the word. She built deep relationships with so many

people because she wasn't scared of intimate conversations and she asked questions without abandon. It's what made her so successful, too. I knew I couldn't dodge her questions. She was like Barbara Walters in her prime. In my head I said to myself, "Here we go." I told her my whole story in a way I hadn't told many others. She was completely judgment free and disclosed some important things about herself as well. I left the conversation feeling refreshed and had a deeper relationship with her as a result. It was another piece of information that helped me understand it was ok to share my story.

In the same chapter of *Option B*, the authors discussed how Sandberg didn't know how to remove the elephant in the room but felt it was impeding her relationships with work colleagues and personal friends. She stated:

I finally figured out that since the elephant was following me around, I could take the first step in acknowledging its existence. At work, I told my closest work colleagues that they could ask me questions and they could talk about how they felt too. (Sandberg & Grant, 2017, p. 40)

Later in the chapter the authors detailed how Sandberg posted her feelings on Facebook and received an outpouring of support, drawing from relationships she had felt distanced from back in. She also revealed that after sharing some colleagues confessed they were petrified in her presence for fear they would say the wrong thing. This chapter was arguably one of the most important chapters for me personally because it provided a case study on how to address the elephant and move toward being more open and vulnerable. It laid out a playbook for addressing the situation and provided evidence on what could be expected as possible reactions from individuals on the receiving end. It gave me the courage to proactively tell my story and convinced me everything could be better by revealing my hidden story at work.

Following Sandberg's playbook, I started to reveal my story and my struggles with FSHD to my close friends at work and to my manager. Each time I shared, the more concise my story became, and the more data I received about how my story was landing on others. I also learned more about my colleagues and built deeper connections with them. I realized most of the time by revealing my story I received a piece of their story in return. This response helped me build deeper relationships and deeper connections with my colleagues. By giving a piece of myself, I got pieces of others' stories. I also had an epiphany like Sandberg noted: I was the "non-question asking friend" because I was projecting how I liked to be treated. I wanted to keep relationships at the surface level at work. I would have rather talked about the weather with others than possibly stir up someone's raw emotions by asking them how they really were holding up after their divorce. When I read how this had landed with Sandberg, I immediately thought, "Uh-oh. Some people are probably super pissed at me and think I'm so self-absorbed that I didn't care to ask them how they were doing." The truth was I was mortified in asking a question that would make others uncomfortable. This behavior was something I knew I had to change right away; I needed to implement a change if I wanted to grow as an individual and especially in my career.

CHAPTER 9

BECOMING AN AUTHENTIC LEADER

Followers choose to be led by humans, not titles, credentials or manufactured management clones. Identify and deploy your personal differences, foibles and strengths to remind people you're human—and to inspire them to apply their energy and talents to help you. (Goffee & Jones, 2012, p. 1)

A year and a half after completing the emerging leaders program at work in which I received the “Ready Soon” metric, an opportunity presented itself. A sales leader received a promotion so there was a vacancy to backfill his spot. I was eager to throw my hat in the ring for the position. I had demonstrated success in my current role and worked hard on the feedback I had received from the program. Most importantly, I reduced my hidden areas and became open about sharing my story with others who asked and those I was close with. I hadn't taken the next step and shared my story with the world, as Sandberg (2017) had done, but I was moving in that direction.

After posting for the job on the internal jobs board, I received a call directly from the hiring manager. The intent of the call was to explore my interest in the position. The call was unplanned, and the first question was: “Why did you join the industry, and where do you see your career going at the company?” This question had always stumped me in the past; my answer had always been: “I really enjoy the intersection of business and science.” It sounded like a robot fed me the answer directly from its soulless hardware. I realized it also came off as guarded, which is exactly what I was. However, during this call I took a risk. I revealed exactly why I had gotten into the industry and why I knew from such a young age I wanted to become a leader in the pharmaceutical world. I responded the hiring manager with these words:

In the past, I would have given you a really guarded answer, but I am going to take a risk in revealing something personal. I hope that this lands with you well and that it's not too much information. However, my purpose for leadership is tied directly to my personal story. I had a life changing diagnosis at age 15. A doctor told me I had a rare disease and that there were no treatments, no cures and they weren't sure of where the prognosis would take me. My goal is to be a leader in an industry that solves these diseases.

The hiring manager loved my answer and thanked me for sharing the information with him. He mentioned how purpose was a powerful driver; it was something he looked for in leaders within his organization. Again, this was another data point I collected on how others reacted toward my story. It was a true inflection point in my confidence, and I felt more comfortable sharing with those I didn't know well. It felt great to reveal the real reason behind why I wanted to work within the industry, and I felt ready to lead other people. When the interview process ended, I got the job! My role was to lead a team of nine sales professionals as a district sales leader.

It was my first time being responsible for working through others. I had been in lateral leadership type roles previously, but this was the first time I had the opportunity to directly create culture. I was firmly entrenched in the MSOD program and spent so much time discussing culture, creating it, changing it, and damaging it. It was time for me to begin applying theory, and I was super excited.

The first authors I leaned on were Goffee and Jones. Their work on authenticity and how to get others to follow was critical. "Know and show yourself-enough" was a key principle in their formula for authenticity (Goffee & Jones, 2012, p. 2). Building on the idea further including following the authors' instructions to show others your story and the values you possess, including your strengths and weaknesses. After receiving the previous feedback from the emerging leaders program, I focused on building the muscle

that would allow me to let others know me. However, addressing a small group about my disease, my story, and my purpose for leadership was something I had not done before in a work setting.

I was determined to let my new employees know who I really was. I wanted them to feel as if they could be open with me. I also wanted to get to know them at a deeper level because I fully believed it was a critical success factor. I set up an introductory team meeting and gave everyone a task. The email I sent to the team asked them to come prepared with one slide. “Share what makes you tick,” I wrote. I had about a week to prepare for the meeting and what would be the first time I would address the group on my expectations. But more importantly, I wanted to share my authentic self with them.

I was feeling confident. But once I started to put the slide together, I had doubts about if I was oversharing or sharing too soon. After a few sleepless nights I decided to practice my story out loud in front of a mirror. It was raw, unpolished, and emotional. However, I kept refining it. Watching myself in the mirror deliver the words of my story, my truth, was therapeutic. After a few iterations and edits I felt as if I could do it. I removed a few parts that were a bit too emotional for me to share. As Goffee and Jones (2012) noted, you should let employees see enough of you yet keep some mystery as a leader, which keeps you interesting (p. 1). During the night before my first team meeting I didn't sleep great. I thought about the reactions or questions I might get. What if someone asks me a question that is too emotional for me to answer? What if I cry?

The next day I strategically presented my slide last. As I suspected, each person kept their slides pretty high level and light, revealing surface level pieces of information about themselves. I learned about people's families, their pets, their favorite vacations,

and some fun facts. I didn't want to present my story—a rather heavy story—and then have others feel pressured to reveal more deeply than they were prepared for. Two people on my team went a bit deeper than surface level artifacts about their lives. One person revealed a cancer diagnosis of a loved one, which gave them their motivation for their job every day. Another person mentioned their child had special needs so their motivation for working so hard revolved around providing the best possible care for their child. When it was my turn to present, I took a deep breath and let it fly.

It was an out of body experience. To this day I can remember the faces looking back at me from around the circular table where we sat. I saw looks of genuine surprise, I saw tears in a few eyes, and I saw someone who looked a bit uncomfortable. When it was over, I felt an adrenaline rush of relief. I also felt weightless, as if I was ready for anything that would be thrown my way. It was a powerful, freeing feeling. The microexpressions of my team were most likely a microcosm of what I could expect from a larger audience, and I felt good about that. I made sure to let my team know they could ask me any questions and that I would attempt to be as open as possible. I also let them know I hoped they would share their stories with me if they felt comfortable. In the moment after I shared my story with my new team, I felt as though I was firmly through the neutral zone and embarking on what Bridges referred to as a new beginning (Bridges, 2009, p. 5).

CHAPTER 10

THE IMPORTANCE OF INCLUSION SAFETY

“Social belonging is a fundamental human need, hardwired into our DNA. And yet, 40% of people say that they feel isolated at work” (Carr et al., 2019. p. 1)

After a little over a year and a half in my role as a sales leader, I applied for a sales training role within my organization. I was successful in getting the role and immediately confided in my manager that I had FSHD. When joining any new group, people generally have a smaller open quadrant within The Johari Window Model (Lofts, 2009, p. 1). I had grown comfortable within my new identity and wanted to make sure I was up front with my manager. The job was going to require new tasks that I anticipated may cause some physical challenges. I really wanted to make sure we had an open relationship and that I squashed any anxiety that came with my inability to complete certain job tasks. I proactively told my manager it was okay to ask me questions.

A few developments had happened in previous years within our company that led me to feel safe enough to reveal information about myself without fear of being treated differently. Our company initiated an aggressive inclusion and diversity initiative that originated from the office of the CEO. Town hall events were held with a sole focus on inclusion and diversity. Speakers from employee resource groups had booths where employees could interact. Topics that were uncomfortable or rarely spoken about at the time, such as race relations and reactions to police brutality, were openly talked about. It showed a large effort and emphasis on bringing diverse thoughts and perspectives to the office. It also created an organizational climate in which it felt cool to be different.

Schein (2010) talks about how climate can be thought of as a product of underlying assumptions and is therefore a manifestation of the culture (p. 24). This initiative didn't just feel different; there were actions behind the words. Using the skills I had learned in the MSOD program for diagnosing organizational culture, I looked for artifacts and tried to connect them to underlying assumptions as a proof source that the culture was moving toward truly embodying inclusion and diversity. I also realized the notion of what the company says and what it actually does or truly believes can be the opposite. Schein noted that through research it was observed some organizations have a disconnect; espoused values reflect the desired behavior but are not reflected in observed behavior (Schein, 2010, p. 24).

The town halls were actions within themselves, backing up the talk of inclusion and diversity and bringing it to the forefront. The most important fact that led me to conclude the organization was serious about the initiative came from senior leadership. Leaders of different color, creed, gender, and sexual orientation were promoted to senior leader positions within the organization, and they spoke openly about their personal experiences and how they experienced the challenges and opportunities that came with being different. All this data was enough evidence for me to have a sense of inclusion safety, which allows us to gain membership within a social unit and interact with its members without fear of rejection, embarrassment, or punishment, while boosting confidence, resilience, and independence (Clark, n.d., p. 4). Essentially, the barriers to entry at the organization had been knocked down, and it felt as if the pressure to conform to the homogenous culture of the past was dead.

Once I got settled into my role, I realized inclusion and diversity initiatives had permeated through the organization. My manager brought our small leadership to an offsite session focused on team building but centered on inclusion. He asked me to talk to my peers at length about my story and how I experienced having physical limitations. He also asked my other colleagues who had equally diverse experiences to share their stories. We sat around a table for 3 hours, sharing our experiences. We laughed, cried, and bonded on a level I had never experienced. Our performance as a team after that day was incredible. We would have all run through walls to help our fellow teammates, and we collectively felt like we could be ourselves.

The support and friendships that were forged propelled me to feel comfortable sharing my story in front of large audiences routinely. I led the on-boarding program for the U.S. sales force and was the first face that new hires saw when they walked through the door. My manager encouraged me to think of a way I could embed inclusion and diversity into the culture from the moment a new hire stepped on campus. When I read Gino and Cable's (2020) article entitled "Coaching Your Team Through Uncertain Times," I realized how exceptional my boss was. This article points out a best practice is to encourage employees to reflect on opportunities to recraft their jobs. Moreover, they should help employees discover their own purpose (Gino & Cable, 2020, pp. 2-3). My boss helped me shape a role with significant white space to achieve both of these goals. He helped show me how my story was my purpose. He coached me to see a perfect forum to connect the dots in my role as I was leading new hire training.

With my boss's support and guidance, I developed my story to have the maximum impact on those who heard it. The results were life-changing. I felt completely

free but the reactions I received from others touched me the most. On one occasion after I gave my talk, a new hire approached me on a break and was visibly teary-eyed. He told me he was secretly battling a new diagnosis of a chronic illness. He had no idea how to talk about it to others, but that my talk was so inspirational he planned to discuss it with his manager. I also received a few different emails noting my talk helped give others a new perspective on dealing with ambiguity or problems they were facing. Survey feedback consistently indicated my talk was the highlight of the on-boarding program. My manager told me about the positive praise he received on how my talk left a positive first impression on our diversity and inclusion initiatives within the organization.

When I reflected on the growth I had experienced in such a short period working for this particular manager, I couldn't believe the progress I had made—both personally and as a leader. I read and reflected on Rooke and Torbert's (2005) seven action logics and characteristics (p. 8; Figure 6). My manager was a strategist as defined by the action logics in that he explored vulnerability and mutual inquiry. He was consistently connecting dots in the organization and routinely modeling how vulnerability could translate into business results. I absorbed his teachings like a sponge and fed off his direction and example. He recognized the power in my story and helped develop me, as well as my story, to have an impact on larger organizational goals. From a coaching perspective, he was modeling the way, which was just what I needed.

I felt the inclusion safety allowed me to develop at a rate I had never experienced. I felt an overwhelming amount of support and became comfortable in being myself. My colleagues asked me how I was doing and routinely offered to help me with things they saw me struggle with.

Figure 6: Seven Ways of Leading (Rooke & Torbert, 2005)

Action Logic	Characteristics	Strengths	% of research sample profiling at this action logic
Opportunist	<i>Wins any way possible.</i> Self-oriented; manipulative; "might makes right."	Good in emergencies and in sales opportunities.	5%
Diplomat	<i>Avoids overt conflict.</i> Wants to belong; obeys group norms; rarely rocks the boat.	Good as supportive glue within an office; helps bring people together.	12%
Expert	<i>Rules by logic and expertise.</i> Seeks rational efficiency.	Good as an individual contributor.	38%
Achiever	<i>Meets strategic goals.</i> Effectively achieves goals through teams; juggles managerial duties and market demands.	Well suited to managerial roles; action and goal oriented.	30%
Individualist	<i>Interweaves competing personal and company action logics.</i> Creates unique structures to resolve gaps between strategy and performance.	Effective in venture and consulting roles.	10%
Strategist	<i>Generates organizational and personal transformations.</i> Exercises the power of mutual inquiry, vigilance, and vulnerability for both the short and long term.	Effective as a transformational leader.	4%
Alchemist	<i>Generates social transformations.</i> Integrates material, spiritual, and societal transformation.	Good at leading society-wide transformations.	1%

I had no idea the story I told would be inspirational to others. It led me to the realization that sometimes you just need to throw fear aside and jump. When I survived the first jump, the subsequent moves became easier. When I embraced my identity and threw fear aside, I became whole.

CHAPTER 11

FINAL THOUGHTS

The Power of Reflection

Although I found a new beginning and accepted and embraced a new identity, I am not close to being a finished product. I am in transition without a cure, both literally and figuratively. Like a squiggly line, I am navigating and making sense of life's journey one day at a time. FSHD will inevitably provide new changes and challenges for me at different points in my life. Change can be incremental, similar to the progression of my disease, or it can be transformational like a lifequake. This is true for organizations or individuals. I will need to continue to build resilience to face the difficult moments of life, which I am sure to encounter.

After spending over a decade in the MSOD program, I have discovered the central key to navigating and deriving meaning from life and its direction is reflection. The power of journaling, reflecting, and interpreting meaning is a key to success. I have experienced this firsthand; this capstone outlines how powerful taking a pause and reflecting can be.

This insight has also been demonstrated in literature by Mezirow (1991), who considered critical reflection to be the distinguishing characteristic of adult learning and saw it as the vehicle by which one questions the validity of his worldview. For Mezirow, transformative learning can be viewed as “an enhanced level of awareness of the context of one's beliefs and feelings, a critique of one's assumptions, and particularly premises,

and an assessment of alternative perspectives” (Mezirow, 1991, p.161). It is this level of self-reflection that can lead to significant self-transformation.

I continually seek feedback from others and reflect on how I am showing up both personally and professionally. Throughout my journey in the MSOD program and professionally at a few corporations, I have come across a number of key quotes or soundbites that have had a significant on my development. One leader used a metaphor of a boat’s wake to understand the impact an individual is having on those around them. The leader said:

Seek to understand the wake you are leaving behind and how people are experiencing it. Are you causing disruption and making huge waves, whether for good or bad? Or are you gliding past with little disruption? Different situations may require a bigger or smaller wake.

This metaphor continues to speak to me and is my focus when reflecting. It is relevant both professionally and personally as a parent. Understanding the wake, I am leaving a critical piece of feedback to reflect on.

A Healthy Relationship With Positivity to Build Resilience

As I outlined in this capstone, I have struggled throughout my life with the concept that positivity isn’t permanent. Fredrickson’s (2009) book entitled *Positivity* really helped me to make sense of a healthy relationship with positivity when she wrote these words: “Positivity isn’t permanent. If it was you would have a hard time reacting to change” (p. 32). Perhaps in my life positivity acted as a shield, protecting me from acknowledging painful change.

In a quest for permanent positivity, I refused to acknowledge or accept the negatives. As Fredrickson (2009) points out, “To experience 100 percent positivity defies and denies the humanness of life. It would mean that you buried your head in the sand (p.

32).” This insight spoke to me. After burying my head in the sand for so long, it’s my commitment to shoot for the 3/1 ratio that that author suggests, not a 3/0. I need to acknowledge the pains of change and then pivot back to focusing on the positives, which is a strength of mine.

Positivity also helped me realize I need to soak up the positive moments to build resilience in preparation for the bad days. It also provoked me to look deeper into the research on positivity. A moment playing with my kids at the pool, a nice meal outside with my wife, and words of affirmation from my loved ones combat the days when FSHD rears its ugly head and prevents me from doing something I used to be able to do.

Positivity broadens and builds. The take-home message is that positive emotions are worth cultivating, not just as end states in themselves but also as a means in achieving psychological growth and improved well-being over time. (Fredrickson, 2001, p. 218). The research is quite astounding. As noted by Cohn et al. (2009), “Change in resilience mediated the relation between positive emotions and increased life satisfaction, suggesting that happy people become more satisfied not simply because they feel better but because they develop resources for living well” (p. 368).

An important finding in the current research is that positive emotions contribute to the ability for resilient individuals to physiologically recover from negative emotional arousal. This finding may be especially important in examining the health-promoting qualities associated with positive emotions (Tugade & Fredrickson, 2004, p. 331). These important findings provide the proof I need to build on positivity to have an impact on the inevitable downside of living with a chronic disease.

Life Is One Big Cruyff Turn

Johan Cruyff is a Dutch footballing icon who created a philosophy called total football, which posits that all you need is the basics: good grass, clean changing rooms, players who clean their own boots, and tight nets; the rest can be taught or learned later (Cruyff, 2021, p. 297). Cruyff's philosophy is about making progress and looking backwards to learn from one's mistakes.

One of his iconic moves used by footballers across the world today is the Cruyff turn, which he learned on the streets of Amsterdam. The move involves a dip of the shoulder in one direction and flicking the ball behind in the opposite direction to pivot. The move is disorienting to the opposing defender and often leaves the defender baffled. Applying this metaphor, we are often the defender being dazzled by a sudden change in direction—victims of life's Cruyff turn. However, the metaphor works in the other direction, too. Sometimes the defender (or life) may have you trapped without great options. Players who are full of confidence and technical ability can execute the Cruyff turn to pivot out of trouble, creating an option with a little ingenuity and creativity. The message of this metaphor is to have hope and ambition when you feel there aren't great options in life. When facing adversity, remember there is always another way—one last pivot or Cruyff turn—left to play.

I am familiar with this metaphor as a former soccer player and student of the game. In my life I have been victim of life's Cruyff turn and also have used the same technique to pivot out of trouble. I feel as if I have been Cruyff turning many times over the last decade. As my FSHD symptoms have progressed, I have found new ways of doing things. It's taken a lot of soul searching and internal strength to not succumb to feeling trapped by life and in a body that is incapable of doing certain things. I also

haven't pivoted without the help of my wife, friends, and support network. To further the soccer metaphor, they have acted similar to the other 10 players on the field and the fans—all combined to support me in my quest to evade defenders.

My experience with this disease isn't all bad. There are moments of adversity on a daily basis I would have never faced had I not had the disease. Some of my greatest strengths have been developed over time through my experiences living in a changing body with changing capabilities. However, I am not the disease, and the disease is not me. It doesn't define me but sure has taught me some precious life lessons.

Grit and Leadership

I'm gritty, not the Philadelphia Flyer's mascot, but I have developed grit. I didn't choose the grit-life; the grit-life chose me. The major life lesson FSHD has taught me is that I have grit and continue to develop the trait. FSHD has forced me on countless occasions to literally get up when I fall down, wash the blood from my knees, bandage them, and get on with my day. Duckworth's (2018) book entitled *Grit* was a great reflection piece for me. She discovered that passion and perseverance were the key elements of grit; it predicted whether new cadets would complete the Beast at West Point (Duckworth, 2018, p. 10).

FSHD has given me both a purpose and perseverance. With respect to purpose, it has directed me toward a career in which I hope to help patients who have heard the same words I have heard: "You have a disease, there are no treatments or cures." It is this purpose that drives me, and I am so grateful to have this as my North Star. It has made me a purposeful leader and allowed me to connect with others authentically. The biggest

lessons FSHD has taught me so far is perseverance and finding new ways to get the same job done.

I have fallen down while training a new hire class at work. In front of 45 people, I tripped and fell over. It was a scene. I got up, had a laugh, and took the next 5 minutes to explain FSHD and my experience to a set of new hires who had never met me. I then completed the training as if nothing happened; yet under the surface I felt waves of emotion. I felt embarrassment, fear, and unease. But I got high scores from participants' feedback, and many people told me after the training how my fall, subsequent recovery, and explanation came across as brave. One person joked with me that it was a great icebreaker, suggesting I should consider doing that with other training classes, which caused us to both laugh. I wish this wasn't the only time something like this happened. I've picked myself up off airport floors, grocery store aisles, and neighborhood sidewalks. However, every time I get up and move forward.

This disease isn't just about falling down and getting up. It's about fighting mental fatigue, too. As I have progressed in my symptoms, I have to think ahead and plan ahead for basic things that people who are not disabled take for granted. A trip to a restaurant that has steep stairs, planning travel at a work trip so I can avoid getting on busses with high steps, planning a picnic near a bench so that I can get up off the ground easily require making adjustments and make me think ahead constantly.

These trials create a mindset, too. I can no longer blindly say yes to things or activities that are spontaneous in nature. I need to process each activity to make sure I am able to do what is required. However, these challenges make me a great person to bring to a brainstorming session because I have developed a muscle for thinking ahead and seeing

things that may not be obviously connected. It has helped me out tremendously as a leader. These challenges may sound grim to people without the challenges, but over time one adapts and can use such learning as a strength. I don't wear the falls or mental fatigue like a badge of honor or to brag; I communicate how such incidents bring color to the events that have shaped my ability to persevere. Just like denial used to permeate through my everyday life, now grit is involved in my day-to-day life.

I became a father to three children during the course of the MSOD program, which is also part of the reason why my tenure spanned a decade. I currently have three children under the age of five years old, and I wrote 25% of my capstone while holding my 2-week-old son. I am bragging about that. Ha ha! I wrote this capstone on my cell phone because it's easier to type on a cell phone than a computer since my right hand isn't super-efficient when using a computer keyboard and a cell phone allows me to type my thoughts with my thumbs. Without the grit I learned from facing the adversity of FSHD, I would not have completed this capstone. I would have inevitably found an excuse.

Becoming a parent during the MSOD program allowed me to practice many lessons learned and especially some coaching techniques with my kids, which is especially true of modeling the desired behavior. I am by no means a perfect parent. If another one other than my wife exists, please send him or her my way so I can learn. Being a parent has also taught me I have the ability to pass down the seedlings of grit to my children, just as a coach in the MSOD program can seed the thoughts of a coachee through proper questioning or modeling.

As I wrote this paper, I reflected on this concept. I thought critically about how I may be shaping my children. A tangible example of passing grit on to my kids came to light. Over time it has become hard for me to pick things up off the ground. As anyone who has young children knows, there are always Legos or a thousand small toys on the ground at all times. I have adapted to the challenge by picking things up off the ground with my toes so I don't have to bend all the way over and risk losing my balance. Most readers may probably be thinking, "just have the kids pick up the toys." Well, I've tried that. Send me your tactics or sorcery that works for you.

The other day my wife saw my two-and-a-half-year-old daughter trying to pick things up with her toes and asked her what she was doing. She replied, "Me doing this like Daddy." It was in that moment when I realized I am modeling perseverance for them, I am showing them the Cruyff turn in action, and I'm teaching them by example about how there is more than one way to accomplish a goal or task. This moment was a microcosm of what we show to our children and also those who we aspire to lead.

Conclusion

Although we may not always be aware of them, we are shaped by our frames of reference. Our individual journeys are driven by them. In Mezirow's (2003) transformative learning theory, we can discover how we can become aware of our prior assumptions. When we critically reflect upon our assumptions and develop our strategies and actions to transform these assumptions, we can liberate ourselves from our unclear or hazy frames of references and be free to create our own unique journeys.

I wrote this introspective capstone to provide hope for others who are chronically ill, who have a rare disease experience, or who are facing adversity in many forms. I also

wrote this paper for those who are afraid of revealing any weakness and for those obsessed with portraying perfection. People connect more with those who have weaknesses. As noted by Schawbel (2013), every superhero has a weakness.

I found introspection to be difficult and felt many emotions as I wrote it. It was quite cathartic for me. My story continues; I won't say it's a happy ending but a happy new beginning. When I started the MSOD program, no treatments existed for FSHD. I am happy to report many clinical trials are ongoing for FSHD, one of which I'm enrolled in. I have high hopes as the drug is fueling the numerator of my positivity ratio. If the trial is successful, I will undoubtedly go through another transition—perhaps even a transition *with a cure*. I close my eyes and imagine being able to do things I used to do, but I'm also living out a parallel dream, and I'm more than grateful.

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APPENDIX A

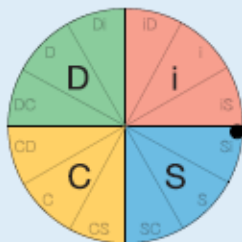
DiSC ASSESSMENT



YOUR DiSC® STYLE & DOT

Your Dot Tells a Story

Your DiSC Style Is: Si



Because you have an Si style, Chris, you're probably a friendly manager who reaches out to others with your warmth and sincerity. You tend to be empathic, and you're likely driven by a desire to like and be liked. You're quick to offer a smile, and you make an effort to get to know people personally.

You tend to be accepting and accommodating, often demonstrating great loyalty. While you're probably able to overlook people's personality quirks and weaknesses, you may have found that you can get yourself into trouble by trusting people who don't deserve it. Most likely, you enjoy meeting the needs of other people, without neglecting your own.

In addition, you're genuinely interested in what people have to say, and you may spend more time listening than speaking. Because you want to connect, you make it clear to others that their feelings are important to you. You may even file away important details about those you work with, such as birthdays or tidbits about their families. You tend to be tactful, and you choose your words carefully to avoid any miscommunication.

In terms of time management, you're probably flexible and willing to adapt your schedule to meet the needs of others. Because you appreciate a calm environment, you may be uncomfortable with rapid, unpredictable change. You probably assume that rules and traditions exist for a reason, but you may be known to run late or miss deadlines.

Most likely, you include the people you manage in the decision-making process. In fact, you may sometimes hesitate to move ahead with bold plans if you're unsure that everyone is on board. And because you're also willing to go with the flow, forceful or passionate colleagues may be able to convince you to support their more adventurous ideas. You likely put substantial trust in others and at times, you may allow your optimism to overshadow potential risks and obstacles.

Like other managers with the Si style, you seek the approval of others, and you're concerned about letting people down. As a result, you may strive to meet everyone's expectations, and you probably feel bad if you think someone is disappointed with you. At the same time, you want to know when you have done a good job, and while you probably don't seek out public recognition, you do appreciate genuine praise.

Also, you believe that well-orchestrated teamwork leads to superior results. Competitive situations aren't really your style, and you probably find it a bit hard to understand people who seem most interested in individual accomplishments.

Because of your need for harmony, you're unlikely to confront others in conflict situations, and you don't respond well to aggression. In fact, you may refuse to deal with negative information even when it's important to do so, and as a result, situations may drag on without resolution. Still, you often prefer the role of peacemaker, trying to find solutions that work for everyone.

Chris, like others with the Si style, your most valuable contributions as a manager may include your commitment to teamwork, your empathy, and your ability to connect with others. In fact, these are probably some of the qualities that others admire most about you.