POWERLESS PATIENT: RECLAIMING AGENCY

POWERLESS PATIENT: RECLAIMING AGENCY THROUGH PATIENT NARRATIVES

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LAY ABSTRACT

Patient narratives are a form of expressive writing that enables the patient to regain their sense of identity and agency following a health illness. When a person first becomes a patient, they leave their known world of familiarity and comfort and enter into a new one on their health journey. Their language and ways of communicating are required to adapt to the world of medicine. The patient loses their sense of identity and agency as a result of their illness. This thesis is presented in two parts, a critical essay and my brief patient memoir, and will explore how the patient, when engaging with patient narratives such as Susannah Cahalan's *Brain on Fire: My Month of Madness*, can reclaim their agency and sense of identity. The first part is an essay exploring the contributions of patient narratives. The second part is my memoir, exemplifying a patient narrative.

ABSTRACT

This thesis aims to rename the term 'illness narrative' to a more disclosive writing called the 'patient narrative' as a means to focus on the patient as a person who experiences illness, instead of the illness label. Exploring patient narratives, such as Susannah Cahalan's *Brain on Fire: My Month of Madness,* as a form of disclosive writing will highlight the need for this tool to act as a more personal and effective communication between patients, healthcare professionals, and caregivers. The thesis is presented in two parts: a critical essay and my patient narrative.

Part One is a critical essay that explores how engaging with patient narratives contributes to the patient reclaiming their agency and sense of identity. In three subsections, the essay highlights the difficulties patients go through with illnesses or rare medical events, as well as the emotional and physical impacts that they experience, going beyond medical symptoms. The essay focuses on three points separated into three sections. The sections are: Recognizing Pathologies and Injuries, Communication and Language in the Patient Experience, and Reclaiming Agency. Part Two is my autopathography centring on the complications encountered while seeking a common surgery. After general anaesthesia, I develop Postoperative Cognitive Changes of unknown aetiology. This greatly complicates the situation when surgery is needed, and the ensuing cognitive impairments have lasting impacts on me academically, personally, emotionally, and socially.

While both parts are distinct, together they mirror how patient narratives have the

potential to bridge the communication gap between medicine and humanities. As such, patient narratives can communicate connections between patients, medical communities, and a broader audience which acts to underscore the need of a deeper awareness for the importance of compassion and empathy for those experiencing any form of health challenge.

Keywords: Autopathography, patient narrative, illness narrative, patient experience, rare medical events, healthcare professionals, patient, caregiver, postoperative cognitive changes, postoperative cognitive dysfunction, communication, cognitive impairment

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Working on my thesis while recovering from Postoperative Cognitive Changes has had its challenges. Health is personal, and as such, so are my acknowledgements. This thesis would not have been possible without encouragement and support from so many people along my journey.

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Special appreciation goes to Kelly Aiello for her empowering encouragement of me to keep going. She helped me relearn to stay focused and find words; together we witnessed the power of neuroplasticity unfold in real time. To creative writing coaches at Firefly Creative Writing long before my academic pursuits began: Brittany Smith, Chris Fraser, and Sophia Apostol. To my mom, dad, siblings & in-laws, and friends: thank you for reminding me of forgotten words, and being part of my journey. To every healthcare professional out there: thank you for working in such a noble profession and striving to help patients when at their most vulnerable.

But mostly, I dedicate all the work I have put into this thesis and the thesis itself,

with so much more than gratitude, to Steve, Isabelle, and Christofer. Thank you for your love, advice, kindness, patience, encouragement, and laughter. Without you, I might still be struggling to pronounce the words from the same book I opened in May 2019 after my surgery. You three hold my heart.

"I am writing, I hope, for a dual audience – the medical community at large, particularly the coming generation of young physicians, which must obviously bear the final responsibility for determining the future of clinical practice; and for the general public – patients – who perhaps can use the stories in these pages to seek and obtain higher, more humane standards of care. They need it – and they deserve it."

- Dr. Herbert Ho Ping Kong,
The Art of Medicine: Healing and the Limits of Technology

TABLE OF CONTENTS

Acknowledgements v

Epigraph viii

Declaration Of Academic Achievement x

Part One: Reclaiming Agency Through Patient Narratives in Susannah Cahalan's "Brain on Fire: My Month of Madness" 1

Introduction 1

1.1 Recognizing Pathologies and Injuries 9

1.2 Communication and Language in the Patient Experience 21

1.3 Reclaiming Agency 34

CONCLUSION 44

BIBLIOGRAPHY 46

Part Two: Powerless Patient: A Memoir 51

Introduction 51

Bibliography 105

DECLARATION OF ACADEMIC ACHIEVEMENT

The following thesis is the result of my cumulative research concerning the relevance and impact of patient narratives, inspired by my personal health experiences. The critical essay component of the thesis and its major arguments are the result of original ideas and considerations of various forms of patient narratives, unless otherwise specified and cited. The thesis also includes ideas developed in discussion or from shared literature with my committee members: Professor Anne Savage, Professor Jeffery Donaldson, and Dr. Demetrios Sahlas.

In addition to those discussions, due to postoperative cognitive impairments which resulted in recovery throughout my M.A. career, I engaged the assistance from various professionals to help me return my cognitive functioning to a sharper academic focus. These meetings also contributed to developing ideas through discussions (aiding in word finding, retraining of analytical and logical thinking skills) with, but not limited to, healthcare professionals, writing coach Kelly Aiello, and my husband Steve Roy. The critical essay component of the thesis incorporates and engages with criticism from major theorists and authors, and credit has been given to those instances.

The patient narrative component of the thesis is written from memory, reconstructed from actual events based on journaling, medical consultations and records, and sixteens years of communications between myself, family, friends, and healthcare professionals who were part of my journey. Aside from my name and my family's, all other names, cities, hospitals, and other identifiers have been changed for privacy.

PART ONE: RECLAIMING AGENCY THROUGH PATIENT NARRATIVES IN SUSANNAH CAHALAN'S "BRAIN ON FIRE: MY MONTH OF MADNESS"

INTRODUCTION

> "The existence of forgetting has never been proved: we only know that some things do not come to our mind when we want them to." - Friedrich Nietzsche

As a person who experiences a rare medical event called Postoperative Cognitive Changes[1] (POCC[2]) of unknown aetiology, I am proactively protective of my perioperative brain health. Following two unrelated surgeries over the span of fourteen years, I experienced POCC with both operations resulting in a lengthy recovery period each time. My cognitive impairment symptomology ranges from difficulty with "processing detailed or complex information" and word-finding to "executive functioning challenges" (SLP report[3]). The cognitive improvements are gradual, however when cognitively overtaxed I develop cognitive fatigue which presents as a setback.

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[1] Postoperative Cognitive Dysfunction is a "cognitive dysfunction [occurring after] surgery and anesthesia [different from postoperative delirium]" (The Brain Clinic). POCD was initially associated with cardiac surgery patients, although evidence reveals this phenomenon also presents following other major surgery that is non-cardiac. Diagnosing POCD involves neuropsychological assessments prior to surgery and following in intervals for up to a year postoperatively. For patients who have not taken these assessments, despite the similarities with cognitive impairments, patients will receive a Postoperative Cognitive Changes label instead of the POCD.

[2] For the purpose of this thesis, POCC will refer to Postoperative Cognitive Changes, whereas POCD will refer to Postoperative Cognitive Dysfunction.

[3] To aid in my recovery after the second surgery in 2019, I engaged the help from a Speech Language Pathologist (SLP) specializing in traumatic brain injuries. Due to strict rules from my SLP's regulatory body, their name or identity will not be revealed. Additionally, any quotes or references made to the assessment executed by my SLP are part of my personal health record, and therefore will not be directly cited. Note: I do have permission from my SLP to include quotes related to the assessment and report in the thesis without citation due to the above mentioned privacy regulations.

In parallel to my POCC health journey, I was, at one point, the patient of a General Internist following an illness that developed after receiving a radiation treatment for cancer in 2008. My internist was Dr. Herbert Ho Ping Kong[4], who is also widely referred to as 'Dr. HPK' and considered to be Canada's 'Dr. House'[5] of Internal Medicine, but with a truly gentle bedside manner. His approach in medicine promotes and encourages a deeper consideration of the patient by "bringing empathy, intuition, out-of-the-box thinking and attention to the entire patient—mind and body—to the bedside or examination table" (HPK xxvi). Having been fortunate enough to be his patient, I witnessed and experienced the power he gifts patients through his holistic active listening, compassion, and empathy. He showed me how health and care, when combined, can create what healthcare is meant to be for patients and practitioners. During one of my final visits with him, he presented me a copy of his then recently published book entitled *The Art of Medicine: Healing and the Limits of Technology.* That work was the first of its kind I had read, introducing me to the term 'medical narrative.'

I would eventually learn that the term 'medical narrative' falls under the growing field of Medical Humanities, which engages "with the humanities and arts, social sciences, health policy, medical education, patient experience and the public at large" (BMJ). Wanting to know more about this hybrid field, I discovered Rita Charon, MD,

[4] Dr. Ho Ping Kong is commonly referred to as Dr. HPK; I will follow convention by referring to him as such throughout the thesis. For more, visit: https://tinyurl.com/2hduuwmz.

[5] Michael Posner's article "As brilliant as House. But nicer" in *The Globe and Mail* highlights Dr. HPK's generous knowledge-sharing with both practitioners, students, and patients. https://tinyurl.com/8xk9wx5e

PhD, the founder of the Narrative Medicine Program at Columbia University[6]. This program, in part, trains doctors how to engage with creative works, i.e. visual art, poetry, journaling, etc. The goal is to foster a higher sense of self-reflection which translates into other-reflection to provide a healthcare approach based on compassion, empathy, and active listening from the doctor. The common term that I most encountered in my readings from the Medical Humanities and Charon's Narrative Medicine Program was 'medical narrative.' This form of disclosive writing exposed me to new literature prompting me to explore further.

I attended a weekend-long virtual workshop called "Narrative Medicine & The Creative Impulse[7]" through Columbia University's Narrative Medicine Program which was headed by Charon and other faculty members. I entered the workshop (mis)understanding the terms 'medical narratives' and 'narrative medicine' to be any form of narration that includes health, because it was part of Medical Humanities. By the end of the weekend, my vocabulary expanded to include more terms. 'Medical narratives' are the accounts about a patient or an experience with a patient written from the perspective and interpretation of the healthcare professional. It was only during the final panel of that weekend that I learned about what I had come for: narratives written by patients. Throughout that weekend, I had repeatedly heard the term 'illness narrative' used by the

[6] To learn more about Columbia University's Narrative Medicine Program, visit: https://tinyurl.com/y23vdnsr.

[7] To learn more about the "Narrative Medicine & The Creative Impulse" workshop, visit: https://tinyurl.com/6p5879np.

faculty members. The more it was used, the more I understood that patient memoirs were included in this 'illness narrative' label.

It was during the final *Drop-In Faculty Q&A* panel[8] of the weekend, when one of the attendees, a doctor, asked Charon if the Narrative Medicine Program engaged with 'illness narratives' as a way for clinicians to better help their patients. Charon spoke to patients having spaces wherein they already engaged with each other, from in-person support groups to online chat forums. She spoke to the immense work that clinicians and other healthcare providers offer patients, from art projects in paediatric clinics to substance use disorder clinics. Having highlighted this wealth of information to the questioner and attendees, Charon further explained that the goal of the program is not to train doctors to become social workers or psychologists, nor do they want for their students to be expected to deliver therapy to a patient (Charon 25 Oct 2020). Her response stood out to me as I had been under the impression that 'medical narratives' and 'illness narratives' were studied in the program. As it turns out, only non-medical works are studied so as not to risk burning out both medical students and healthcare professionals alike.

This realization led me to consider the purpose of patient memoirs, rather 'patient narratives.' My thesis changed focus from 'medical narratives' to 'illness narratives' so that I could argue for the need to rename the latter term to 'patient narratives.' As a person medically identified as a comorbid patient, I found the term 'illness narrative' reducing as

[8] Charon, Rita, panelist. Panel discussion. "Narrative Medicine and Creative Impulse Virtual Workshop and Course," 25 Oct 2020, Columbia University, NY.

it focuses only on the illness, therefore my desire to rename the term. Additionally, following my patient experiences with POCC, I realized the importance of this form of expressive writing as a means to help patients heal and reclaim their agency following any form of illness, but particularly rare or uncommon illnesses and medical events.

To do this, I needed to argue how this would work while also cognitively recovering. I knew what the puzzle pieces of my thesis were, however I did not understand how to create the outline. It was too complex for my thinking[9]. Each piece seemed equally as important as the next. My SLP coached me to pace myself, and ways to not develop cognitive fatigue. I had sessions focusing "on the development and practice of strategies to support" (SLP report) my cognitive communication challenges and other tips, which worked well. Yet, I was unable to remember how to think logically. With support from the logical people in my life, through our discussions, I was able to take those puzzle pieces and relearn the significance of each component, and how to build the framework of my analysis. From there, the outline was born and I knew how to argue the relevance of patient narratives.

This thesis presents in two parts, each being distinct from the other. Part One entitled "Reclaiming Agency Through Patient Narratives in Susannah Cahalan's *Brain on Fire: My Month of Madness*" is a critical essay focusing on the importance, and the potential, of engaging with patient narratives as a way to reclaim patient agency, following the call to rename 'illness narrative' to 'patient narrative.' While patient

[9] The SLP assessment report mentions "information processing challenges" which developing the outline fell into.

narratives come in various forms, from visual art to musical to written, the goal of this thesis will focus on the written form. Patient narratives, like Susannah Cahalan's[10], explore the experiences from the patient perspective highlighting what the patient witnesses and how the patient responds emotionally during an illness both preceding and following a diagnosis. This close examination brings awareness to what patients undergo with regard to illness throughout the various stages as well as the subsequent life-altering impacts of said illness, which includes communication with caregivers and medical communities.

To address this, I explore three aspects of the patient experience from the symptomology to the healing as examined in Cahalan's memoir and other patient or caregiver narratives. These three aspects are presented as subsections to Part One. "1.1 Recognizing Pathologies and Injuries" explores the person's sense of identity and agency (and the stripping away of them) throughout the various stages of an illness, with impacts that move through the social, personal, familial, as well as physical and emotional. Engaging with critical works by, among others, Rita Charon, Arthur Frank, and Demetrios Sahlas, I examine the impacts of illness with regard to the interactions between patients, healthcare professionals, and caregivers. In "1.2 Communication and Language in the Patient Experience," I explore the encounters of communication between healthcare professionals, patients, and caregivers while engaging with critical works from scholars

[10] Susannah Cahalan's patient memoir, *Brain on Fire: My Month of Madness,* was first published in 2012 and later adapted for film in 2016. This thesis focuses only on the published work as a patient memoir, not the film.

like linguist Suzanne Fleischman, and Shane Neilson. I highlight how the lay-language blending with the medical language creates a communication gap for the patient in an already stressful situation. The language used in medical reports, an interpretation of the patient's voice, contributes to the patient's sense of identity and agency further being removed. In "1.3 Reclaiming Agency," I engage with other patient narratives from writers Virginia Woolf and Anatole Broyard calling attention to expressive writing as a significant influence towards recuperating the physical and emotional affects from illness. I demonstrate how instrumental employing patient narratives is to developing a more holistic sense of self, further enabling the patient to reclaim their agency. Part One, the critical essay, contributes to the field of Medical Humanities by underscoring the importance of recognizing the patient as a person with a full life, beyond that of an illness. The goal is to foster a form of bridging of communication between parties and an acknowledgement of how a patient's sense of identity and agency can be eroded. The most notable benefits are within the medical and the general communities as they will gain a deeper appreciation for understanding the significance of engaging with patient narratives—either as the patient or the audience—as a tool for reconnecting with the self throughout illness, while also developing a stronger sense of other-reflection.

In Part Two, *Powerless Patient: a Memoir,* I explore my tightly focused patient narrative exemplifying the argument made in the critical essay. The patient narrative component follows my health journey seeking to receive the proper care needed for a common surgery while ensuring optimal perioperative brain health support. My primary

goal was protecting my postoperative cognitive functioning. The first surgery in 2005 resulted in consequential and traumatic experiences for myself and my family due to the lack of knowledge about POCC and POCD and the subsequent lack of support. *Powerless Patient: a Memoir* begins after I learned in 2017 that I needed surgery. The story reflects my determination to prevent a cognitive impairment recurrence. The goal of my patient narrative is to reach a broader audience in the hope for a wider recognition of this uncommon medical event so that future patients will not have to struggle for answers and support as much as my family and I have.

1.1 RECOGNIZING PATHOLOGIES AND INJURIES

> "[The Utopians] view the contention that you can't actually feel health as far from true: for who when fully awake doesn't feel himself to be healthy —except for someone who isn't? Who is so weighed down by dullness or lethargy that he won't admit that health is pleasing and delightful?" - Thomas More, *Utopia*

To appreciate how each person adds value to their sense of identity, we must be able to recognize that an individual is a "distinct and self-enclosed body" (Bennet 183) who develops their being through experiences and awarenesses. We use social media tags to indicate whether we are single or married, teacher or barista, student or self-employed, or how we are represented in a family: mother, father, brother, sister. Those identity labels are on the surface. However, the unnamed identities of an individual go much deeper than this. In Susannah Cahalan's *Brain on Fire: My Month of Madness*, for example, she writes about her career as a journalist for the *New York Post,* where, when her unknown autoimmune disorder attacked her brain, her journalistic identity is at risk.

When a person in good health transforms into a patient with an illness, the declaration of 'I am' turns into the question of 'who am I?' This "[emerged] singular entity" (Bennett 183) shifts from an acknowledged whole being—that of being more than labels—to one that feels fractured due to the onset or lingering effects of an illness. Their sense of identity shifts from a whole person to that of being a patient. When a person becomes a patient, they lose control of their sense of identity. Dan Gottlieb refers to this acquired vulnerability as a kind of Western medical colonization of a patient's body:

> "We stop being people and start being patients […] Our identity as people

> and the world we once knew both are relinquished; we become their patients and we live in their hospital." (Gottlieb)

As a person's sense of identity is impacted through physical loss, like illness, social perceptions from a healthy person, whether intended or not, dictates unrealized demands onto the person with an illness: "When adult bodies lose control, they are expected to attempt to regain it if possible, and if not, then at least to conceal the loss as effectively as possible" (Frank 31). The impetus to fit in with the wider world is then on the patient, which brings the risk of an additional emotional impact. The physical changes and impacts from an illness on the body results in the person-turned-patient to more acutely recognize these losses through social, emotional, and physical settings. The occurring illness and loss of the holistic self are the first injuries that a patient experiences.

An emotional impact of a patient's loss of control is the injury from a stripped agency, and consequently how the patient responds to these changes. In his chapter "Body-Relatedness" (Frank 33), Arthur Frank explores patient examples of dissociation and association with the body, and *how* the patient responds to their losses. The non-linear spectrum ranges anywhere from embracing what comes with the illness to rejecting one's own body through animosity. No matter where the patient is with regard to their illness response, the loss of control inevitably dents or fractures their sense of identity. In this state of vulnerability, patients grapple not just with needing to adapt to physical and emotional changes in the personal sphere, but also with needing to navigate through a

system, social or medical, outside themselves which can seem unhelpful or alienating.

Throughout Cahalan's autopathography, she reflects on the person she was prior to her illness. The reader learns that she acknowledged part of her identity as "someone people wanted to include" (Cahalan 186) at social events. She does this to both remind herself and to inform her audience about who her pre-illness self was. She describes that part of her identity as a lively, sociable and appreciated person. Despite the cognitive changes brought about by her illness—a rare auto-immune disease called anti-NMDA receptor encephalitis—her boyfriend, Stephen, and her brother, James, would catch glimpses "where the 'old Susannah' would shine through" (183). They knew her as a loving sister, daughter, and friend willing to engage in deep conversation and enjoy outings. With her intelligence and curiosity, Cahalan found journalism to be thrilling (8); the memories attached to the articles she had written evoked in her various emotions like happiness and nostalgia (7-8).

During the stages of her illness, particularly prior to being diagnosed, the various losses, subtle and obvious, of her former healthy self bring confusion to both herself and those around her. When the head editor of the Sunday paper and her boss tasked her to interview John Walsh, the host of *America's Most Wanted*, about a drug-smuggling scheme, Cahalan is unable to remain focused in her role as a reporter. She repeats her introduction after verbally and mentally veering off the interview topic. Taking control, Walsh and his publicist guide Cahalan back to her goal. At one point, she maniacally laughs at a non-comical word Walsh said, to which his publicist terminates the interview

(Cahalan 29). Subsequently, reflecting on the event, she recognizes Walsh's kindness over her "eccentric effusiveness that was in fact divorced from [her] typical interview style" (30). Other times, she is unable to recognize when she is in a heightened anxious state, as when she was obsessed with an imagined bed bug infestation. She is unable to connect with, nor recognize, her formal rational state of being. Later, during her recovery, she would learn of the support and advocacy of those closest to her, especially how her boyfriend, Stephen, provided her with "security and meaning [during] a very difficult time" (184).

During the recovery phase of her illness, Cahalan expresses feelings that, for instance, she was a burden on others, or that her presence was a "source of shame" for the people closest to her (Cahalan 186). By contrasting the healthy Susannah to the Susannah with an autoimmune disease, Cahalan demonstrates the losses of identity and agency from the onset of her disease and the multiple ways in which it impacted her life. Only once cognitively recovered is she able to recognize how multifaceted her autoimmune disease impacts her. After treatment begins, the stages of her recovery process presents in the reverse order of her symptoms, from catatonic back to psychosis before returning to a normal healthy self (167). The more cognitively healed she is, the more she is able to comprehend how much time she lost. She begins to question what happened to her and who she was during that time. This part of her journey, the investigative part, was a reminder to herself that her "old personality was intact, just buried" (184).

Any illness interrupts a person's life, adding layers of complexity through social

ramifications, financial constraints, as well as the overall toll on the emotional wellbeing. The life interruptions from day-to-day could require daily doses of medication to maintain life to the inability to function on any level. When illness, specifically a prolonged or complex illness, happens to someone, the disruptions with a person's identity can be considered "as any change to existing identities: abandoning old identities, adopting new identities, or changing the structure of the self-concept" (Burke 840). In Cahalan's case, all of these mentioned identities are impacted during her illness and treatment. For example, in order for Cahalan to survive the brain inflammation caused by her autoimmune disease, she needs to take numerous costly medications. One drug to help her is called an intravenous immunoglobulin (IVIG) infusion, which, at the time of her illness, cost $20,000 USD per infusion (Cahalan 116).

In *Feeding My Mother: Comfort and Laughter in the Kitchen as a Daughter Lives with her Mom's Memory Loss,* Jann Arden writes about personal experiences with caregiving for her mother afflicted with Alzheimer's disease:

> "This book is a glimpse into my journey with memory loss but it's also a journey that thousands and thousands of us are on with our mothers and fathers and sisters and brothers and husbands and wives and uncles and aunts and grandmothers and grandfathers and even children" (6).

Immersed in the thick of any illness, the patient and their caregivers can experience feelings of isolation and social distancing. Although Arden's quote was directed to the caregivers of a specific degenerative illness, she reminds patients and caregivers alike that despite possible feelings of isolation when faced with an illness, they can find

connections through patient and caregiver narratives. Nevertheless, the existence of an illness still disrupts the identity of the patient with or without a sense of correlative community, and with or without a diagnosis.

In his article "Dementia With Lewy Bodies and the Neurobehavioral Decline of Mervyn Peake," Demetrios Sahlas explores the posthumous diagnosis of Mervyn Peake (1911-1968) who was "an accomplished British artist, poet, novelist, and playwright [who was also] a prolific and talented illustrator" (Sahlas 889). Unfortunately, in his forties, Peake received a provisional diagnosis of Parkinson's disease, with "insidious cognitive decline" (889) in his fifties. Standardized diagnosis for Dementia with Lewy bodies (DLB) was established in 1996 (890), almost thirty years after Peake succumbed to his then unknown illness. Peake's health story emphasizes the gravity in which illness disrupts one's sense of identity. An interesting aspect of Peake's experience with DLB were the brief moments when his Parkinson's-like symptoms stopped and he was able to reconnect with his creativity by drawing with focused intent and ease (891-2), even when institutionalized without the comforts of home and family. While Peake's creativity was unrelated to a health narrative, his declining artistic works were evidence of his craft being impacted by the illness. Peake lacked the ability to fully comprehend his losses; however, his family were witness to it, aware of their losses of his presence. In their situation, they were able to be present for each other throughout their emotional processes. Arden expresses what it is to be a caregiver and a family member watching someone whose life is significantly, and permanently, impacted by a progressive illness:

"When someone you love has a disease, you live it with them. You suffer it with them. You hold them inside your heart, and you breathe in what they breath out, and you *keep on going*" (114-5). Through Peake's losses, his experience was able to bring awareness and impact of DLB.

The traditional approach of referring to a patient's narrative—narrative being one's account of a story—reflecting on their personal experiences with their illness is as an 'illness narrative.' This widely accepted term is dogmatic and reducing in nature. Combining 'illness' and 'narrative' overlooks the patient's whole being in favour of their illness. The term 'illness narrative' does not acknowledge the patient's personhood. However, by using the term 'patient narrative,' the patient as a whole—including their personhood—is part of the story sharing. The focus is no longer the illness. By renaming the term 'illness narrative' to that of 'patient narrative,' unrecognized biases and perceptions are removed from an already alienating situation. With this in mind, settings absent of a patient's narrative can produce similarly reductive judgements. While attending a family wedding, Cahalan is highly cognizant of the new way people interact with her. She perceived the intonations from others in their inquiries about her current state with "falsely enthusiastic, carefully enunciated tone people used" (Cahalan 187) as talking down to her, not conversing with her. At the same event, a woman approached Cahalan's mother offering sympathies for Cahalan's diminished cognitive functioning. During this interaction, the woman asks Cahalan's mother if "[Cahalan will] ever get back to her old self again" (188) emphasizing the injuries caused from Cahalan's illness, not

acknowledging any stage of recovery.

The labels used in describing a diagnostic become part of a person's identity. This nomenclature contributes to the sense of reflection someone has about themselves and others. Consider the comparison between the verbs 'be' and 'have.' According to the *Oxford English Dictionary,* 'be' is "to exist as the person or thing known by a certain name or term" while 'have' is "to possess (a quality, tendency, ability, etc.) as an attribute or characteristic." Indiscriminate use of these verbs when making a diagnosis has an impact, either positive or negative.

Of her step-father's brother, Cahalan writes: "Allen's brother was schizophrenic" (Cahalan 46). In using 'was' to associate the mental health condition with the brother, the receiver is informed that Allen's brother is only identified through this label. However, if we change the verb usage to 'have,' Allen's brother instead can be seen as the bearer of schizophrenia. Among the many labels of his personhood, he is no longer reduced to the person whose identity is solely the illness. The verb 'is' conveys a permanence and a removal of agency from *the thing* whereas 'have' gives agency to the person. The same nomenclature can be used for all forms of illnesses. This, in turn, can empower the patient to self-identify as more than an illness.

Attempting to self-diagnose in rapid pursuit of answers for her debilitating symptoms, Cahalan writes that her friend suggests, "Maybe you have bipolar disorder" (Cahalan 48); yet later, Cahalan tells a doctor "I'm bipolar" (52). Having bipolar disorder, should this have been the diagnosis, shows that the illness is only a part of who she is.

Being bipolar makes her personhood the entirety of a mental illness, thus, reducing her to a single identity label. A person has cancer, they are not cancer.

The lack of a clear diagnosis is stressful as it contributes to uncertainty for one's identity. This unknown also results in the patient feeling a sense of loss. In Cahalan's case, she and her family were told her symptoms were psychological in nature because they were unable to find a definitive diagnosis. Unfortunately, the lack of clear diagnoses and prompt treating timelines resulted in emotional strain on Cahalan and her caregivers, adding a layer to her injuries. This can be seen when Cahalan's father "was determined to support [her] as much as possible, but it was taking a toll on him; he had withdrawn from the rest of his life, even from [his wife]" (Cahalan 95).

Conversations held between patients, medical practitioners, and caregivers regarding illnesses, especially those that are rare or challenging, can develop into (unintentional) emotional injuries. The impact of the multiple-layered injuries can be far reaching and sometimes abstract, especially when the exploration is lengthy. As patients respond differently to their health situations, healthcare professionals must differentiate the pathologies of illnesses from the injuries caused by them, an arguably non-obvious task. Once the pathologies of illnesses are recognized, the patient needs to recover from the injuries. How they are able to do this is dependent on resources available to them. Through communication and understanding, healthcare practitioners hold the key to implementing a more effective health journey with minimal struggle for the patient.

When pathologies of illnesses are in the process of exploration, the struggles

patients encounter can develop into a challenging journey, particularly for uncommon illnesses and conditions. Responses to health inquiries from struggling patients are often relayed to other healthcare professionals as medical interpretations with possible loss of information. The communication between healthcare professionals is done around the patient, instead of including the patient in the process. In *The Wounded Storyteller: Body, Illness, and Ethics,* Arthur Frank writes his intentions for his book: "I hope to shift the dominant cultural conception of illness away from passivity—the ill person as "victim of" disease and then recipient of care—toward activity" (Frank xi). The shifted perspective in health care to include the patient voice will also help create new, more trusting relationships that foster communication. As healthcare professionals work to incorporate patient voices that expose vulnerabilities surrounding their health journeys, the movement of patient-doctor collaboration will enable further recognition of patterns for new, progressing symptoms, while also demonstrating patience and understanding. This is particularly important when faced with complex cases, specifically when acknowledging a patient's lifestyle, barriers, and support systems.

Rita Charon's Narrative Medicine[11] program at Columbia University focuses on training medical students to consider how they will view their role once they become practitioners. Coming from the perspective of a healthcare professional, Charon reminds her fellow practitioners that:

"[the seriously ill people] are no longer defined by work role, family role,

[11] Narrative Medicine Program at Columbia University: https://tinyurl.com/4p6fpwex

> or state role and not yet defined as simply awaiting death but de-differentiated by cotton hospital gowns and plastic wristbands to be side by side only with others who, too, find themselves in the limbo regions of sickness" (Charon e-book).[12]

This comment on patient identity validates how patients feel throughout their health journey. It reaffirms that there is room enough for them to be heard and to be included in the conversation surrounding their medical conditions. The self-reflection taught in the Narrative Medicine program indirectly teaches the learner to reflect on the other, the patient. This then allows them to reconsider their medical understanding from that of symptoms being identifiable in a confined box to that of recognizing differing patterns of new, progressing symptoms, sometimes requiring a team of healthcare professionals, patients, and caregivers to exchange in dialogue for the benefit of patient healing. As healthcare practitioners take up the challenge of utilizing their wealth of medical knowledge, "[the healthcare professionals] who have elected to live our lives with the sick must "wholly attend," must be with them, must open ourselves to porous transit on their journeys while building collectives of our own that help to get the work down" (Charon e-book).

Cahalan's health journey begins with an unconfirmed *mis*-diagnosis of mononucleosis by a gynaecologist (Cahalan 19) to erroneous comments made by other healthcare professionals who state "there's nothing wrong with you […] it's all in [your head]" (64). Throughout all this, Cahalan and her family grow overwhelmed by the

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[12] Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. New York, Oxford University Press 2006, e-book.

symptoms and are confused by the absence of an easy diagnosis. As her illness progresses, the symptomology of unknown origin worsens, making it a challenge to determine a diagnosis. Healthcare professionals focusing on diagnoses within their range of expertise grapple with understanding how to consider anything different. As Cahalan risked being admitted to the psychiatric ward due to physicians' inability to isolate the origin of the fast-debilitating illness, Cahalan's family are her greatest advocates, despite the emotional toll the unknowns take on them (136). Not everyone is so fortunate.

"In the diagnostic moment one story is told and another one is triggered" (Jutel 14) which is at least as true when it is a *mis*-diagnostic moment. Communication difficulties widen the gap between patient and healthcare professionals risking misunderstanding by the patient and caregiver alike. When delays occur moving through the symptomology to determine an aetiology for the goal of treatment, the emotional, physical, financial, and even social practices can cause unintentional injuries. These unacknowledged injuries are not always considered as part of a healthcare practice.

1.2 COMMUNICATION AND LANGUAGE IN THE PATIENT EXPERIENCE

> "Whoever among us has learned through personal experience what pain and anxiety really are must help to ensure that those out there who are in physical need obtain the same help that once came to him. He no longer belongs to himself alone; he has become the brother of all who suffer. It is this "brotherhood of those who bear the mark of pain" that demands humane medical services…" - Albert Schweitzer, 1921

For most patients, the language used by healthcare professionals during medical exams often contain unfamiliar language. When such language is used, it pulls the patient away from themselves (the source of the illness) and brings them into the world of medicine. While spoken language is alive, it enables speakers to move within their known vocabulary. The medical knowledge base, the language, and the understanding of the significance of the terminology is one of the barriers patients face during medical exams. This removes the patient from what is personal, their health, and contributes to an already confusing situation.

Throughout COVID-19, blood oxygen saturations (BOS) have been discussed openly in news articles emphasizing the gravity of this virus. Long before COVID-19, BOS has been a common test, typically going hand-in-hand with blood pressure monitoring. The device used to read it, called a pulse oximetry[13], is a gentle, non-invasive clip usually fastened to the tip of a patient's finger where the red and infrared lights shone from it are able to detect the oxygenated hemoglobins (red blood cells carrying oxygen throughout the body to all organs). But, knowing the range of oxygen saturation levels is

[13] "Pulse Oximetry: The Definitive Guide for Monitoring Oxygen Saturation." Cables and Sensors. Web. 06 Feb 2021. tinyurl.com/1d1vx0ik.

not common knowledge to non-medical persons.

Consider how elementary students learn at a young age that their academic achievements are based on numeric percentages. With that grading system in mind, it is understandable that someone might assume a 94% reading for oxygen saturation levels would be normal, if not near excellent. Unfortunately, it is not, and the patient should be considered for oxygen therapy. Severe hypoxia, that being a significant decrease in blood oxygen levels, is less than 85%. Similarly, patients 'know' their average blood pressure ranges, but understanding the significance is often not explored during an appointment. If the patient knew the relevance behind the numbers, they would better understand how their diet and level of exercise impact blood pressure.

In "Leadership, Communication and Healthcare: Understanding the Role of Communications in Building Collaborative Healthcare Teams," Christina Pellegrini writes how the essential role of successful communication "in all aspects of society and miscommunication can cause significant damage, however, in healthcare, effective communication can make the difference between life and death" (Pellegrini 3). In *Brain on Fire: My Month of Madness,* Susannah Cahalan informs the first neurologist that she consumes two glasses of wine per night. The first neurologist asserts to her worried parents that "[Cahalan is] exhibiting the classic signs of alcohol withdrawal [her symptomatology of "anxiety, depression, fatigue, irritability, mood swings, nightmares, headache, insomnia, loss of appetite, nausea or vomiting, confusion, hallucinations, and seizures are"] (Cahalan 70-71). Later while researching the medical notes for her book,

Cahalan discovers that the neurologist claimed she "drank excessively up to two *bottles* of wine per night" (86). The discrepancy between the patient's account and the neurologist's account accentuates the risk of ineffective communication and the resulting life-and-death treatment.

The first neurologist's insistence that her symptoms had fallen into the alcohol withdrawal category without considering other possibilities is, as Cahalan explains, due to a malfunctioning health system. Even though her neurologist was "one of the best […] in the country" (Cahalan 226), Cahalan reports that the healthcare system[14] puts him, and other doctors, in the position to see almost three dozen patients per day. This then gives each doctor approximately five minutes per patient[15]; "I was just a number to him" not a person with an illness (226). By tending to patients with significantly restrictive time limits, a dependence is introduced on the *law of the instrument,* as psychologist Abraham H. Maslow argues, "it is tempting, if the only tool you have is a hammer, to treat everything as if it were a nail" (Maslow 16). The few minutes given to patients and resulting restricted communication not only limits the healthcare professional's ability to witness the truth of a patient's experiences, but it also risks missing key symptoms to correctly diagnose a patient.

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[14] For context, Cahalan's memoir is written from the perspective of a patient based in the United States healthcare system and not representative of other countries practicing Western-based medicine. Each country, state, or province has their own requirement standards for common medical practice which include time allowances for new patients, follow-up appointments, etc.

[15] During a discussion with Dr. Demetrios Sahlas, a neurologist in Ontario, Canada, he expressed that in his practicing experience as a neurologist, the "five minutes per patient" seems extreme and not representative of a neurological consultation, be it a new patient or a follow-up consultation.

The language used in medical reports is not from the voice of the patient, but from the healthcare professional in a form of unilateral storytelling (Leduc 49). While consultation notes are a form of narrative written by the healthcare provider, they are an interpretation of the information provided by the patient and translated into medical terms by the healthcare professional. Cahalan's first neurologist encounter underlines a doctor demonstrating his disbelief when he changes her two glasses of wine per night to bottles.[16] He infers "She's partying too hard, not sleeping enough, and working too hard" (Cahalan 49). In addition to the patient body, the patient language becomes the subject of the healthcare professional wherein they reinterpret what they hear. "The [medical] chart becomes the official story of the illness" (Frank 5). However, that story is an interpretation of the writer—the physician—based on their training as a healthcare professional, but also based on their own personal perspectives, which include judgements. Cahalan's tale shows how the patient's narrative can unfortunately be discounted.

Cahalan opines that the interpretation and medical declarations may be due to her being young (Cahalan 71). The doctor even suggests, indirectly, that she is dishonest about her alcohol consumption (49). The doctor's *mis*-interpretation, or personal judgements, skewed the truth of her words, negatively impacting the official story as presented in the medical report. What is not mentioned in these stories are the impacts on

[16] During a discussion with Dr. Demetrios Sahlas, I learned that medical "students have been advised for years" to multiply reported patient alcohol consumption by six, which was based off of a study (date unknown) out of Boston. It is possible that the study is antiquated and might not represent current practice.

the person, their social and familial relationships. “The story told by the physician [that being the medical narrative] becomes the one against which others are ultimately judged true or false, useful or not” (Frank 5). Additionally, the amount of alcohol, as made official in a medical report, creates the opportunity for amplification.

Consider a patient telling a doctor they do not drink alcohol because the taste disagrees with them or it makes them feel unwell. In *Companions in this Age: A study of Pain in Canadian Literature*, Shane Neilson writes, “Western culture expresses pain in negative terms and then denies meaning to chronic pain through the etiolating medical gaze” (Neilson 12) which circles back to the language used in consolation notes: ‘patient *denies* drinking alcohol’ (emphasis added). As the healthcare professional is the person interpreting and writing the patient’s narrative, there is no acknowledgement of the implication of the word choices: denies, refuses, etc. The words ‘deny’ and ‘refuse’ are not objective words, but subjective. ‘Deny’ connotes falseness or defensiveness. This in itself is injurious to the relationship where trust is paramount and should be bilateral. ‘Reports’ or ‘says’ connotes neutrality.

The choice of the words used in medical reports/charts gives the impression that the patient could bear false statements about their health, thus creating an environment lacking in trust. In *The Body in Pain: the Making and Unmaking of the World*, Elaine Scarry writes about the lack of trust physicians have in their patients’ stories, condemning them to the role of “unreliable narrator” of their own body’s experiences. Exploring the patient’s reportage of their physical pain, Scarry writes about the physician’s response:

"The doubt of other persons, here as elsewhere, amplifies the suffering of those already in pain" (Scarry 7). The suffering patient experiences the physician's doubt, which contributes to the lack of trust in that relationship.

However, there is a range with which physicians approach the diagnosing of patients. On one side, Robert Zussman writes that physicians "don't have to examine a patient [because] the numbers or diagnostic images, or cardiac tracings are more reliable" (Zussman 33). This results in not including the patient's voice, experiences, and self-awareness which can further negate the patient and strip their agency. Limiting the diagnosis to the reading of test or imaging results narrows the physician's perspective to what will fit in a tightly focused box. On the other side, there are healthcare professionals like Dr. HPK who practice with the belief that "nothing is more important than the human faculties—treating patients with compassion, understanding, empathy and solid clinical judgement" (HPK xxvi). Physicians who practice medicine outside of a vacuum (261) engage with their patients, learn the personal and family histories through dialogue, touch the body they are treating, and weigh test results along with the clinical assessments. This leads to the patient and caregiver trusting in the received care.

In "When Bodies Need Voices," Frank writes about a patient's excruciating cancer story requiring major surgery to the face and jaw (Frank 11). Due to the medical significance for wider knowledge, the patient's cancer experiences were photographed, written about, and published in a medical journal without attributing or acknowledging the patient's name, due to privacy. This was, however, the patient's story that was shared

by his medical community with the global medical community. Patients have a right to privacy with regard to their healthcare. However, the personal impacts on his life from the cancer were not shared and not explored. Only his illness was. Frank highlights how the patient becomes objectified in the examination room. The personal is cast aside, leading the person to experience a loss of agency and sense of identity. "The individuality of that suffering cannot be acknowledged" (12) through the objectification of the person as a patient.

After Cahalan was diagnosed with her autoimmune disease, her patient status was upped to that of being an ""interesting consult" for a host of attending doctors, interns, and residents hoping to catch a glimpse of the girl with the unknown disease" (Cahalan 159). Her case would be discussed in front of her and her family as though they were inanimate objects[17][18] with little regard to their feelings, whether this was the intent of the healthcare professionals or not. During one visit, a young doctor with a group of younger doctors discuss her rare autoimmune disease and the range of presenting symptoms in front of her. Her autoimmune disease is so rare that at the time of Cahalan's diagnosis in 2007, she was the 217th person to be diagnosed (151). The young doctor mentions in front of Cahalan and her father that fifty-percent of such patients have their

[17] The CanMEDS Framework "identifies and describes the abilities physicians require to effectively meet the health care needs of" their patients. With the goal of improving patient care, the seven CanMEDS roles encouraged for the healthcare professional to maintain and be aware of are the: medical expert, communicator, collaborator, leader, health advocate, scholar, and professional. This includes involving the patient in their healthcare discussions. For more, go to https://tinyurl.com/2e5b8pzs.

[18] In ""Best Practice" for Patient-Centered Communication: A Narrative Review" King and Hoppe explore the "6-Function Model" which focuses on the best practices in a patient-physician encounter. These goals highlight the importance of improved communication in the medical setting. This includes involving the patient in their healthcare discussions. For more, go to https://tinyurl.com/mhpy7n6p.

ovaries removed (159). Cahalan and her family were unaware about this possibility, learning it alongside the younger doctors. Cahalan became very emotional, and her father reacted protectively. By objectifying her case, and her as a patient, the doctors do not acknowledge the emotional and personal impacts that she and her family live through. The lack of awareness between professionals about what was and what was not discussed with the patient and their family is striking. This kind of error can be avoided. One potential example is that the young doctor could had involved Cahalan and her father in the discussion with the younger doctors. Inquiring with the patient about their knowledge of the disease, the patient's distress—in an already distressing situation—can be kept to a minimum. While the intention is to not objectify a patient and their case, the result is that the patient and their illness become objects.

Even when a person with an illness shares their experience with someone, say their spouse or parent, there still remains the fact that, as the person suffers, the caregivers are indirectly affected as well. Cahalan's boyfriend, Stephen, chooses to stay with her while she struggles through the stages of illness. While it is difficult for Stephen and Cahalan's parents to listen to her and watch over her, together they advocate on her behalf to the healthcare professionals. Their witnessing of Cahalan's journey encourages them to show strength for her during frightening times. Right before the brain biopsy, she writes about her father, "Fighting back tears, my dad knelt beside me" (Cahalan 139).

On writing about the significance of language and what it means to live with an illness or impairment, linguist Suzanne Fleischman says, "your sensitivity to the nuances

of words used to describe [the illness or impairment in relation to the body] is inevitably heightened. You become critically aware of the subtle ways in which lexical choices define you as a person" (Fleischman 7). By arguing this, Fleischman draws our attention to the medical language reducing a person to their symptoms, illnesses, and conditions. Even so, sometimes the lure of false hopes for a diagnosis can also foster misunderstanding. Cahalan, who is desperate for answers, is told by her gynaecologist that she "possibly [has] mononucleosis, though we don't have the blood tests back to prove it yet" (Cahalan 19), but she hears 'you have mono.' Emotions, like Cahalan's desperation, can get in the way of understanding the difference between hypothesis and diagnosis. Recognizing the patient's state of mind when giving a diagnosis ensures that the patient clearly understands the message given by the healthcare professional.

Health is personal, and "medicine—the word itself derives from the Latin *medicina*, meaning the healing art—remains as much an art as a science" (HPK xxv). Communicating the process to patients and recognizing limitations can avoid potential confusion and misunderstandings. While the scientific method[19] is non-linear, the method follows a general approach allowing for variations (Table 1).

[19] For an overview of the scientific method, see: "How Science Works" from University of California Berkley https://tinyurl.com/ehhn6zpr.

Table 1. Comparison between the Scientific Method and the Science of Health/Medicine

Scientific Method	Healthcare Process
Question	Health problem/illness
Hypothesis	Possible diagnosis
Experiment	Testing, imaging, medication
Data analysis	Results
Conclusion	Positive response in patient health, or return to another possible diagnosis

Cahalan's symptoms crossed multiple possible diagnoses, starting with mono and leaning towards schizophrenia before the correct diagnosis of anti-NMDA-receptor autoimmune encephalitis (Cahalan 151). This process may be correct and obvious for a healthcare professional. The doctors involved in her case demonstrated a willingness to embark on this scientific process of discovery. But to Cahalan and her family, the process of ruling out one potential illness after another and arguing with doctors against certain diagnoses was an emotional experience: health is deeply personal. Between the scientific and the personal lies an opportunity for stronger communication.

The first neurologist, as reported by Cahalan in the memoir, demonstrates an unwillingness to deviate from his initial assessment by repeating that her symptoms are "a reaction to excessive alcohol consumption" (Cahalan 71). However his intention to rule out this possibility is quickly outpaced by the faster-developing symptoms. The family, having constant access to Cahalan as well as a different set of insights, senses the growing health urgency whereas the first neurologist, based on his initial diagnosis, does not. This

results in the family having to react in a confrontational manner to have their daughter admitted to the hospital (70-1). Through this intervention she eventually does receive a proper diagnosis. Unfortunately, Cahalan and her family are left with a negative experience. From the limitations in communication to the inaccurate consultation reports, the treatment plan was delayed and unnecessary emotions were added to an already frightening situation.

The "diagnostic shock" (Frank 39) which patients experience upon receiving a diagnosis requires an acknowledged transition from healthcare professionals. The treatment plan of moving from point A to point B is prescriptive, typically following predetermined guidelines, while also needing to be communicated. Unanswered questions or uncertainty about a diagnosis can translate into a confused conclusion for the patient. A lack of recognition that a person is being thrust into the role of patient by the healthcare professional when they deliver a diagnosis can leave the patient feeling alienated in their new patient status. The mental processing required to understand the initial ramifications of the illness is significant enough in the experience.

Cahalan's initial neurologist diagnosing alcohol withdrawal gives the appearance of him prejudging the situation based on her age. Not giving due consideration to a patient's observations and narratives in diagnosis contributes to the 'diagnostic shock' and the patient's mistrust towards the medical community. On finding the right doctor to diagnose her, Cahalan writes, "I'm the one who is an exception. I'm the one who is lucky. I did not slip through a system that is designed to miss cases just like my own—cases that

require time and patience and individualized attention" (Cahalan 226). While diagnosing is a process of exploration, Cahalan highlights that "the rate of misdiagnosis in the United States has shown no improvement since the 1930s" (226). At a time when medical knowledge has never been greater, are we witnessing the limitations inherent in avoiding a more holistic and collaborative approach?

While Western medicine encourages the "common practice of dividing experts from the patients" (Neilson 62), errors risk being overlooked if the patient is not included in the medical reports, as evidenced above. Those potential errors or incorrect interpretations of the patient's story then contribute to future *mis*management of the patient's illness, and hence the patient holistically. The potential errors also contribute to the injuries a patient might sustain. Effective communication from all those involved, especially between the patient and the healthcare professionals, is crucial in increasing positive health outcomes.

The unconscious language within each of us stems from personal cultural understanding, backgrounds, and experiences. While physician-to-physician dialogue is important in the communication process of diagnoses, recognizing that a patient is a person with differing self-experiences, understanding, and agency is equally as important. As such, for patients wanting to better understand and express their symptoms in pursuit of a diagnosis or treatment plan, a common language shared between patients and healthcare professionals is needed, with the intention to comprehend one another. Taking time to explore the new and unfamiliar medical language with the patient allows the

patient to reclaim the language and conclude with an understand that makes sense to them.

Patients encounter medical language from practitioners that explain or identify aspects of health and illness. Avoiding prejudiced and assumptive language helps to eliminate misunderstandings between patients and healthcare professionals while also including more consideration and compassion of cultural experiences, gender-based experiences, and other factors. Emphasizing the effectiveness of communication in the patient-doctor setting by including the patient in the consultation note-taking process works towards eliminating communication misunderstandings while encouraging trusting relationships.

1.3 RECLAIMING AGENCY

> "The miserable have no other medicine
> But only hope." - William Shakespeare, *Measure for Measure*

In the chapter "Telling One's Life," Rita Charon writes about the lack of training provided to healthcare professionals in listening to patients. Due to time constraints, insufficient training, and billing requirements, healthcare professionals are limited in the time they can allow each patient to share their story[20] which contributes to the patient's general sense that they were not fully heard[21]. While patients are not afforded the time to share the full impact of their story with their healthcare professional, they can express the same stories through their own creative expression. By creatively expressing their stories and through intentional story sharing with others, patients can develop a way to reclaim this sense of agency.

Making sense of the multiple impacts that one's health journey has had on the personhood can be daunting and at times confusing. The shift from lay-language to medical terminology as a patient can leave them feeling lost. This is especially true with long or invasive illnesses that have interrupted one's life. Reconnecting with oneself in the quagmire of what it means to be a patient moving through serious or complex illnesses helps the patient to discover a new or changed identity. One method to enable

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[20] Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. New York, Oxford University Press 2006, e-book.

[21] Going through websites like RateMDs or other patient forums, random comments by patients will support their lack of feeling heard. Additionally, Charon's chapter brings attention to this but from the physician's perspective.

the reestablishment of the self is through documenting experiences by writing, also known as a patient narrative. Engaging with these patient narratives, be they in the form of a personal journal or a published memoir, can give healthcare professionals the opportunity for improved doctor-patient communication and understanding.

In her essay entitled "A Sketch of the Past," Virginia Woolf writes on the significance of writing about different forms of injuries, which can equally be applied to those brought on by ill health:

> "I feel that I have had a blow; but it is not, as I thought as a child, simply a blow from an enemy hidden behind the cotton wool of daily life; it is or will become a revelation of some order; it is a token of some real thing behind appearances; and I make it real by putting it into words. It is only by putting it into words that I make it whole; this wholeness means that it has lost its power to hurt me; it gives me, perhaps because by doing so I take away the pain, a great delight to put the severed parts together" (Woolf 72).

On highlighting a patient's positioning during or following an illness in *The Wounded Storyteller,* Arthur Frank writes:

> "Seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away. The voice speaks the mind and expresses the spirit, but it is also a physical organ of the body" (Frank xii).

The act of a patient becoming their own storyteller—or story sharer because the patient is sharing their story—whether it be written, oral, or visual, is the moment they begin to reclaim themselves. As an investigative journalist by training, Cahalan takes the pieces from her health journey and does just that: make sense of what happened. To do this, she examines the "deepest part of the self—personality, memory, identity—in an

attempt to pick up and understand the pieces left behind" (Cahalan xi). This reassembly of the self is an act of reclaiming one's agency.

It is understood that not all patients have the capacity and the means to create their own narrative, for a variety of reasons. As such, exploring those patients are outside the scope of this thesis due to complexities moving in another direction from the main focus. For the patients—and even caregivers like Jann Arden—who do engage with the process will move through the narrative creation in the following three phases[22]:

1. **Self-permission:** Give themselves permission to create their narrative. Recognizing the written form as a way to encourage healing from a health event, including any associated emotional injury and other by-products, implies that the writer understands the necessity of this solitary undertaking, ergo an act of self-permission.
2. **Acceptance:** Having a fresher perspective of the health events that transpired enables the emergence of a healthier, more beneficial approach[23]. Through this, the language encountered can be reallocated from the patient experience and morphed into the growing person. The patient gains a clearer understanding of the impact on the self. They will be able to regain a sense of self-worth. This, in turn, allows for the patient to

[22] Arthur Frank's *The Wounded Storyteller: Body, Illness, and Ethics* describes control, desire, body-relatedness and other-relatedness in chapter two (30). While reading, I found there was a disconnect between one's sense of identity and the body. Dealing with cognitive dissonance and trying to understand his attempt at describing those conditions and the "four ideal typical bodies" (40), I found it to be inaccessible. My goal was to focus on a holistic approach for a patient's health journey as a means to reclaiming agency. Reading multiple patient narratives, and writing my own, I recognized a commonality which contained these three phases.

[23] In "The Writing Cure: How Expressive Writing Promotes Health and Emotional Well-Being" Stephen J. Lepore and Joshua M. Smyth write about the differences between trauma-focused writing (negative) and writing that focuses on positive outcomes from negative experiences. The latter "enables a person to adjust" (8) easier, resulting in health benefits.

make peace with the events and impacts that transpired throughout the health journey, including the recovery. This is especially important should the patient have experienced shame, guilt, grief, etc. over the losses of identity.

3. **Reclaim Agency:** From the growth that was required to arrive at this point, the patient has a new or strengthened sense of agency. The patient will have gained a broader perspective and renewed understanding of their experience. By reclaiming agency, the patient will gain a more holistic self, correlating directly with their sense of identity.

In Anatole Broyard's posthumously published book entitled *Intoxicated by My Illness: And Other Writings on Life and Death,* he writes about a form of self-permission when facing illness. From his perspective as a patient, he suggests patients engage with different activities or try approaching the same activity with a newer perspective—perhaps a romancing of oneself—as a way to keep "from falling out of love with yourself as the illness attempts to diminish or disfigure you" (Broyard e-book). In this process, the patient learns to be patient with themselves.

When possible, self-permission in the face of illness comes as a choice: "you can turn toward this knowledge or away from it" (Broyard). Through this form of acknowledgement, further struggles that will be encountered along the patient's health journey can be met with readiness, not reluctance. Incorporating this self-permission into the health journey enables the patient to feel a sense of preparedness in understanding the situation while navigating through the emotional and physical tolls of the illness. This then empowers the patient to regain a sense of identity and agency. Through this process,

they will be better equipped to examine themselves, to self-reflect. A benefit of self-reflection is that the patient be able to consider others more: other patients on different health journeys, caregivers' experiences caring for loved ones, healthcare professionals helping patient after patient.

What this self-reflection will highlight in the patient's mind is that, up to this point, their health journey was not previously expressed through their words. In the health setting, the patient's words are defined by the constraints of medicine via a new language that the patient has up until now no choice but to adopt. The use of language in health and its focus on "pain as negative experience as expressed by metaphors of weaponry and damage" (Neilson 52-3) create a hostile environment for the mind and body, a balance of discordancy. The descriptors of illnesses and the impacts thereof inform the recovery and healing processes. When negative metaphors are depicted, they counter the body's aim to heal and recover.

Through language, the mind and body work towards accepting the visible or invisible disfigurement, the emotional or physical scarring caused by the illness; to be successful, the body and mind must collaborate using this reclaimed language. This alliance then demonstrates that the health journey is lived by a person, not just a patient. The ability to recover in a more unified identity, the end goal of reunification of the self, will become possible and can lead the patient back to personhood. Because "those who have been objects of others' reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own

truth, in her own words" (Frank xiii). To reclaim this agency is to holistically recover, in part, through the writing and sharing of the patient's journey in their own words.

As the patient works to reclaim the language attributed to their health, focusing on the events that transpired affecting their life will enable them to understand how language tainted them. In his chapter, "The Self in Moral Space," Charles Taylor argues that human identity, in part, is based on the lived-within frameworks for which we as a society create. He furthers this by stating that the life a person creates and chooses to live within "is constitutive of human agency, that stepping outside these limits would be tantamount to stepping outside what we would recognize as integral, that is, undamaged human personhood" (Taylor e-book). When illness strikes, however, one does not *choose* to 'step outside' a self-created zone to become an injured human. A healthy person does not choose to become ill. Illness happens to a person which results in the person's identity to become fractured. Being forced to live in a realm without their original self-chosen framework contributes to the sense of having lost agency and one's identity. Reclaiming agency, however, can be recognized as a returning to the frameworks with which a patient decides or is able to assume. Consider, for example, Cahalan's inability to effectively interview John Walsh. In that moment, the loss of her professional framework, which she had until then taken for granted, allows her to recognize the importance of reclaiming her agency. Her sudden unexplainable behaviour with Walsh has a medical explanation, and, once recovered, she is able to capture it in her writing, establishing a sense of self-worth in her journey.

During an illness experience, patients can feel "embarrassed revealing intimate aspects of themselves. Illness makes them vulnerable and fearful" (Zaharias 3), which contributes to feelings of shame. Retelling one's health journey story to someone, even via creative means, allows the patient to feel heard, alleviating those feelings of shame. The patient is able to make peace with their journey by crossing into their original framework, or by developing a new self-chosen one. A patient moves toward the point of reconciliation on a holistic level by reflecting on the health journey, the language used, the impact on the personhood, ultimately coming to a better understanding of their self-worth.

"Stories are a way of redrawing maps and finding new destinations" (Frank 53) which aids in the patient's path towards reconnecting with the self. By retelling and reshaping their health journey using their language, the patient incorporates the parts of the journey towards emotional and physical recoveries. How stories are delivered does matter to the person delivering it. About patient narratives, Frank writes, "the obvious social aspect of stories is that they are told *to* someone" (3). Yet, the health benefits found in patient narrative writing can be beneficial even when there is no intended audience (Valtonen). The act of writing one's patient experiences without an intended audience contributes to recovery, for the patient narrative is expressed in their words. Even brief periods of writing one's health experiences has shown to bring positive changes in both the psychological and physical well-being of the patient (Valtonen). The benefit of writing a patient narrative is in the ability to recognize the losses, the injuries, and even the gains

from the health journey experiences which is part of the patient's map-redrawing efforts made towards reclaiming their agency.

Engaging with this form of expressive writing allows the patient to examine "the most hopeful aspects of our lives through writing—our best imagined futures […]—might also bestow on us the benefits of writing that have been long assumed to be tied only to our traumatic histories" (King 806). It is important to note that some experiences may be too traumatic for the patient to revisit which can unintentionally cause different traumas; therefore, those patients should explore writing patient narratives under the guidance of a healthcare professional (Valtonen).

The act of a patient becoming their personal story-sharer, whether it be written, oral, or visual, is the moment in which they begin to reclaim themselves. Cahalan's ability to tap into her journalistic background, writing daily at the encouragement of her family, and researching the events of her experience are the moments where she works on this process. Her memoir serves as a tool to help her reclaim her lived health journey experiences, which up until then was buried in the annals of medical reports and consult notes. Writing her patient narrative in her voice from her perspective is a declaration to share her health journey on her terms, to not be objectified.

Cahalan's patient narrative gives prominence to the precipice between living healthily and suffering from misdiagnosis. Cahalan navigated the healing waters required by her illness through researching the memory gaps, accepting the absent pieces as part of her identity, and moving forward in her patient narrative. To make sense of her memory

losses, to understand the impacts on her overall health, and to find connections with herself, her family and the healthcare professionals involved in her health journey, Cahalan writes her patient narrative to share her health journey and to bring awareness of her rare autoimmune disease. This then circles back to her reclaiming agency: self-validating and announcing this validation. In doing so, she reclaims the authority over her life and her health journey.

Frank argues "Ill people still surrender their bodies to medicine, but increasingly they try to hold onto their own stories. Refusing narrative surrender becomes one specific activity of reflexive monitoring, and thus an exercise of responsibility" (Frank 16). By this, and through engaging with the act of patient narratives, 'ill people' control the essence of their story, their history, their identity, and ultimately, reclaim their agency. By not engaging with the patient's narrative, the official medical narrative diminishes the patient's health story, making it devoid of the emotional, physical, social, and professional impacts that the patient and their caregivers experience.

The way into narrative healing is through sharing stories. As the science of medicine continues to evolve in its current standing due to medical and technological advancements, the practicing of medicine, that of healthcare, should also evolve with the patient whose needs require having their voice represented in the exam room. Employing and engaging with patient narratives allows for the understanding of and compassion for the patient's humanity. This form of expressive writing further highlights to the writer and reader the universal need to reclaim one's agency, especially when the losses are

profound. In *The Body in Pain: The Making and Unmaking of the World*, Elaine Scarry says that a person becoming whole is not accomplished by simply seeing the injuries, but through acknowledging the injuries as a part of the person (Scarry 225). As the needs of the patient expand into embracing and accepting their injuries, they will then be better positioned to accept the losses incurred and to attain becoming a whole being.

The journey of reclaiming one's agency also involves recognizing the grieving for losses, accepting the differences or changes, and finding how to love that person unconditionally. When a person's world turns from being healthy to feeling consumed by the state of being a patient, their identity takes on a new shape. They require a balance between being alive and the caring for their health. From there, they must learn the delicate appreciation and understanding of the holistic self. Cahalan's patient narrative communicates her experiences with her illness while deftly showing the impacts on her personal, familial, social, and professional life. Throughout it, she addresses how her identity became fractured, but also how she was able to reassemble the pieces, even accepting the absent ones. Throughout the sharing of her story, she demonstrates the hardships patients face when uncommon or rare illnesses are misdiagnosed. Through her story, she aims to both enlighten the medical community about a rare autoimmune disorder and to remind patients and healthcare professionals to remain resolute throughout the health journey. Cahalan's story reminds her audience of the benefits of reclaiming one's agency from the realm of 'patientdom' for a much needed healthier balance.

CONCLUSION

"The wound is the place where the Light enters you." - Rumi

To make sense of her losses, to find connections with herself and the healthcare professionals who helped save her, Cahalan employs patient narrative to reach others, to expand knowledge, and to accept the vulnerable state she was in prior to diagnosis. The journey to reclaim one's agency includes recognition for grieving of losses, and accepting the differences or changes. When a person loses sense of control over their life as the focus shifts from being healthy and having agency to feeling bound to an illness and its symptoms, the patient needs a balance in their life so that they may be able to appreciate and understand delicate situations with regard to the impacts of their life and health.

The person—which includes the body and all the lived experiences, be they healthy or of ill health—begins their story from the perspective of having had life experiences pre-illness. The reflections on their pre-illness state serve to bear witness to the losses incurred, including the loss of control, identity, and agency. Through their telling and sharing of their truths, asking questions of the unknowns, the story-sharer begins to reclaim their agency, even when that agency is not as it was pre-illness. They observe their losses through experiences, they recognize the events of the experiences as well as the new interactions had during them. The medical interactions become a part of their story, including the newly adopted medical language which contributes to the new or transformed identity. Recognizing patient narratives as part of the medical narrative, part

of the official story, is just as, if not significantly more, important for patient recovery, patient reclamation of agency, and acknowledgement of personhood. In *The Wounded Storyteller: Body, Illness, and Ethics,* Arthur Frank sums up the necessity for others to *hear* the messages written within patient narratives as a means to further communicate with the broader community, specifically within the medical community:

> "After having cancer I attempted to read some of the professional literature describing the experience I had gone through. I found the language too distant from the immediacy of embodied suffering that I had recently experienced. […] The professional text needed my body, but it could not acknowledge that need" (25).

Patients who choose to share their stories do so not just to tell their tale. They tell their storied experiences more to share themselves with others, to allow for solidarity to be achieved. The patient who chooses to share their story speaks not just for themselves but for the collective experiences of those enduring illnesses, specifically and indirectly for those unable to express or process illnesses, and the impacts their illness has on their lives. These shared stories are a reminder to caregivers and healthcare professionals how to remain connected to their compassion. The benefits of patient narratives are not just for the health of the patient, but for the contribution to awareness, understanding, and compassion for others, including caregivers and the broader public.

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PART TWO: POWERLESS PATIENT: A MEMOIR

> "Living stories are to be heard, witnessed, and even responded to." - Grace Kehler

INTRODUCTION

Powerless Patient: a Memoir explores the pathologies and injuries, physiological, emotional, and personal impacts following a rare medical event. My following patient narrative is a splice from a much larger health journey, thus it will only focus on my experiences seeking surgery. My patient narrative will move through personal experiences with healthcare professionals who were either willing or unwilling, capable or incapable, to be part of the surgical team for my surgery due to the complexity of my case. My unique health situation has resulted in me being defined as a 'patient outlier.' I will examine various forms of communication through the lens of language used by healthcare professionals and myself. My patient narrative is self-reflective with the intent to underscore the systemic-wide issues patient outliers often encounter.

Powerless Patient: a Memoir is an exploration to understand the differences between me and those who were part of my health journey as my inquiries were often met with me feeling abandoned. Armed with my penchant for answers from my patient experiences, I wear my scholarly hat and endeavour to explore how shared patient experiences help patients to reclaim their agency in a situation where health illnesses and medical systems have removed it. Apart from my name and my family's, all names, cities, hospitals, and any other identifiers have been changed for privacy.

Prologue: April 23, 2019

Finally, this day arrived. I was lying on the hospital bed looking out the window. Trees stood between me and the rising sun. I felt like I had just emerged from a hard-won two-year battle as the day's birthing light welcomed me. A steady calm washed over me. Internally, a tornado had disappeared and was replaced with quiet. I would not have known this peace without first having passed through that battlefield. Part of this serenity was owed to the fact that I accepted the outcome no matter what. I knew that I had done my part to ensure I was with the most knowledgeable people in their fields.

I looked out the window at the growing golden-orange orb, rising in its dawn ritual to brighten the world. Light shone through the windows, adding to the already well-lit nearly empty operating hallway.

A woman wearing a smile, green scrubs and a hair cap approached me after exiting the double-doored operating room from across the hall.

"Good morning, Virginia," she said. "I'm Dr. Greene, the anesthesiologist for your surgery today. I thought a lot about your case this morning on my way into work, going over the drug options to give you. It is limiting. But our goal is to avoid what you experienced last time."

For a moment, I was impressed that on her way into work she was already preparing for my surgery. I wondered if she had had a long enough commute to review my file. *Did she drive, take the train in, was she driven in?* I wondered if she had a chauffeur.

She asked me a few questions and answered some of mine. She gave me the space to remain calm, not rushing me into the operating room. Dr. Greene's relaxing, compassionate presence immediately earned my trust. I knew she would, in part, have my life in her hands. The surgeon would have the other half.

"You ready to follow me in?" she asked.

Unburdened by the weight of maintaining self-control, I slid off the bed and followed her, crossing the grey-tiled floor. Entering the room, I noticed how brightly lit the space and the table were, mirroring my internal lightness.

January 15, 2018: The First Surgeon

"The endometrial biopsy we did last month was negative," the gynaecologist said. I awarded her the name Dr. Compassion because of her kindness, understanding, and gentle approach. She looked from her computer monitor where the results were displayed to me, sitting beside her.

We were at her desk in the examination room, tucked in a corner on the fourth floor of a small medical building complex. The brick walls had recently been painted white. The painters' tools were stacked at the end of a corridor for the nightly painting schedule. They had been working on brightening the hallway; the exam room air still had the lingering fresh paint smell. I wondered how Dr. Compassion was able to work an eight-hour shift breathing in those fumes. As for myself, I was lightheaded and ready to leave after fifteen minutes.

"As I mentioned a few months ago, back in October, your uterus is about the size of an eighteen- to twenty-weeks gestation. A healthy uterus is roughly the size of a small pear," she said, before I could ask. "So, I still do recommend a hysterectomy."

I had expected her medical advice. Three months earlier when I first met her, she had told me to 'start considering' this as a possibility. I didn't plan on having more children. I wasn't emotionally attached to my womb. If anything, I was so uncomfortable by its enormity that I wanted it out. Even though it had been twenty years since my daughter was born, I remembered twenty-weeks gestation was the mid-point of pregnancy. In my current situation, I was not 'with child' but with 'bulky uterus.'

"That's a pretty big uterus," I said. I was sitting on the edge of the chair with my feet flat on the floor, facing Dr. Compassion. Particularly since the biopsy, I was only able to sit in a ramrod upright position. Otherwise, I had difficulty breathing, feeling as though I wasn't getting enough oxygen. At home on the sofa, I sat with two cushions padded behind me. My husband, Steve, on occasion would comment how much he missed sitting next to me, that the cushions were not warm like I was, that we were misaligned and unable to properly hold hands. I knew my situation added an element of serious and frustrating change to our relationship, but we both knew that it was out of our control.

Needing to sit so straight required me to focus on various muscle groups to keep me in an erect position for any prolonged length of time. Usually, by mid-day, my back would be so sore that I would end up hunching forward, giving the muscles a break. My goal during this appointment was to stay as straight as possible for as long as the

appointment lasted. Five minutes in and I was ready to hunch over, but I didn't. I willed myself not to move.

"It is. And once it's out, you'll feel so much better," Dr. Compassion said. Her warm smile reached her eyes, comforting me.

"I don't remember what it feels like to not be uncomfortable. I miss sleeping on my back; it'll be nice to be able to do that again," I said. I leaned to my left and rested my elbow on her desk, alleviating some of the weight off my back. I thought back to what twenty weeks had been like. Unfortunately, my pregnancy had landed in the one-to-two percent cases of pregnancy. I was monitored nearly every week due to a polyhydramnios womb, an excess amount of amniotic fluid. There was so much fluid that people repeatedly mistook me for carrying twins. I was certain that my experience of twenty-weeks gestation was not the same size she had mentioned.

"I'm scheduling surgeries for March, so I can get you in then," she said.

"Which hospital do you go to for surgeries?"

"City One Community Hospital, here," she said, pointing downward indicating City One, not her desk.

"Oh. Can you go to City Two Hospital instead?" I asked. I pulled my elbow back to my side and sat straight up. During our initial appointment, I had briefly mentioned an unexplained event following my first surgery for a thyroidectomy back in 2005. It scared me enough to search for answers from various doctors for more than a decade. No one really was able to provide me with defining answers, so I was unable to have a proper

surgical plan in place.

"No, I only work at this hospital," she answered. "That's where I'm authorized."

"Um, okay," I said. I clasped my hands together, twisting my fingers. "I've been told by a few anesthesiologists to avoid community hospitals because of what happened to me after my last surgery," I said. All the previous doctors I discussed my case with would only tell me their impressions, their thoughts, their assumptions about what had happened in 2005. No one would provide me with an official letter to carry forward, to deliver to any potential doctor. It resulted in me recounting the events over and over again, giving the next doctor the position to determine how to handle my case. I was the messenger between professionals telling other professionals that they may or may not lack knowledge in their field. "I've been told by other doctors, some anaesthesiologists, that community hospitals wouldn't have the expertise to handle my case."

"What happened to you again?" She swivelled her chair away from her desk and faced me. Our knees were inches away from each other.

"In 2005, I had a thyroidectomy for cancer. I've been told what I experienced was something like Postoperative Cognitive Dysfunction. I don't remember about three-to-six months after the surgery. And," I said, looking down at my tightly clasped hands, "my husband said my personality changed, that I yelled at him all the time. He said it was a good six months before I stopped yelling at him. Anaesthesiologists that I've met with in the past told me to avoid the same drugs I was given in 2005. They suggested that larger city hospitals would be better positioned to help me."

"City One Community Hospital is a good hospital. The surgery wing is newly renovated. You can take a tour of it if you like," she said. "It might reassure you."

"I'm sure it is really nice, but I don't want to take that risk," I said. "I can't. Are you able to refer me to another gynaecologist at City Two Hospital?"

"No, your family doctor will have to do that," she said. She turned back to her computer and wrote a brief few sentences to my family doctor, Dr. Kindlady, requesting her to refer me to a gynaecologist at City Two Hospital. As I left, I noticed Dr. Compassion's demeanour, while still warm, turned brisk. I was no longer her patient.

April 7, 2005: A Québec Hospital

You follow a nurse into the operating room. You feel exposed because you are only wearing a hospital gown. Not permitted to wear jewelry during the surgery, your wedding ring adorns your husband's pinky. You know he sits in a waiting room in a different wing of the hospital with your seven-year-old daughter. Your thirteen-year-old stepson sits at his desk in school waiting for news about the day's events. You and your husband spoke once with the surgeon a week or two ago, a week or two after your cancer diagnosis. The surgeon told you that the surgery would be quick, that you would be in and out of the operating room within an hour. He assured you that he would inform your husband about the progress. You never met with the anaesthesiologist. It was never offered.

When you sit on the surgical table, the anaesthesiologist doesn't speak to you. He sits at the head of the table wearing green scrubs. Beside him sits a young woman in

identical attire with black hair. You say hello. They look at you.

You wonder if the surgeon informed the anaesthesiologist that you are hypersensitive to certain medications. You turn around and say, "Je suis très très très sensible à tous les médicaments. J'arrête de respirer avec la morphine." You say with an added plea, "I'm very sensitive to drugs. I'm allergic to morphine. Please be careful."

He nods, not looking at you, but at his instruments. You don't feel that he heard you. So, you say it again, in both languages. He nods again and whispers something to his assistant. You turn around to see the nurse who is waiting for you to lie down.

April 6, 2018: The Second Surgeon

My appointment with the new gynaecologist was to be in six days, on April 11th. She was unable to see me any sooner following my appointment with Dr. Compassion. That afternoon, after I complained about the level of pain and swelling I had been dealing with since the biopsy, the new gynaecologist's assistant advised me to go to the emergency room at City Two Hospital. I was told to ask for the on-call gynaecologist. Prior emergency room trips, I had requested for the on-call specialist. However, each time my request was refused. This time though, I was the messenger between doctors and was told to name-drop.

Steve came with me. Somewhere after the eighth emergency room trip over the span of three-and-a-half months, we lost count of how many emergency room visits I had made since the biopsy. We figured it was at least more than ten times. My abdomen had

swelled so much and was so tender that even the elastic waistbands from my panties induced pain. Two months earlier, embarrassed and frustrated, I broke down and purchased maternity pants and panties.

"I'll give you sixteen- … eighteen-weeks gestation," Dr. Tallman, the gynaecologist, said. "That's a *huge* uterus."

"Yes, I've been told it's large," I said. "But it doesn't explain the pain and swelling I've been in since the December biopsy." I was sitting on the examination bed, still wearing my sweater with a paper sheet for my lower half. Dr. Tallman had just examined me.

"So you don't normally look six months pregnant," he said. I looked at him, unsure how to respond to such a comment.

"No. This is not normal for me." I wondered if I should defend myself, let him know his comment was insulting, or just move on.

"Tell me again why you didn't have your surgery at City One Community Hospital?"

A flash of irritation flickered through me, my spine tingling. Every single time I met with a doctor, I would be asked to repeat the same story: once in the start of the meeting, and once after they assessed me. I knew that I shouldn't complain because they were being thorough, but the repetition was a bit much.

"Because I have been advised from multiple anaesthesiologists to avoid general anaesthesia at community hospitals. Specifically to avoid the drugs given to me during a

thyroidectomy in 2005 because I developed Postoperative Cognitive Dysfunction, or something like it." Some doctors had told me that my young age and non-cardiac surgery disqualified me from that diagnosis. Some had told me because I hadn't had the pre- and post-operative neurological assessments, they were unable to diagnose me with POCD. Some said my symptoms were 'something like Postoperative Cognitive Dysfunction' and one even said that it was that. I lacked a proper diagnosis, but I sort of had one. It was confusing.

"So, what happened then?"

I looked up at Steve who was standing on my left side. I hated talking about that period in front of him because I couldn't remember it. I knew that period was also painful for him. When I pressed him for details, he would look away from me, avert his eyes and look down. Usually, he would reservedly talk about that period, emotionally shielding me from the pain he had endured. He would tell me that he stayed with me because he believed in our love and that he "would hold on for dear life." Sometimes, I would ask more questions prompting him to talk more about it. Those times though, he pulled back. He would tell me he couldn't talk about it anymore. Talking about that period to doctors in front of Steve meant I was telling his story.

Steve looked back at me and reached for my hand. He knew this was difficult for both of us, but he also recognized that this was my health story. He squeezed my hand, encouraging me to answer Dr. Tallman's question.

"I don't remember about three-to-six months after the surgery. Steve," I said,

looking up at my husband, "said that I yelled at him a lot. He said my personality changed. And that it took me about six months to stop yelling at him." As an after thought, I added, "I also lost my photographic memory."

The gynaecologist, no longer wearing examination gloves, held his chin pensively. His nurse stood beside him, watching him think. Steve and I joined in on the observation and waited for Dr. Tallman to speak.

"You say that you have an appointment with Dr. Gyne next Wednesday?"

"Yes."

"Dr. Gyne will end up sending you back to me because I take on all the high-risk cases. I won't take you."

I heard his words but my mind couldn't process what he meant. "I don't understand," I said. I felt small sitting on the examination table with three people standing around me, looking down at me. I wanted to stand up, to feel like an equal in this conversation. But I only had a fragile paper sheet between us.

"I'm the head and chief of gynaecology here at City Two Hospital. I take on the complex cases. Dr. Gyne would see that your case is complex due to the postoperative cognitive issues and send you back to me. So, I'm letting you know now that your case is too high-risk for me. Our anaesthesia team doesn't have the expertise to help you if something goes wrong."

I stared at him, confused and overwhelmed. My brain couldn't compute this new information. City Two Hospital was a newly constructed hospital and kept advertising

how 'state-of-the-art' the facilities were. Yet this head-and-chief was telling me something completely different. I saw him look at his watch on his wrist. *So he won't take me?* I thought. My eyes stung with emerging tears. Steve reached down and squeezed my shoulder to give me strength.

"So, where am I supposed to go?" I finally said. I felt diseased and discarded.

"City Three Hospital. It's a tertiary hospital with more expertise. Plus, if something does go wrong—and it sounds like it will with you—they'd be able to help you immediately. They're equipped to handle those kind of emergencies. Here, we're not."

The words 'it sounds like something would go wrong during surgery' chilled me. My ears rang. '*Go wrong*.' That was not encouraging. *Why would someone say that to a vulnerable patient?* I screamed inside my head. *What the fuck is wrong with them?* I wondered.

"I know the head-and-chief of OB/GYN over there. I'll send an urgent referral to get you in right away."

"Okay," I said. While I knew it was important to be at a hospital that was better equipped to handle my case, I felt like a beachball caught in the wind without any control of my destination.

"And I'll let Dr. Gyne know my decision. No need for you to contact her. I'll do it."

"Thank you, Dr. Tallman," Steve said. I watched, emotionally numb, as the two

men shook hands.

As the nurse and doctor were leaving the room, I quickly said, "Thank you." I looked back at my socked feet sticking out of the paper sheet.

"This is good news," Steve said, holding onto the beam of light I had yet to see. "You'll be in better hands."

April 7, 2005: A Québec Hospital

You ask the nurse if you can see the surgeon before the surgery starts. You're lying on your back with your hands balled tightly together across your abdomen. The surgeon appears beside you and smiles. "Hi," he says. You say nothing. You look into his eyes, wanting to say good morning, but your mouth won't work. You wonder if he remembers that you love your family, your husband and children.

"Did you think I forgot about you?" he asks, smiling. You don't answer. You try to open your mouth, but can't. The muscles refuse to work. You eyes are wide with fear. "You'll be awake before you know it," he says and squeezes your arm, avoiding the IV line. It is nearing nine-thirty in the morning.

Your eyes close.

May - June 2018: The Third Surgeon

At City Three Hospital, I met with the third surgeon, Dr. Blunt, on two occasions. During those visits, he told me that his clinic didn't perform the classical, bikini-cut

hysterectomy that I wanted. He said his clinic performed laparoscopic hysterectomies. As I had done some research on the types of hysterectomies after my first meeting with Dr. Compassion, I understood that laparoscopic hysterectomies were either under a power morcellator—think of an internal food processor—with the chopped bits suctioned out, or the uterus was pulled out through the vagina.

"I've been swollen since the biopsy in December," I said during my first visit. "I've been like this for six months." The examination room was smaller than the other two gynaecology examination rooms I had visited. This one was so compact I felt my personal bubble was being invaded. "Even these maternity clothes are painful." I motioned to my loose fitting pants.

"I don't know why you responded to the biopsy the way you did," Dr. Blunt said. "We do three or four biopsies a day and I've never seen a reaction like this."

He could not provide an explanation for the incredible swelling, nor did he offer to investigate it. I angled questions around nicked uterine veins or other considerations. He wouldn't entertain those notions. Instead, he performed an ultrasound, pressing on the tender swelling of my abdomen. During the ultrasound, I had to be on my back. The growing chest pain was so intense that my eyes filled with tears. It also didn't help that he had to firmly press the ultrasound doppler down on my abdomen. The pain was sharp. It reminded me of the rawest, deepest bruise being pressed into by a pointy object, like a finger. It might have been possible that I wept from both: the chest pain and the bruising pain. After the imaging was finished, he referred me for an MRI to get a better picture of

the uterus to rule out that it wasn't compressing on the renal system.

"All of your symptoms for uterine fibroids and adenomyosis are atypical," he said. "I'll see you in a month or so to review the MRI results. From there, we will discuss your options."

Steve attended the next appointment with me. We were in a different examination room from my first visit which was just as compact. Dr. Blunt, in as few words as possible, informed us that the uterus was large and had fibroid tumours of varying sizes. Dr. Blunt went on to say that he had patients with fibroid tumours as long as his forearm and they didn't need surgery. He said they were fine. That they were able to live with theirs. Since mine were 'small' in comparison, I should be able to live with it without surgery. I pressed him, saying that I wanted the surgery. I indicated that I was still as swollen, if not more, than I was when I first met him. He did not acknowledge that swelling.

"I want the hysterectomy. I delivered my daughter via C-section. But I'm not comfortable having this really big uterus being pulled out of my vagina," I said. I knew what I wanted but hoped I didn't sound like a defensive 'know-it-all' patient.

"Well, this is a minimally invasive clinic. We don't do the classical hysterectomy," Dr. Blunt said. This was the third surgeon in six months that I had met. Between Dr. Blunt and Dr. Tallman, I wondered what I, as a patient, was doing wrong to encounter disdain from those in a position of authority. I didn't know what my next steps could be. I was a patient. They were the doctors. I quickly debated in my mind about asking Steve if we

could refinance our house so I could go to the United States for surgery.

"You don't offer other options?" I asked Dr. Blunt.

"Why are you here?" Dr. Blunt said, not acknowledging my question or pain. Over the course of the two appointments, this was his third time asking me this question.

"I need a hysterectomy and Dr. Tallman said you were the best," I responded each time, unsure what other kind of answer to give.

"It sounds to me like Dr. Tallman passed the buck because he didn't want to risk his reputation on your case," he said. He spoke quietly, but with irritation.

I wasn't sure what to say to that kind of statement. Steve sat in a chair across from me, watching my reaction. My head was spinning, my heart was racing. I thought I had misheard him, but when I replayed his last comment in my mind, I knew I hadn't misheard him. I heard his insult correctly the first time.

I wasn't sure how to respond to Dr. Blunt's remark about Dr. Tallman's reputation potentially being lost because I needed a hysterectomy and wanted to protect my perioperative brain health.

Following my silence, Dr. Blunt repeated his question to me, stressing the final word, "Why are you *here*?"

"I need a hysterectomy and Dr. Tallman said you were the best," I responded. If the last five minutes were any indication, I preferred Dr. Tallman's bedside manner to Dr. Blunt's, regardless of who was the better surgeon.

The anger and frustration coursing throughout me warred with the emotional hurt

that Dr. Blunt had caused. What I perceived as a callous attitude regarding my situation seemed unconscionable. Humiliation splashed over me like ice water. My swollen abdomen prevented me from bending over to tie my shoes. I had to buy maternity clothing to reduce the pain regular clothing caused. I couldn't sleep on my back because the uterine fibroids and adenomyosis that was now my uterus compressed on the vena cava, the vein pumping blood to my heart. I was supposed to be in the prime of my life, but had no sex life. This surgeon who was said to be the best wouldn't explore why my abdomen was so swollen following a biopsy. And he wasn't willing to surgically alleviate my growing discomfort. Dr. Blunt made it clear: my emotions, my humanity, my personhood was all an object to him. I was a case, not a person. Dr. Blunt's comments and dismissiveness clearly stated that I was not worthy of being considered a human being.

Looking down at my lap, I shielded my eyes from him. I would not risk him seeing the shame and helplessness I knew was on my face. I would not let him see the tears in my eyes. I was confused how a surgeon could talk to a patient like that. As a patient being the target of that kind of *mis*treatment, his words seemed condescending and disrespectful, malicious in nature. I was not able to forget his elongated '*here'* to his 'why are you *here*?' question.

Dr. Blunt ended our meeting by telling me to consider drugs to shrink my uterus. Those drugs had serious side-effects. Since a radiation treatment for cancer in 2008, my body had changed. I developed an even more hypersensitivity to drugs, and medicinal allergies that made pain relief a complicated affair. I wasn't willing to trade in the pain

and swelling for side effects. And Dr. Blunt wasn't willing to discuss surgery with me. After that appointment, I felt that his approach to help patients was not collaborative.

Steve and I left the appointment unsure about what direction my care was going in. I wouldn't accept the drug he wanted to put me on and he wouldn't discuss any other option with me. He did not work with patients, he dictated to them.

A week or so after that last appointment, I called Dr. Blunt's nurse leaving a message. I told her that no patient should ever be spoken to the way he did me. "No patient should ever be left without any direction for their healthcare," I said. I knew my face was a deep shade of red when I said the next bit. I could feel the heat. I told her that Dr. Blunt's unwillingness to perform the surgery was inhumane and that no patient should ever be treated the way I had been. When she returned my call after discussing my message with Dr. Blunt, she told me his response was for me to return to my gynaecologist, Dr. Tallman. I reminded her that Dr. Blunt was my gynaecologist. Surprised, she said she would call me back after talking with him more.

Seething from that phone call, I went to my family doctor's office. Thankfully, Dr. Kindlady took walk-ins and was able to see me quickly. I wanted clarity about my situation and the mistreatment I had experienced from Dr. Blunt. I told her what he had said to me. Ashamed that such an insult was made against me, I wiped my tears on the back of my sleeve. Her expression changed between sympathy, compassion, and disappointment. In a comforting tone, she said that Dr. Blunt should not have said what he did to me about Dr. Tallman because it wasn't professional. That it wasn't a reflection on

me, it was a reflection on him. She suggested that Dr. Blunt must have been having an off day, as though that excused his insult.

Since I hadn't seen Dr. Kindlady in a month, she was shocked to see how much larger my abdomen was from the swelling. I begged to be sent to any of the City Four hospitals, that maybe someone there would help me. In the end, I hopped on a train with my medical file and referral from Dr. Kindlady. She suggested I present myself at one of the several emergency rooms in City Four. Any would do. Her hope was that someone could help me and stop bouncing me around.

April 7, 2005: A Québec Hospital

Your eyes open.

There are two women and a man standing several feet away from you beside a counter, talking and laughing. Your eyes close. The sounds are thick, black. Your eyes open again. Standing around you are the three nurses. One of them pulls something from your mouth and air slides down your trachea, touching you again. But you don't feel it. You notice the big white clock—but it is somehow black—hanging on the wall behind the counter where the nurses had been standing. You read that it is after three-thirty.

"Five and a half hours," you say. Your voice is hoarse. You will later realize, and be impressed by this fact, that you did math so quickly despite all the drugs in your system intended to cloud the body's pain receptors and brain functioning. "It was supposed to be an hour. Something went wrong."

"The surgery was an hour. Nothing went wrong. It just took you a really long time *for you to wake up," one of the nurse's say, laughing.*

They all laugh. You can't recall if they spoke to you in English or in French.

Your eyes close.

Late July 2018: The Fourth Surgeon

I left Dr. Kindlady's office and headed straight for the train station to City Four. I was on the train for ten minutes by the time Dr. Blunt's nurse called me back. She was surprised to learn that I was going to another emergency room when I could have presented at City Three Hospital. I reminded her that Dr. Blunt said hours earlier he was not my gynaecologist. My family doctor and I decided that I therefore needed help immediately. The nurse asked me if I could turn around, to hop off the train and go to City Three Hospital because one of Dr. Blunt's fellow surgeons was willing to see me. I decided to trust someone other than Dr. Blunt at City Three Hospital, so I agreed to go back. Steve met me there.

Back at City Three Hospital, Steve and I met with a fourth surgeon, Dr. Angel, who ended up being Dr. Blunt's acting fellow surgeon. Dr. Angel's compassion, knowledge, and eagerness to perform the surgery eased my concerns about Dr. Blunt's condescending attitude. She listened to Steve as he told her how he watches helplessly every day while I try to hide my pain level from him. He told her that I was working my way through my undergraduate degree, trying to focus on that instead of the pain, but that

he knew I suffered. We told her that Steve couldn't touch my abdomen, even when I slept. If he did, I would cry out in pain. Dr. Angel agreed that I needed surgery and offered to perform it. The contrast between her and her boss was striking: she acknowledged my pain. He ignored it.

"The size, the weight of your uterus, must be incredibly difficult," she said. She told us she had reviewed the MRI from several weeks earlier. "There are over twenty fibroid tumours in there."

"That's a little village," I said. I was lying on my left side in an empty area of a quiet maternity ward. Instead of being in the cold emergency room, they had brought me upstairs so Dr. Angel could see me in between her other patients. Dr. Angel was sitting on a stool in front me. By talking with me about my condition at that level, my head height, showed me that she considered me more than just a patient. She considered me as a human being with feelings.

"There are also a few pedunculated fibroid tumours. They are growths that hang off outside of the uterus," Dr. Angel said, telling us more about the imaging results than Dr. Blunt had. She used her index finger as an example, slightly bending it to provide a visual. "They hang off like this," she said, looking between me and Steve. He was standing behind me, resting his hand on my shoulder and rubbing his finger in circles.

"The swelling and pain that you're in is because these tumours will outgrow their own capacity and rupture. They bleed internally until they coagulate, like an internal scab. Other times, due to friction, like the rubbing against the peritoneum—that's the lining of

your abdomen— from movement like walking, will make these tumours rupture. And sometimes they'll stick to the peritoneum. All of this creates all of your swelling and pain."

I started crying. Still on my left side, the tears rolled from my eyes, sliding over my nose and wetting the pillow I rested my head on. Suddenly, my pain was validated. There was an explanation. It was real. It wasn't in my head like Dr. Blunt had made me feel. Dr. Angel reached forward and rubbed my forearm. Steve wiped the tears from his eyes on his sleeve.

"Let's get this out of you so you can have your life back," she said. "I'll contact my assistant to get you booked in immediately."

I leaned backward to look up at Steve. The tip of his nose was red and tears continued rolling down his cheeks.

"Thank you," Steve said. "Thank you so much."

The end was approaching. Dr. Angel was confident in her ability to extricate the diseased uterus that was causing this incredible pain and swelling that disrupted my life on so many levels. Steve and I were desperate for pre-patient life to return. Relieved, Steve and I listened as she discussed how she would perform the surgery: a sort of partial laparoscopic hysterectomy, no morcellator since they didn't use those at City Three Hospital. She said they would insert a sterile bag inside my abdominal cavity, under the uterus and cut it into chunks through a small hole in my abdomen, pulling the pieces out through that hole. The idea was faster healing and reduced infection risk. She said she

was compromising between the classical method and the laparoscopic method. And she acknowledged my perioperative brain health concerns.

"I am fully confident in the entire surgical team," she said. "You'll be able to discuss your perioperative brain health concerns with them at your pre-op."

April 7, 2005: A Québec Hospital

Your eyes open.

Someone rolls you down a hallway on a bed. The bright fluorescent ceiling lights are dull. You see your husband's face. It is pinched inward, eyebrows pulled tight. You know he is worried. He clutches your daughter's hand as he searches your face. Your hand raises. He will tell you later that he waited over six hours to see you, to have any news about you. The nurses talk to your husband. You don't understand. Your eyes close.

Your eyes open. Your husband stands on your left side. Your daughter is at your feet, watching you. You don't see your stepson. Everything is dark. There is a curtain that hangs in front of your eyes, inside your mind, and the rest of the world outside of you.

"I'm so glad you're okay," he says, his voice is a mixture of relief and worry. You don't feel his breath against your ear when he kisses your cheek and whispers."I thought something was wrong. The nurses wouldn't tell me anything. I kept asking them. They said they couldn't tell me anything even though I'm your husband. It took you so long to wake up."

There are nurses moving between your husband and your daughter. They are

moving lines, taping your arm. You don't speak.

Your eyes close.

August 16, 2018: City Three Hospital, Pre-op Appointment

A week after seeing Dr. Angel, Steve and I learned that a surgery date was around the corner. First stop, pre-op appointment. To prepare, I gathered all my documents regarding my 2005 surgery and put them in a manilla envelope, leaving them at the front door. It was easier to remember if it was at the door.

Unfortunately, the end that Steve and I had believed was fast approaching got pushed further away and out of sight. The newest brick wall came from a reluctant doctor whose role was crucial to protecting my brain health: the anaesthesiologist. Dr. Angel's comforting words and compassion disappeared into a void.

Steve and I were at City Three Hospital in an even more compact room with only a desk and three chairs; the anaesthesiologist sat in the third chair at his desk. His desk reminded me of one that might be found at a secondhand office supply store: battered wood married with metal in a clashing disunity, oversized drawers that hogged leg space for its user, and the plastic chair that moulded to his body. The desk took up more space than the room permitted for its three occupants. I had given the contents of the manilla envelope to the nurse, who then gave it to the next healthcare professionals along my pre-op journey. This last stop was with the anaesthesiologist. So far, everything seemed to be in order. Steve and I sat against a wall opposite the door in case a nurse had to open it,

which happened in the first few moments of us being in the room. The anaesthesiologist was to our right. We had little room to turn in our seats to face him.

"No," the anaesthesiologist said, raising his chin as he spoke. The effect gave us the impression that he was looking down at us from his nose even though we were at eye level. "We'll give you the same drugs and the same dosage that you had in 2005." He dropped the papers I had given him onto the pre-op file destined for my upcoming surgery, and then he looked at me.

"But I can't have those drugs," I said to the anaesthesiologist. In my hands, I clutched at the identical papers he had dismissed, copies of copies from my previous surgery. I wondered if he had even read the list of drugs and compared it with my growing list of medicinal allergies since my radiation treatment. From the way the conversation had rapidly deteriorated, Steve and I sensed that he was dismissing the information contained in the documents from my medical record. I pointed to the list of drugs administered to me on my copy of the 2005 anaesthesia report for the thyroidectomy. Next to the listed drugs I had written '*NO NO NO'* in red ink. "I've been told to avoid those drugs."

"Not from me."

Obviously, I thought. "From other anaesthesiologists I've spoken to over the years," I said. My tone was thick with exasperation. I looked from the anaesthesiologist sitting behind his desk on my right to Steve sitting on my left in his corner of the room. Steve's expression was calculated, non-reactive, but I knew he was listening to the

exchange with intent. I was aware that my face expressed my growing frustration and confusion at this doctor's refusal to hear me.

"Who told you this? From where?" he asked, asking me to defend my past experience.

The word 'patronizing' came to my mind.

"Two from Québec, and a few from here," I said, motioning to the City Three Health System that he was a part of. "Three anaesthesiologists from here told me in 2014. You should have access to those records since you're on the same system. And the Québec Hospital; I gave you the translated report. I was told to avoid those drugs to prevent a similar occurrence of what happened to me in 2005. Just no one can explain what happened." I wondered how many more times Steve and I would have to repeat this to him.

"Well, I don't see a report from here that says that," the anaesthesiologist said after quickly clicking through screens on his computer, ignoring the translated report. At this point, my impression of him was that any challenge outside his knowledge base was an effort he was unwilling to invest in. "I've never heard of what you say you experienced __"

Steve stopped him. "I witnessed it firsthand. I experienced it." His tone was firm, direct, and full of conviction. "It happened."

Instead of feeling like we were all working together towards the common goal of a healthy patient outcome, I felt like Steve and I were unified against a doctor who seemed

to be intentionally uncooperative.

"There are studies on it," I said. "If you look up a clinic in City Four you'll see that they do research on Postoperative Cognitive Dysfunction." I started rifling through my collection of papers. "Wait a second, I have the clinic name right here—"

"It's not our job to look into other clinics' research."

I stared at him, bewildered by his statement. I closed my eyes and took a deep breath. I decided not to remind him that he was working in a teaching hospital himself where knowledge is supposed to be shared. I opened my eyes again.

"If you want a second opinion," he said, standing up, "I'll get one of my colleagues." Steve and I pulled our knees in as he brushed past us. We watched as he left the room, leaving the door ajar.

I don't remember if Steve and I spoke to each other in the doctor's absence. If we had, I would have whispered to him words laced with my shocked disbelief. And Steve would have responded to me in normal tones, not shy to share his opinions about this otherworldly pre-op meeting. A meeting that had catapulted over the optimistic Inner Solar System and straight out inside the catastrophic Asteroid Belt.

The second anaesthesiologist was a giant of a man, towering over us. He leaned against the closed door inside the small room, sandwiched between the desk and Steve. This second anaesthesiologist thumbed through the relevant papers, skimming the information for himself, but mostly he listened to the first anaesthesiologist recount what we had told him from his perspective. I tried to interrupt, to use my words to describe

what happened. Unfortunately, the first anaesthesiologist spoke over me, refusing my voice. Initially, the second anaesthesiologist's approach seemed to be a bit more accommodating.

After he listened to his colleague, he turned to me and Steve and asked us to tell him what I was told by other anaesthesiologists. Because he appeared to be listening, Steve later told me that he felt that second one seemed to consider, at first, my experiences and prior discussions with others. Yet, the more I spoke about it, even after showing him old reports and the name of the other clinic's study, the more obvious it was that he sugar-coated what his colleague had said. Perhaps he took cues from his colleague and preferred not to create a workplace friction. We didn't know. He did, however, assure us that I would be monitored during the entire surgery.

"We don't give you the medicine and just walk away," he said, crossing his arms and standing straight, away from the door. I wondered if people actually thought that that was what happened during surgery.

"I am well aware of what anaesthesiologists do during surgeries," I said.

Steve and I repeated our concern that if I was given the same drugs I have been told to avoid, that we would experience a repeat of what happened in 2005. Our concern, if I was given those specific drugs, was not that I was *not* going to wake. It was that when I *would* wake, I would lose my memory and not be myself. That I would be lost to my family for an undetermined length of time. We could not go through that again.

Despite the evidence before them, both doctors interrupted me and Steve when we

asked them again to look at information from the other clinic. The two anaesthesiologists demonstrated to me and Steve who was allowed to talk and who controlled the space. They ignored our pleas to be heard. The more Steve tried to interrupt them, the louder they spoke. As someone who avoids confrontations and raised voices, the volume in the room was so loud that my ears were ringing, and my heart was pounding. I wanted to run out of the room. To me, it sounded like a yelling match was taking place between the two doctors with Steve talking to the air. I wondered if they were trying to mute Steve.

But, Steve wouldn't be ignored. He spoke his sentences with concise words until his message was delivered. He ensured that what he had to say was said, whether they listened to him or not. He seldom spoke to others about his experience from 2005. And there he was, saying it loud and clear to the people who needed to hear it most. As it was difficult to for me to isolate his voice from the two competing anaesthesiologists, I knew how precious that moment was and that those two men lost out on a valuable lesson.

After Steve stopped talking, they declared to us that between their combined twenty-plus years of experience, and because *they* had never having heard of such a thing before, they would not change the pharmaceutical recipe. The conversation was factual only on their terms without any consideration of current literature I had attempted to share. I was numb from my rage and their raised voices. I wanted to scream at them, to insult them as they had me when they dismissed my experiences. I wanted to demand to see the head and chief of their department. I wanted to broadcast to the world the incompetence that I witnessed.

I didn't know what their prior experience was. I didn't know what their education was. But sitting there, being talked *at* as I had been, and having my history dismissed the way it was was a disheartening experience.

They were in a position of authority.

I was powerless under them.

Instead of showing them my anger, I followed Steve's lead. They wanted control of the room, they could have it. I closed my mouth and looked at them.

They offered me the option to accept surgery using the same drugs at the same dosages from 2005, or not to have the hysterectomy at all.

Despite the earlier verbal brawl, in his desperation for me to have the surgery, Steve was willing to accept the risks of reliving 2005.

"Maybe you should have it here," he said, shrugging his shoulders helplessly. He ignored the men watching us, talking to me gently, but with desperation. "I can't keep living like this, with you in pain all the time. We need our lives back."

Not having memories from that period, but having heard the stories of the emotional pains I inflicted on my family and friends, I couldn't accept that kind of risk. Steve had cried to me when talking about the things I would yell at him. My mom couldn't finish a letter I apparently had written her; later telling me it was so cruel and heartless, nothing like she'd ever heard from me before. One of my oldest friends wouldn't talk with me for eleven years because the words I had said were so brutal. The palpable guilt I lived with from that period was physically gut-wrenching. I had spent the

better part of ten years researching literature and articles, speaking to and interviewing with specialists, and attempting to piece together memories from a time that I would never gain access to, except only from others' stories.

The two anaesthesiologists offered to send me to a neurologist, which would take several months for the first appointment. Those two anaesthesiologists had lost any trust I had blindly given them when first walking into that room. Any confidence I had in their ability to hear me as a patient, to have compassion about the experiences both Steve and I had lived through, disappeared the moment they refused to learn about a serious postoperative event. Anything they offered me at this point was moot. I declined their offer to see one of their neurologists because I believed my case would again be dismissed. I couldn't accept my surgery happening at a hospital where one of those men might hold my life in their control. I did not feel my life was safe with those doctors.

"I won't take that risk," I told the anaesthesiologists. "I can't put my family through that. Not again."

A week later, when I picked up copies of the clinical notes from the pre-op appointment, I read what the first anaesthesiologist had written: "Surgery: should not proceed." The report said that he had consulted with two other anaesthesiologists, and together they all agreed that what I experienced was unrelated to anaesthesia and that they had never heard of it. So it wasn't real. I couldn't understand how three anaesthesiologists in 2014 had heard of Postoperative Cognitive Dysfunction and my cognitive and memory impairments, while three anaesthesiologists in 2018 in the same health system had never

heard of it.

In the comfort of our home following that surreal appointment, Steve would tell me that it felt like we were on different planets from them: we were on Earth with concrete information, and they were on their planet telling everyone, 'nope, it's not a thing.' We would spend hours processing and sharing our combined bewilderment about how they could refuse to acknowledge or even accept that a patient would try to self-advocate to protect their brain health. We couldn't comprehend their unwillingness to not expand their knowledge.

"They dismissed your experience because the alternative inconvenienced their capacity to be challenged," Steve would say.

But first, before we would discuss our disbelief, and without wanting further delays, I called Drs. Blunt and Angel's assistant from the car on the way home after the pre-op appointment. I explained what had happened and said, "Please refer me to City Four Hospital where they accept knowledge and specialize in anaesthesia. I'm done being bounced around. I'm done."

April 7, 2005: A Québec Hospital

Your eyes open.

A man stands over you, on your right. The room is shrouded in dark grey. He looks like the surgeon, but he is blurry. His green surgical scrubs are dark, almost black. "The surgery was a textbook case—in and out," he tells you.

You say something. You might be asking him why it was more than an hour. Your husband says something to the man. You know your husband is on your left. You don't understand the words being spoken.

"It took you a really *long time to wake up, dear," the surgeon says with a chuckle. You think he puts his hand on your shoulder and squeezes.*

"And see," the surgeon says, smiling. "You still have your voice."

You know he mentions that you didn't need to be so worried about the risk of vocal cord paralysis. You think about the audio recordings you made for your daughter. All of her favourite bedtime stories recorded as a precaution for that potential loss. The thought that you will be able to read to her, any story she wants, comforts you.

Someone is talking. You hear a question. Or maybe a statement? Someone, the surgeon, tells your husband that they will know more when he receives the pathology report. He says he thinks they got it all.

Your eyes close.

October 5, 2018: City Four Hospital Anaesthesiology

Three weeks after the meeting with the two anaesthesiologists at City Three Hospital, Steve and I drove forty-five minutes to meet with the fifth surgeon, Dr. Great, at City Four Hospital. Dr. Great agreed that the village of fibroid tumours needed to be removed, but that I was starting at zero on the surgery list. We were told it would be ten or so more months of waiting. In the meantime, he offered to send me to an

anaesthesiologist for a consult. He suggested that depending on what the anaesthesiologist informed me, I could return to Dr. Blunt.

Not skilled in diplomacy the way my logically-minded husband was, and because I had lost complete confidence in the two anaesthesiologists from City Three Hospital, I said no and I said why. The surgeon urged me to reconsider it an option if I was unwilling to wait almost a year for surgery. I wouldn't change my mind.

A month later, I went by myself to meet the anaesthesiologist for a consult.

*

"Tell me what happened following your thyroidectomy in 2005," the anaesthesiologist said. I named him 'Dr. Wiseman the anaesthesiologist' because he saw what others had not seen. In our first and only meeting that would last more than half-an-hour, Dr. Wiseman sat at a disproportionate wooden desk that was unable to accommodate his long legs. He crossed his legs between the desk frame and me.

"I don't know because I don't remember that time. My husband said my personality changed after I woke up. He said I went from being a loving person before the surgery to angry after it. Like a personality change," I said. I looked down at the file of papers in my hands resting on my lap, unseeing the words. "He told me I would just start yelling at him for no reason. That's not like me," I said, looking back up at him, imploring him to believe me. "I don't yell."

"Okay. What do you remember about it?" he asked.

"Nothing. It's black. I don't have memories about that time," I said. "I call it my

Black Hole Period." I smiled, hoping to change the atmosphere into something lighter than its current serious tone.

"You don't remember anything?"

"I have a few memories, like there's a dark cloud around them and they're all in fragments, not whole memories. I do remember bits and pieces right after the surgery. But mostly, any memory after that doesn't make sense." I noticed that his questions focused on my memory detail more than any doctor before him.

"And how long did that last?"

"Definitely three months. My husband said that by six months I was returning. More, he said by then I had at least stopped yelling."

"So, six months? What did you do about it?"

"I don't know. You'd have to ask my husband," I said. He declined my offer to call Steve. Despite the many times I have recounted what happened postoperatively to me in 2005, it never got easier. I found it difficult to disconnectedly talk about my experiences for which I have no memory of living.

"All I know is that once I started to remember things after the surgery, I discovered that I lost my photographic memory and I repeated myself all the time. My short term memory is better now, but it was a really long time before it improved." To demonstrate the poor memory skills, I shared with him a story to illustrate how unfortunate things had turned. "A friend told me she visited us sometime after my surgery and had left something at my house when she left. I called her and told her what she had

forgotten, and she said she'd come by another time to pick it up. Five minutes later, I'd see the item, not remembering that I had just called her, and called her again. I did that three times. The second time she thought I was joking. The third time she realized something was wrong. This is what it had been like for several years after the surgery."

Dr. Wiseman took the time to listen to me and to ask questions—a lot of questions—about what I was able to recount, even second-hand. We reviewed my health history, what happened to me following the radiation treatment in 2008, and the list of allergies and hypersensitivities that developed post-treatment. But he kept returning to my postoperative experiences. I felt that no matter how many times and no matter how many different ways he asked me about what I remembered after the thyroidectomy, my answers were the same.

"My husband told me that he would tell doctors, 'This isn't my wife. I want my wife back.' He told me that they wouldn't give him any support," I said. I finally felt my postoperative concerns were really being heard for the first time in years with the intent to hopefully give us answers. The more I answered his questions, the more my mechanical responses turned emotional.

Whenever I thought about the stories that Steve told me about what he experienced, I would feel this deep guilt inside my chest. During this appointment with Dr. Wiseman I could feel that deep pain resurfacing. I needed to envision shoving it back down. I knew that if I allowed myself to fully feel it, I would cry. I didn't want to cry in this meeting. I wanted my experiences to be acknowledged and respected, not reduced

and dismissed as some emotional response. To turn off my guilt, I imagined that it was a dark wiry cloud, similar to the shades of my 2005 postoperative memories. I pushed that cloud to the bottom of a glass jar before slamming the stopper atop it, locking the guilt inside. Only when I was alone would I give myself permission to open the jar and feel the guilt as it encircled me. Maybe I did this as a form of self-punishment for what I unknowingly put Steve and others through.

"Steve, my husband, said doctors would tell him to bring me to a psychologist," I said.

"And you say this *personality change* lasted for…?" Dr. Wiseman asked me again. I was beginning to feel like this was a test. But what mattered to me was that he listened, that he considered my experiences, and that he might determine medically what could have happened. I hoped to leave with answers, not questions.

"He said I started to come back to him about six months after the surgery." Steve usually looked down and away from my eyes when he would tell me this. By concealing his eyes from mine, Steve would try to shield me from the pain he still feels today. Sifting through old journals and emails from that time, we have since discovered that Steve endured more than six months of me yelling at him for no known reason, of me telling him I didn't want to be with him. In those emails and journals, I read words written by my hand, but not from me. Those words were full of hate for the man I love so much. None it made sense.

April 7, 2005: A Québec Hospital

Your eyes open.

The room is still dark.

Your eyes close. *You hear noises.*

You hear voices. *There are sounds.*

People keep touching you.

You hear your name.

Your daughter calls out, "Mommy?"

A sharp scratching on your arm pulls you closer to the little voice.

Your eyes open.

October 5, 2018: City Four Hospital Anaesthesiology

Dr. Wiseman looked again through the papers from the 2005 surgery, the recovery room report, and the nurses' reports from the patient room.

"Your blood oxygen saturations dropped here," he said, pointing to the recovery room report. "It doesn't say why or for how long."

I wanted to know how low my oxygen sats had dropped. When I was a teenager with pneumonia, it had dropped to sixty-two percent before I was given oxygen treatment. I decided that I would look at my copy of the reports when I got home. Dr. Wiseman had demonstrated his time was being well used and I didn't want to take advantage of it by asking for a crash course in anatomy and physiology and medical

reporting.

"And here," he said, pointing to another page, "they gave you this again. And again, more."

I leaned forward to see the page, hoping to remember which one it was he was looking at. I wasn't sure, but from what I saw, it could have been from the recovery room report. He put the papers down and clasped his hands on his lap while looking at me.

"From what you've told me, it sounds like two things happened after the thyroidectomy. The first, the personality change was a geriatric reaction to the benzodiazepines you were given," Dr. Wiseman said. Despite the factual delivery of information, his compassion was present. "So, avoid drugs from that class." He held my gaze, ensuring that I understood the information he was giving me.

I felt like a sponge absorbing all the water in the room. Any information he provided, I wrote it down, I verified spelling, I asked questions if I wasn't sure.

"A geriatric reaction?" I said, laughing in disbelief.

"Yes, like dementia."

"But I was only thirty-years-old when I had that surgery?"

Dr. Wiseman went on to tell me that it was uncommon, but that it can happen, especially in high doses like I had been given. What he said didn't make sense. Geriatric reactions to benzodiazepines happened to people of a certain age: those over sixty-five. How could my thirty-year-old body react as though it had been a septuagenarian? I thought of my grandmother who died a few years previously. She had had dementia. The

last time I saw her, she cupped my face in her frail and cold hands, asking me in her deep southern-US drawl, “Where have you bin?” before kissing my lips. She thought I was her sister who had died some twenty-years earlier. To me, dementia was kind and loving and frail and confused. Dementia wasn’t abusive and angry and cruel and hurtful.

Unfortunately, during my unexpected and unintentional pharmaceutically-induced geriatric reaction, I had said terrible, hurtful things to the people closest to me. I had been cruel. Some people disappeared from my life, some returned. Some confronted me about those times, others didn’t. My 2005 postoperative behaviour was uncharacteristic. Eventually, most of those friendships would fade away when we moved from Québec to Ontario.

Since Dr. Wiseman told me about my geriatric response to a pharmaceutical drug, I continued to marvel that that could happen. When I read literature on dementia-like symptoms as a result of medicinal side effects, I couldn't help but wonder how many other people out there experience what my family and I had. Especially to someone so young. I wonder how many people’s lives have been ruined, irreparably altered by this class of drug. I thought about how fortunate I was to be in a country where healthcare did not financially drain me. But I also thought about how long it took me, someone of relative privilege, to finally get some kind of an answer.

Considering the time that Dr. Wiseman gave me, I moved on from the benzodiazepine reaction. “And you mentioned that a second thing happened?”

“It’s possible that you experienced, and will experience again, a severe

idiosyncratic reaction to anaesthesia."

"What do you mean?" I scrunched my eyebrows, uncovering them from under my brown and grey bangs.

"I can't predict what type of reaction you will have," he said. "But I am certain that you will experience something again."

"Like cognitively, or otherwise?"

"We will avoid benzodiazepines. We'll use another drug and do everything we can to mitigate the risk of Postoperative Cognitive Dysfunction."

I tried to understand what idiosyncratic event he might be referring to. I wondered if my heart would stop, or was he suggesting that I would experience anaesthesia awareness? My mom had surgery when she was in her thirties. She said she could hear everything that was going on in the operating room. She had tried to yell to the doctors, to alert them that she could hear them. She wanted to know what they were doing to her body. When she was able to speak hours later, she told them what happened. No one knew what she was talking about. She didn't feel the surgery, but she could hear everything they said.

I wondered if this is what Dr. Wiseman was suggesting as a potential idiosyncratic reaction. He couldn't tell me definitively what kind of reaction I might have, just that he believed I would.

"Do you still want to go ahead with the surgery?" He explained to me that he was weighing the level of pain that I was in with that of my quality of life. "If you were my

sister or mom, I would recommend that you go ahead with the surgery."

He didn't need to say that though. I was already convinced to have the surgery at City Four Hospital. Because of his compassionate responses and empathy, and his ability to provide answers, it was a clear decision, idiosyncratic reaction or no.

April 7, 2005: A Québec Hospital

Your eyes open wide. Your mouth opens wide. You hear the long, sharp intake of breath as it fills your lungs.

You see a teenager, a kid, a young woman standing on your right, scratching your arm with a piece of prickly Velcro. Her white uniform is dark grey. "Madame. Respirez! Respirez madame, respirez!" she says, calling out to you.

During this same intake of breath, you roll your head towards the left and see your daughter standing on a chair at the foot of your bed. She looks at you. Her face is contorted. Something clicks and you recognize her emotion as being scared. Your daughter is scared and it is because of you. You continue rolling your head to your left and see your husband, holding your left arm.

Your husband calls out to you, "Honey, breathe, honey. Keep breathing."

You still hear that same sharp sound of air entering your lungs. And then it stops.

Your eyes close.

April 3, 2019: Visit with Dr. Kindlady

Unfortunately, communication from one hospital surgeon to another left room for improvement. For several months, Dr. Great was under the impression that I had refused surgery at City Three Hospital. This explained why I started at zero on the surgery wait-list. Only after several more months of me complaining to Dr. Kindlady about the increasing pain and swelling, and repeated calls and letters to the surgeon's office, were we able to understand the error. During my last visit to Dr. Kindlady before my surgery, she read to me parts of a letter from Dr. Great that stated *I had refused surgery*, therefore I had to wait until August.

"I didn't *refuse* surgery," I said. I was leaning forward with my hands on my knees and the wall behind me. Steve sat near me in a chair. By this point, I was unable to stand upright or sit. I was only able to lean forward with my hands on my knees or lean over a counter to rest my back. If it wasn't either of those positions, I would lie on my left side on the sofa or my bed. I was unable to attend any of my classes. One issue was that the fibroid-tumours-adenomyosis-filled-uterus was now pressing against my right kidney. The pain was unbearably intense. It was either a sharp chest pain that made me feel like I was suffocating, or a violent piercing throughout my abdomen and chest. I hadn't sat at the dining table for a proper meal with my family in two months. I couldn't imagine waiting any longer. I couldn't imagine how anyone could think that I refused surgery. "I didn't refuse surgery. I *was* refused."

"But I don't have documentation to show the surgeon," she said.

I looked up from the floor to her. The room was lit from the late spring sun shining through the window of the examination room. The sunlight shone behind her, illuminating her in an aura. She looked at me, helpless. I could see that she wanted to help, but that, due to the health system, she was stuck.

I leaned against the wall and cried. "I don't fucking believe this." I covered my face with my hands. The stabbing pain in my kidney kicked in and I was forced to lean forward again, resting my hands on my knees to lighten the weight and discomfort in my lower back.

"The two anaesthesiologists from City Three Hospital refused Virginia's surgery," Steve said. I wondered if he was embarrassed by my sudden swearing.

"I'm sorry," I said. "I'm sorry for swearing. I know it's not your fault." My eyes welled with tears. I was exhausted by these frequent wavy emotions.

"I hear you, but *I* don't have it in writing to show the surgeon," my doctor said again.

Something clicked in my mind. "But Dr. Great has a copy of it. I gave it to him when I transferred to his clinic," I said. "The paper, it said from the anaesthesiologist, 'surgery should not proceed.' See? They refused me."

"But *I* don't have that paper to back up this claim," she said. Through the frustration in the room, I was able to understand that she needed more. When not dealing with cognitive dissonance, organizing and planning were among my strengths.

"I do. If I fax the document to you, could you send it to Dr. Great? You could let

him know that I didn't refuse surgery."

She agreed to write back to Dr. Great if I sent her the report proving my claim. Before we left her office, she asked me gently if part of what I was experiencing was fear of dying during the surgery.

Dying from the surgery? I thought. "No! I'm in a lot of pain. I need it to stop. I keep telling everyone how much pain I'm in. It's a nine-over-ten. I *want* the damn surgery. I'm not afraid of dying from it," I said. I was flabbergasted, and pissed off, that my response to the pain level I was living with was being dismissed and relegated to an emotional, mental response, not considered as a physical one. Pain level was not a requirement for help.

I was angry that someone could even think the pain I was in was induced by anxiety. I was frustrated with how my immune system responded to stronger medications making it near impossible to be medicated. I was angry that the only offers available to alleviate the intense pain were over-the-counter analgesics or a prescribed anti-inflammatory. I was already maximizing my daily allowance. I was resentful that I had been bounced around between four cities, four hospitals, and five surgeons. And I was furious that the only solution to my current situation was unavailable to me in the near future because a former surgeon inaccurately communicated the situation.

Unfortunately, channeling my pain through anger at others made it possible for me to tolerate the pain to a lesser degree. Somehow through my anger, I was able to find acceptance of my body without feeling resentment towards it because of the medical

intervention restrictions.

"Doctor," Steve began, his voice calm and level. "Virginia can't sit anymore. Isabelle and I have to drive her to her appointments." He tapped through his fingers on left hand, using his right index finger. As he moved through the fingers, he counted various aspects from my life that had been severely impacted since the biopsy sixteen months before. "She hasn't sat at the table for a meal in two months. She stands like this, leaning over the counter for hours doing homework or lies on her left side. She can't go on walks because the fibroid tumours rupture. Her abdomen is so swollen she's wearing maternity clothes. She has no quality of life." He took a deep breath, looked from me to Dr. Kindlady, and said, "Her pain level is really high. Her current situation is unsustainable."

I was taken aback by Steve's final sentence and realized that he was right. I hadn't considered my predicament as unsustainable. As much as it felt like I was carrying a small moon inside me, I couldn't continue living this way much longer. When I felt truly desperate from the pain and inability to function properly, there were times when I wondered if I should deliberately hurt myself to make the surgery more urgent. But the idea of self-inflicting pain, feeling more pain than I already did, prevented me.

It wasn't a matter of choosing if I could. It was a matter of declaring that I was unable to continue.

"Send me the fax of that report and I'll write to Dr. Great again," she said.

April 8, 2005: A Quebec Hospital

A woman, a nurse, wakes you. She calls your name. She shakes your shoulder to wake you. Your eyes open. Her white scrubs are dark grey. Her hair is brown and short. You look around and notice that you are in a dark room with five other people: three across from you and two to your right.

"Madame," the woman says again. "Prenez ceci, c'est le moment de prendre votre médicament." She hands you a tiny cup with pills in it. You don't recognize the pills. She tells you to take the medicine. You tip the cup upside down above your mouth. The pills land on your tongue. The nurse gives you a cup of water. You drink it, swallowing the pills.

Your eyes close.

A woman, a nurse, wakes you. Urgently she calls your name, "Madame," she says. Her voice is full of anxiety. She speaks quickly and pushes a piece of paper at you, ordering you to sign it. You don't understand. The words on the paper don't make sense. You recognize the letters, but your mind can't assemble them into words. You don't understand what the nurse tells you. She speaks too fast.

"Sign dis," she says. "Now."

You try to understand what happened. She runs out of the room. She runs back in and says, "I give you wrong medicine. Sign dis. Now." She points to a patient in a bed near you and back to the paper.

You tell her no. You tell her to call your husband. You say that French is confusing

you. You used to speak French, but since yesterday, your second language doesn't compute.

She pushes the pen at you. She forces your fingers to close around the plastic. "Sign. Now."

"No," you say. "I will wait for my husband. Mon mari."

"Non. Signez immédiatement."

She is panicked. She speaks in French again, pushing your hand holding the pen to sign the paper that doesn't make sense. "Sign."

You sign the paper in sloppy cursive.

She takes it and the pen before she quickly leaves the room. No one tells you what wrong medication you were given. No one tells your husband.

Your eyes close.

April 15, 2019: Final Exam

Thirteen days after Steve and I complained to Dr. Kindlady, I was on the university campus writing my final exam. Instead of the required two hours, it took me four. Thankfully, the university accommodated me based on my health condition. During the exam, as the only person in the room, I had paced back and forth when not leaning over the desk. I would hold my back like a pregnant woman cliché, or lean forward to rest my hands on my knees. I had to reread multiple times questions aloud to myself to ensure I understood them. Finally, after I completed my essay responses, I gathered the papers,

left the room, and handed the pile to the exam invigilator. Then I walked around, looking for my ride. After a few minutes, I found Steve wandering outside the building, waiting for me. His work laptop was tucked away inside his blue backpack.

"How'd it go?" Steve asked before kissing me. "I'm so proud of you."

"Thank you. I did it," I said. "That's all that matters. Mind if we go see one of my profs before we head home?"

"Sure," he said, slinging his backpack higher on his shoulder, smiling down at me. "I love this, picking you up after your final exam. It's so romantic." He took my hand in his and brought it to his lips, gently kissing the top of my hand. "I love you."

After a short walk to another building on campus, and while talking with my professor and Steve, my cell phone rang. It was from City Four Hospital. Stepping into a stairwell for privacy, I answered the call. Nervousness tugged at my stomach. I was worried that Dr. Great would tell me to go to another surgeon in another hospital because Steve and I had advocated so strongly for my surgery a few weeks earlier.

"Hello?" I answered.

"Hi Virginia," Dr. Great's assistant said, introducing herself. "We had a surgery cancelation for next Tuesday, April 23rd. It's for eight in the morning. Do you want it? Are you available?"

"Yes and yes," I said, a bit more excited than she probably expected. "I'd skip my own graduation if I had to." After a brief laugh, she scheduled me in, giving me information about pre-op appointments and pre-surgery preparations. I was to meet with

Dr. Great the next morning for a last-minute discussion. Steve would need to drive me, and I would again be reclining in the passenger seat lying on my left side, facing Steve's hip.

With tears in my eyes, and a smile I could not suppress, I told Steve the news about my surgery date. He reached forward and hugged me, leaning away from my abdomen. We had not been able to properly hug in over a year. Hugging had become an arms-and-shoulders up affair. After sharing the news with my professor, Steve and I left for the car feeling light in spite of the physical situation. Before we crossed the parking lot, I was on the phone with Isabelle. Tears, joyful ones, rolled down my cheeks.

"Finally. The demolition of my first home," she said, giggling. "Congratulations, Ma! I'm so happy for you." I appreciated her humour and lack of attachment to my uterus. It made me feel that Steve and I had raised her well. At twenty-one, she showed us that her value system was of practicality and quality of life over that of sentimentality.

"Hey kiddo! Guess what!?" I texted my stepson, Christofer. He was working in Québec where he lived. Unsure of his work schedule, I tended to text him first so as not to interrupt.

"Hey! What's going on?" he immediately texted back.

"My surgery is next Tuesday!"

"Finally!" He texted. "Thank god!"

I relayed the conversation to Steve, keeping him a part of my chats with our children. Christofer offered to video chat with us later that night when he got home from

work. After I shared the cheerful news with them, I turned my focus back to Steve. He had just pulled onto the highway heading home. Giddy, we both wondered if, when I woke from surgery, I would remember him. We wondered how much of my memory might be impacted. As a joke, we agreed that I would call him Dan who had been my high school boyfriend. And if I called Steve Dan, he would know that I was fine.

Back home and still excited and bursting to share the news, I called my parents who lived in the United States. They both had listened to my increasing frustrations over the last eighteen months, supporting from afar. I was grateful for them having listened to me venting about the difficulty I faced trying to protect my perioperative brain health.

Idiosyncratic reaction or not, my surgery was right around the corner.

April 23, 2019: City Four Hospital

You wake up flat on your back, flat but for the pillow lifting your head. The ceiling lights shine brightly around you, illuminating the sterility of the room. On either side, you know there are people like you, supine on their own hospital beds recovering from surgery. Like you, they are groggy and not yet feeling the pains they soon will once the drugs filter out of their systems. The wall in front of you has a white clock with black hands pointing to a time you do not understand. You wonder if the hands point to eleven. Eleven in the morning? Or eleven at night? You wonder if the name of this clock-type is analogue, but the words are not yet formed in your mind. It is just a thought that flickers in and out, like blinking. You see a woman sitting on a chair at the foot of your bed.

You watch her stand with a clipboard cradled in her left arm. Her hair is short. Your brain can't decide if it's black or red or auburn. Her face is a blur.

"Do you know where you are?" she asks you.

"On a beach in Hawaii," you say, pronouncing the state in three syllables.

"I wish I was in Hawaii," she says under her breath and giggles. You notice she pronounces it in two syllables.

You smile. You feel a glow of pride that your humour is still intact, as well as your language skills.

You realize that you're on your back and suddenly you wonder about the chest pain. You don't feel any. You haven't rested on your back for more than two years. The last year induced intense and sharp chest pain. The pre-surgery memory returns to you:

In the operating room, you tried telling to the surgical team to prop you up and off of your right side. You fought and pushed away at the four hands from doctors and nurses who tried pressing the mask tighter over your face. Other hands tried to hold you down. The mask was releasing an anaesthetic agent into your lungs to course through your system, to silence your mind. The panic took over because the pain was so intense and you were unable to escape it.

You heard Dr. Great's voice calmly tell everyone that you needed a pillow, that you can't be on your back. The four hands released the mask allowing you to shift onto your left side. A kid, because that's what he was to you, shoved a sterile pillow under your right side. You lied back on it. The pain disappeared. You saw the light's reflection shine off of

the pillow's plastic sterile covering. You didn't need hands to hold the mask to your face anymore. You could do it.

"Thank you," you had said to everyone. You saw Dr. Greene's upside-down face next to yours. She smiled.

"You ready?" she asked.

The room, still bright, disappears as your eyes close.

"Did they get it all?" you ask the nurse who wants to go to Hawaii who is with you in the bright post-op recovery room. You reach for your lower abdomen, gently touching the squishy mound. You see the nurse look up and roll her eyes.

"Yes, they took it out," her tone is almost flat. The sandy beach disappears as irritation rolls in with her sigh.

You hold your belly and sigh, relieved. You wonder how big your uterus was. A few months ago, the general internist told you it was the size of a small volleyball. Dr. Great said he would take a picture for you. You hope he didn't forget because you really want to see what had caused you so much pain.

"She's anxious," you hear the nurse tell another one.

"No, I'm not," you say. You want to explain to them what it means to be on your back. You want to tell them that you haven't been able to lie on it for several years. While you try to defend your state of mind, they talk quietly, ignoring you. Something is done to the IV line leading into your arm.

The room disappears.

April 23, 2019: City Four Hospital

"Do you know who I am?" Steve asked me. I had just been wheeled into my patient room and the nurses left me with ice chips to suck on since I wasn't yet permitted to drink. Steve's back was to the window, the sky outside was white, like his shirt. With his back to the window, the afternoon sun shining behind him was a ring of light, illuminating him.

"Yes," I said, "you're Dan." I don't remember if I smiled.

Before Isabelle could say anything about my having wrongly named her Papa, Steve looked at her and said, "She's alright, honey. Mommy's fine."

"Mom?" Isabelle said. I couldn't identify the emotions displayed on her face. I heard Steve explaining to her our inside joke.

I closed my eyes and fell asleep.

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