

Undue Hardship:
A Scholarly Personal Narrative about Working with
Invisible Disability in an Ableist Daily Newsroom Culture

by

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Abstract

I worked as a journalist for twenty-five years with an invisible disability, systemic lupus erythematosus, until I left my difficult but successful career after failing to win doctor-recommended accommodations. I share my journey using a Scholarly Personal Narrative (SPN) format informed by interviews with thirty-seven current and former journalists with disabilities, and twenty-one union officials, newsroom managers, and media executives. Using my experiences at three daily news organizations as the through line, I uncover previously untold stories from other journalists with invisible disabilities to explore the prevailing fear of disclosure within a macho, competitive news culture; workarounds and side deals that erase disability as a workplace issue; the habitual denial of accommodations; and how those exiled from daily news organizations write about their stories — as I have — outside the mainstream. This SPN has implications for journalism education, the journalism profession, and critical disability studies.

Keywords: ableism, invisible disability, daily news organizations, erasure, newspaper, journalists, undue hardship, work accommodations, disclosure, memoir fragments, Scholarly Personal Narrative, media studies, disability studies, representation, disability representation, diversity, diversity in media, Accessible Canada Act, long-term disability, newsroom culture, lupus, autoimmune disease, mental illness

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Prologue: A Beer, a Bold Question, and an Imaginary Job

Coddling a celebratory pint, I sat near the end of a long table in the infamous Print Room, the ground-floor bar of the *Toronto Star* tower. The class of 1986 had just endured a four-day orientation for the summer intern program at Canada's largest daily newspaper. Nearby, grizzled editors and a few staff reporters sank ever lower into their seats as the pitchers before them emptied. I snuck sips of my beer because, at twenty-one, I still thought it was foolhardy to drink on the job.

Our cohort included seventeen would-be journalists from all parts of Canada. Only four of us were women, including two who were racialized.

We were told there would be no jobs at the end of the summer, with three men who had also been interns the summer before. One of them, Paul Watson, had just completed his master's degree at New York's Columbia University and would go on to win a Pulitzer Prize for Spot News Photography. Also among our ranks: a future editor-in-chief of the *Globe and Mail* (John Stackhouse); a journalism program head at Carleton University (Allan Thompson); a prominent Montreal politician and "Me Too" movement crusader (Sue Montgomery); a bestselling crime author (Rick Mofina); a renowned *Toronto Star* columnist (Heather Mallick); a multiple National Newspaper Award winner (Andrew Duffy); and me. On that day, the most notable thing about me was what I was hiding. How I handled this secret would predict future career success, or failure.

As we sat there, the head of the intern program turned to me: "So, how is your health?"

My health? I gaped at him. The floor seemed to fall away. Time stopped. I

imagined all the other interns looking at me. I took a huge gulp of warm Coors Light.

“What do you mean?” I asked, borrowing the fail-safe question from every reporter’s toolkit. I had thought my secret was safe.

“One of your professors told me how sick you’ve been.”

I clicked through my internal Rolodex. I had not told a single professor about my health struggles, nor asked for any special treatment at Carleton University’s School of Journalism, even though I could have used some support. So I was shocked that my personal health information would be shared with an employer. I considered how to answer. Another swig. What did it mean that the program head knew I had been sick? Was hiring me an act of mercy or did he assume, as I hoped, that I was healthy again? Did it mean that he, and the city editor who hired me, had extremely low expectations for my performance?

Turning toward the program head, I said, “I’m fine,” straightening. “Really great.”

I scrutinized his face, framed by a goatee and thinning spiked hair. He quickly moved on to the next agenda item.

I was shaken. I had spent the past year coping with a diagnosis of the life-threatening autoimmune disease systemic lupus erythematosus, having no idea it would morph into a lifelong sidekick, an invisible disability that dogged me. The only outward sign hinting at anything “off” was my chubby cheeks, an inflammatory hangover from the 80 milligrams of the steroid prednisone prescribed a year earlier to save my life.

I ordered another beer, pretending to be a hard-drinking gal reporter, while I fretted. Would management’s knowledge of my health problems prevent me from getting

the full-time job that did not exist? Or block me from getting the type of assignments that would allow me to stand out? I had no idea how my invisible disability would impact my dreams, let alone my ability to do a high-pressure journalism job. At the same time, I assumed my editors would underestimate its seriousness because I appeared fine, and without a wheelchair or a cane or a big fat bandage on my head, I did not fit society's limited understanding of what disability looks like. I decided this worked in my favour; I decided to remain hidden.

The following day, I had a sense that my health status might have already put me in the corner. The four-month program was measured in weekly increments. Some of the students would be based at One Yonge Street, the *Star's* mothership, acting as summer replacements for police and general assignment reporters, coveted crime beats and breaking news coverage. Others would head out, two at a time, to suburban north, east, and west bureaus to focus on community-based reporting. Some got editing shifts. I had already worked at a big-city daily newspaper in Vancouver the previous summer, so I felt I could handle anything. Not the editors. While those around me were sent to cover the three C's — car chases, calamity, and council meetings — I was assigned fluff: a feature story for a "Fun in the City" supplement. Another female intern and I would be ambushing moms with runny-nosed kids for the inside scoop on local landmarks.

With the program head's question clanging in my ears and my lame assignment in hand, I realized I had two knocks against me: I am a woman, and I had a little-understood disability that would likely disqualify me from permanent employment. I decided in that moment not to talk about my health challenges and, if asked, to downplay them as much as possible.

I would do my best to over-perform, not realizing the decisions I made during those four months would define much of my working life. Silence instead of stridency, overcompensation instead of accommodation, solitude instead of solidarity, ableism instead of equality. I became an unwilling and unknowing participant in a culture that diminishes disability representation in daily news organizations, and therefore in public discourse. That decision, made as a young adult, would stalk me throughout my career.

Introduction: The Scene of the Accident: Returning to Carleton University

I spent twenty-five years working as a journalist with an invisible disability. Over time and sometimes simultaneously, lupus ravaged my kidneys, heart, lungs, brain, and joints, following me to three news organizations. I took a lot of cytotoxic therapies — orally and intravenously, at home and as a hospital patient — to knock the condition on its heels. My pain, inflammation, chronic fatigue, and immunosuppression were mostly mitigated by the purpose and joy I felt as a journalist. I once dreamed of travelling the world, or at least chasing scoops and daily deadlines, but instead I explored the landscape of people's lives. As a senior feature writer at the *Ottawa Citizen*, my job demanded patience, calm, compassion, and craft, and the willingness to sit and watch. I could do all that within my limitations. It also required insight into human suffering, and I had that, too. I won three National Newspaper Awards and numerous health, science, and investigative journalism awards, and I acted as writing coach to the *Citizen's* intern program, influencing dozens of future reporters. Unexpectedly, I lost my hard-won journalism career after a major health setback and a failed fight to win doctor-recommended workplace accommodations. Instead of occasionally being allowed to write from home and space out deadlines to manage stress, I was forced onto daily general assignment, something I had done only as a cub reporter.

I decided to take a buyout instead of risk my health chasing fire trucks, real or metaphoric. On that day, I put my head down on my desk and cried inconsolably. I felt utterly alone. That was 2012. I had downplayed my illness for many years, so well, in fact, that no one believed me when it finally became more than I could handle without

accommodations. Should I have spoken out sooner? I have often wondered, not just for me but for others silently struggling with invisible disabilities inside a work culture that glorifies survival of the fittest. I have also wondered why it all had to be so hard — unduly hard, to borrow a phrase so often used by daily news organizations and other employers. One thing was certain: I had an issue to explore and a story to tell, at least about the infrequently described experience of working with unrelenting and hidden chronic conditions. Few were telling stories like mine, not even me.

In 2020, I applied to Carleton University, where I had earned my Bachelor of Journalism in 1986, to pursue a master's thesis that examines invisible disability within news organizations. This is my attempt to counter my own silence, to seek out the lost voices of other journalists with invisible disabilities, in many cases helping tell their stories for the first time. When I told journalist friends my plan, some were surprised. “But this isn't your identity,” said one, who had been a colleague for more than two decades but had not noticed my struggles, just my achievements. With invisible disabilities, people cannot see — and therefore cannot imagine — what we are overcoming.

Returning to journalism school at age fifty-five takes a certain amount of humility. I was older than my professors and more experienced than my classmates, so it would be easy (and obnoxious) to presume I knew better or to repeatedly jump in with dated anecdotes. I worried that my classmates would create a drinking game for every time I interjected with “back in my day,” so I tried not to, especially because I had so much to learn.

It was, and is, an historic period at Carleton University's journalism school. Just a

few months before I started classes, in June 2020, journalism students and alumni identifying as Black, Indigenous, and People of Colour (BIPOC) released more than thirty calls to action demanding institutional change, including to staffing, curriculum, and accountability (Thompson). They wanted to revisit the concept of objectivity “created by white, straight, cis-male journalists whose human rights were never at risk by keeping silent in the name of their craft” (Thompson). One of the group’s architects, Jolson Lim, told *The Charlatan* that racism faced by working journalists was “first experienced at journalism schools” (Piper).

It was exhilarating to see students question the underpinnings of white, macho, workaholic news culture. I had cut my teeth on it, aping those prized masculine qualities to the detriment of my health and fragile identity as a journalist with an invisible disability. In response, the journalism school’s leadership set out five key steps it planned to take, including hiring a new chair of diversity and redesigning a first-year course and launching a new master’s course, to emphasize diversity.

During one lecture for my master’s course work, University of British Columbia journalism professor Candis Callison, of Tahltan First Nation, called out the whiteness and lack of diversity in newsrooms, which she described as “untenable and indefensible” in her 2019 book (with Mary Lynn Young), *Reckoning: Journalism’s Limits and Possibilities* (6). This important book, now mandatory reading in many courses at Carleton, enumerates the failings of Canada’s mainstream media to represent marginalized voices. There is plenty to cite, including colonial roots that uphold systemic racism and a habit of dismissing non-white perspectives as “bias” instead of valuing their expertise (6; 11; 17).

As someone keenly aware of the invisibility of journalists with disabilities, I noticed Callison and Young did not mention our challenges in their more than three-hundred-page work on marginalized journalists, albeit their focus is on the negative impact of colonialism, not ableism. Beyond that influential book, none of the many guest speakers to our journalism classes, from academics to activists to racialized journalists, expressed concern for the marginalization of people with disabilities, journalists or not. Even though inclusion was in the air, disability diversity was not part of the conversation at Carleton. My inquiry into the experiences of journalists with invisible disabilities seemed even more necessary. First, I had to find the invisible. Did the numbers support my theory that we were underrepresented?

Where are the Journalists with Invisible Disabilities?

Among marginalized groups in Canada, those with disabilities are by far the largest, making up 22% of Canada's total population. In 2017, one in five Canadians over age fifteen — about 6.2 million individuals — had one or more disabilities (Morris et al. 4) and of working age Canadians (25 to 64), 20% had disclosed a disability (Morris et al. 7). According to the *Accessible Canada Act*, which became law in 2019 and received very little media coverage, a disability is “any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that in interaction with a barrier, hinders a person's full and equal participation in society.” The Act calls out “evident or not”; invisible disability accounts for as much as 62% of all disabilities among white-collar workers (Jain-Link and Kennedy).

It is difficult to tease out how many journalists with disabilities (visible or invisible) work at daily news organizations, because few count. One international study found fewer than 1% of those working in media self-identify as having a disability (McEachran). As far back as 1985, one study noted the number of employed disabled workers at U.S. newspapers — 1.2% — was far below the 8.9% of people who self-identify as having a disability in the general workforce (Popovitch, qtd. in Ellis 35). In 2005, the Canadian Association of Broadcasters (CAB) found employees with disabilities comprised less than 2% of people working in broadcasting and production industries, even though persons with disabilities then made up 15% of the nation’s population (CAB 2).

Numerous organizations advocate on behalf of racialized journalists, including Canadian Journalists of Colour and the Black Journalists Association of Canada. Their 2020 demands have industry leaders and staff representatives hustling to get on the right side of history. Paul Morse, head of Unifor Local 87-M, representing 1,800 journalists at major media organizations that include *The Toronto Star* and *The Globe and Mail*, called it “a very pressing issue.” When asked why his union has not included disability in its advocacy efforts, Morse explained, “Disability has not been identified as an issue.” The union had not surveyed members to ascertain this importance.

I asked *The Globe and Mail*, *The Toronto Star*, Postmedia, and the Canadian Press (CP) how many journalists with disabilities each employed; none provided numbers. The Canadian Broadcasting Corporation (CBC) must adhere to the federal *Employment Equity Act* and tracks and publishes the number of employees who self-report having a disability that disadvantages them in the workplace. In 2007, 1.8% of

CBC employees self-identified as having a disability; by 2020 it was 3.4%. The public broadcaster knows it has more employees with disabilities, and its goal is to have more than 8% of its workforce self-identify as having a disability (see Chapter 4 for discussion).

Terri Monture, of the Canadian Media Guild, represents CBC staff on human rights and equity issues. She said the number of people who work with disability at the CBC is much higher than the 3.4% stated in 2020, but most “are very reluctant to disclose because they feel it’s going to hamper their advancement at work.” In particular, she referenced employees with invisible and episodic disabilities, such as multiple sclerosis (MS), lupus, mental illness, and post-traumatic stress disorder (PTSD), who are hiding in plain sight. Compared to employees who are Indigenous or people of colour, employees with disabilities represent the largest group within the CBC, said Monture, who is a Mohawk woman. The recent social reckoning about diversity and inclusion in the workplace does not include disability, exacerbating the marginalization. “Disabled people and their accommodation issues are being left out when it is absolutely part and parcel of diversity and inclusion,” she added.

Nick Davis, CBC’s executive director, equity and inclusion, and a former journalist and radio producer, said the Canadian broadcaster is working to improve the culture at the CBC so journalists feel safe disclosing disabilities. “We are creating the conditions so more people will disclose whatever disability they have, whether visible or non-visible. Because if you don’t feel you can disclose, not only are you not bringing your whole selves to work, we’re [the CBC] also perpetuating negative behaviour or the negative attitudes around people with disabilities, and doing nothing to actually improve

workplace culture,” Davis told me in an interview. He added that the CBC’s efforts — including the creation of an employee resource group and hiring programs for people with disabilities — have resulted in a doubling in the number of CBC staff who have disclosed disabilities in its annual “cultural survey” since 2017.

Methodology

My guiding questions for this work include: Is there something unique about the culture and attitudes of daily news organizations that made my experience particularly difficult? And what can be learned to make the journey easier for other journalists with invisible disabilities? I elected to use a Scholarly Personal Narrative (SPN) format, pioneered by University of Vermont professor Robert J. Nash, which focuses on the journey of the author while combining “scholarship, personal stories, and universalizable themes in a seamless manner” (Nash and Bradley 24). In the SPN, academic research situates stories as the parcel of measurement conveying the meaning and significance of our lives. Beyond simply sharing a personal story, Nash writes in *Liberating Scholarly Writing* that his approach includes personal as well as social; practical and theoretical; reflective and public; local and political; narrative and proposing; “self-revealing and evoking self-examination from readers” (29).

To Nash’s methodology, I have also added journalistic inquiry and practice, including extensive interviews with more than fifty participants to explore many of the themes I identified through self-examination. The key themes that emerged verified my own personal experience, including issues of identity, disclosure, side deals and workarounds, the difficulty of getting official accommodations, and self-location through

writing about disability. (See Appendix A for an explanation of my methodology).

Among the more than fifty people I interviewed are thirty-seven current and former journalists and twenty-one union officials, newsroom managers, and executives from several Canadian news organizations. In most cases, interview participants are named and the information they provided is on the record. Employed journalists and journalism students, meanwhile, have their identity protected so any disclosures about disability do not negatively impact their careers. (See Appendices B and C for the interview list and explanation of approach).

The thirty-seven current and former journalists have a variety of disabilities, many of them considered invisible, including visual impairments, mental illness, chronic pain, mobility disorders, MS, PTSD, chronic migraine, endometriosis, hearing-related disorders, autoimmune diseases, and repetitive strain injury. I describe their diseases and conditions here and throughout the thesis instead of always using the blanket term *invisible disability*, so readers know exactly what is invisible and what the current and former journalists have experienced.

Fourteen are men, including one who is racialized, ranging in age from their early thirties to late sixties. Twenty-three participants are women, ranging in age from their early twenties to mid-sixties. Eight women identified as racialized, either Black, mixed race, Chinese or South Asian descent. Throughout this document I note participants who identified as racialized because each told me this intersects with their disability status and negatively impacts their experiences as journalists, as Professor Kimberlé Crenshaw foresaw in her seminal 1989 work on intersectionality.

The interview subjects work (or have worked) for major Canadian news

organizations, including the CBC, *The Globe and Mail*, *The Toronto Star*, a variety of Postmedia news outlets, and CP. Several are freelancers who have not won a permanent role within a daily news organization, which they attribute to their disability. Four are retired, while five receive disability support payments from the government and/or private insurers. Of the twenty-one union officials, newsroom managers, media executives, and subject-matter experts I interviewed, five are also included in the list of current or former journalists I interviewed with invisible disabilities.

Amid a changing landscape for diversity and inclusivity, invisible disability is still unexplored territory. It is my intention to offer multiple examples from these detailed interviews to show the richness of experience of journalists with disabilities whose stories have not been previously examined. Some spoke about the politics of disability identity in the newsroom, and how they grappled with stigma, stereotypes, and disability misrepresentation. Some told heartbreaking stories of human suffering and marginalization. Depth and breadth have been prioritized over brevity. This stands in juxtaposition with stereotypes currently distilling disability identity into tropes with newsrooms, where journalists write inspiration porn and “Supercrrips” overcome adversity.

Theoretical Underpinnings

When it comes to the employment of people with disability in media, the “topic is significantly under researched” (Ellis 6) and by focusing on the employment of journalists with invisible disability in daily news organizations, this thesis addresses a neglected area of media diversity. I investigate both the structural limitations that exclude

journalists with invisible disability from daily news organizations, as well as their experiences within these daily news organizations. To some extent, I lean on critical disability theory to understand the ableist systems that shape the experiences of journalists with invisible disabilities, and how it impacts their perception of themselves and their experiences. I consider the lens of ableism to better understand the structures and obstacles that impacted the careers of those I interviewed.

Like the journalists with disabilities themselves, discussion of ableism is mostly missing in mainstream media, perhaps linked to fear of reprisal and lost opportunities. Few I interviewed — including those who had faced significant employment barriers due to their disabilities — used the term ableism to frame their experiences, as though they were uncomfortable being strident, political, or defining their plight using an ‘ism.’ Their relative silence sets them apart from numerous racialized journalists who have recently called out mainstream media for its racism, colonialism, and failures of representation.

Journalists like Egyptian-born Pacinthe Mattar, one-time senior producer at CBC’s *The Current*, described in *The Walrus* (2020) what happened when she pitched stories about racial injustice. “The awkward seat shifting. The averted stares [...] it is on us to fill this void and “prove” the existence of racism.” Waubgeshig Rice, a journalist from Wasauksing First Nation, penned a warning (also in *The Walrus*) to young Indigenous journalists: “They’ll call your objectivity into question and doubt your capability to cover Indigenous-related stories just because of who you are. Paradoxically, they may not let you cover anything else.” And former *Globe and Mail* editor Denise Balkissoon, in “I Tried to Talk to My Bosses about Racism at Work,” described newsrooms as places where “white supremacy takes the form of homogeneous editorial

teams producing simplistic and often harmful stories—and where racialized journalists have long pushed for change.”

Even though most of my sources identified ableism only obliquely, it helped make sense of the myriad systems and social factors within daily news organizations that were working against those I interviewed.

There are many definitions of ableism, including this succinct one from the Law Commission of Ontario, which states that it “may be defined as a belief system, analogous to racism, sexism or ageism, that sees persons with disabilities as being less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others” (OHRC 3).

There is personal and systemic ableism, which can be conscious or unconscious. Activist and writer Andrew Pulrang described personal ableism: “Feeling instinctively uncomfortable around disabled people, or anyone who seems ‘strange’ in ways that might be connected to a disability of some kind.” This can manifest in many ways, he wrote in *Forbes*, including awkwardness around people in wheelchairs, being “viscerally disgusted by people whose bodies appear to be very different or ‘deformed,’” as well as avoiding talking to disabled people to avoid embarrassment. According to Pulrang, who has had lifelong disabilities, ableism is also holding stereotypical views about disabled people, including them “for advantages or privileges you think they have as a group.”

Systemic ableism includes laws and regulations that restrict the freedom and equality of people with disabilities, such as social policies that seek to “care for” disabled

people through intensive supervision, protection, and isolation from everyday society, or reduce or eliminate disability from society (Pulrang).

In daily news organizations, based on my interviews, ableism is reflected in the language that is infused into news stories — wheelchair bound, crippling debt, turning a blind eye, or falling on deaf ears — to the stereotypes of superhuman journalists who are portrayed as dashing into burning buildings, war zones, and closed-door meetings (Macrae; Edwards 85). It is also seen in job descriptions that demand driver's licences, even in cities with good public transit and newsroom taxi chits (Lu). Almost every CBC job posting in September 2021 sought a candidate with an ability to work flexible hours in a high-pressure environment, often in unexpected overtime situations (CBC, "Current Openings").

Ableism is also an attitude that perceives any difference as weakness.

"There are a lot of mean and nasty ego-driven people in newsrooms that attack your vulnerabilities," said Steven Ladurantaye, who disclosed his bipolar disorder in 2021 after a rapid rise in numerous media organizations and then what he calls an "epic flame out." As soon as a reporter discloses a disability they are perceived as weak, and it colours how people see our abilities as a journalist, he told me. "Suddenly you're a shitty employee because you're struggling to function and then you are not productive, and you won't get the support of management. It is a vicious cycle."

Lynn McAuley, my editor at the *Ottawa Citizen* before she left to take a senior position at the *Toronto Star*, also spoke of a cycle of hiding and secrecy necessitated by ableist attitudes. She told me: "Nobody wants anybody else in this business to know anything about them when it comes to invisible disabilities." She explained how

supervisors, including herself, frequently help on the sly, “so sick days don’t go on the record. There are a lot of off-the-books accommodations because the minute you go to HR, they feel it’s incumbent to get over involved.”

Why Examine Daily News Organizations?

In this research, I focus on daily news organizations because that is my playground and background, and the most common workplace where journalists congregate. Conventional career success is most often equated with landing a full-time job at the CBC, *The Globe and Mail*, or *Toronto Star*, among others. Also, the workplace culture of a daily news organization (as described in Chapter 3) is competitive, macho, and seems to be the anti-thesis of the negative stereotypes heaped on people with disabilities.

At the same time, daily news organizations are where vigorous debates over representation are now occurring, albeit around racialized and Indigenous journalists. The issue of representation of journalists with disabilities cuts across gender, race, and indigeneity. If not now, when is the right time to consider disability representation?

If people with invisible disability are not counted, neither are their stories, leaving gaps in perspective and, therefore, in daily news coverage. In 2012, Chelsea Temple Jones, an assistant professor at Brock University specializing in critical disability studies, documented an inevitable consequence: The onus to write about disability falls on the very few openly disabled journalists working in Canadian media (“Literature Review”). If journalists with disabilities are not hired — or are in hiding — who is left to cover the issues impacting Canadians with disabilities, the largest minority group in Canada?

Davis agreed having journalists with disabilities on staff increases coverage of related issues and deepens coverage in general. When CBC radio producer Ing Wong-Ward worked at CBC Toronto's flagship radio program *Metro Morning*, she drove coverage on disability issues, according to Davis, who worked with her for eight years. Wong-Ward, who died of cancer in 2019, was born with spinal muscular atrophy and used a motorized wheelchair.

"When Ing left CBC, there was no more debating the coverage of people with disabilities in Toronto," Davis added, reiterating how important it is to encourage people with disabilities to bring their full identities to work. The alternative, categorizing their work as biased or advocacy reporting, leads to shallow stereotypes and weak coverage. "The best thing about having Ing on our team was that she saw all stories differently, whether they were about disability or not, because of her lived experience. That richness brought a depth to our journalism that was really valuable."

Prior to her promotion to weekend and special projects editor at CP, blind journalist Michelle McQuigge was indirectly responsible for disability coverage across Canada. She penned articles for CP "because of personal interest and obligation," wire stories that subsequently appeared on news platforms across the country. With her promotion, McQuigge had no time to write stories on disability issues, and there was no reporter assigned to take her place. I asked her former boss, CP's Editor-in-Chief Andrea Baillie, if CP planned to start covering disability issues again, more than a year after McQuigge's promotion. She said: "I hope so. We're still trying to figure that out."

Given all this, the presence of journalist with disabilities in daily news organizations is important to the overall discussion of disability issues in this country. I

wanted to examine what happens when journalists with a stigmatized and hidden disability seek work in that environment.

Why Invisible, Not Visible?

First, my disability is largely invisible, except during certain acute exacerbations involving my joints and connective tissue when I use a wrist brace, cane, or walking cast. Also, as stated above, most workers have disabilities that are hidden. In addition, the few academic studies on journalists in Canada have mostly focused on those with obvious impairments or mobility disorders, such as the academic work of Jones in 2014 (“Why This Story?”) and 2019 (“Dropping the Disability Beat”), and Jones and Saujani in 2021. International research has also focused primarily on visible disabilities among journalists, such as Ellis’s *Disability Media Work: Opportunities and Obstacles* (2016).

I could not help wondering if the hidden nature of certain disabilities has contributed to its invisibility as a research topic. Visible impairments — because they are seen — seem to have more credibility. Sufferers are more often believed. CP’s McQuigge called it a “hierarchy of disability in terms of what garners society’s sympathy and support.” She is blind and uses a guide dog. “I’m a highly privileged disabled person because my disability is immediately identifiable, easy to explain to someone, and not attached with additional stigma,” she told me. “I say I had cancer as an infant that’s kind of a one and done,” adding those with invisible disabilities “have a much harder time. I can’t imagine the labour involved in having to explain a more complex case again and again.”

People with invisible disabilities are often labelled malingerers first, and must convince others that they are not lazy, underperforming hypochondriacs, among other negative characterizations. The late Sharon Dale Stone, of Lakehead University, said that individuals with invisible disabilities are often faced with a dilemma: “If they keep quiet, they run the risk of being judged as lazy, incompetent or something else equally derogatory. If they tell, they run the risk of not being believed, of being judged as inappropriately looking for sympathy, or of simply being an attention-seeker” (Stone 295). With invisible disabilities, there is no general sense of what we are masking or over-compensating for, and it is therefore difficult for us to lay claim to the overcoming narrative (see Chapter 3) that infuses journalism (Titchkosky 188). The Ontario Human Rights Commission (OHRC) explains the stigma that comes from disability:

Regardless of whether a disability is evident or non-evident, a great deal of discrimination faced by persons with disabilities is underpinned by social constructs of “normality” which in turn tend to reinforce obstacles to integration rather than encourage ways to ensure full participation. Because these disabilities are not “seen”, many of them are not well understood in society. This can lead to stereotypes, stigma, and prejudice. (OHRC, “Non-Evident Disabilities.”)

To understand the experience of journalists with invisible disabilities, I first wanted to know more about those of journalists with obvious disabilities. When I approached personal finance journalist Aaron Broverman, who has cerebral palsy and uses crutches or a mobility scooter, he questioned my intent: “I’m not clear on how visible disabilities inform a paper about journalism and invisible disabilities. What is your take?”

As our discussion progressed, it was obvious he did not think I have a disability.

He said: “Sometimes I think people who say they have invisible disabilities just have illnesses that are disabling. It’s an intermittent thing, rather than you have a disability all the time.” He also said that because we can hide, people with invisible disabilities “are reluctant to join the disability community,” which he finds upsetting. “You don’t want to be a part of us. You’re saying, ‘I am not you.’ Probably for reasons of employment they think if they admit that they have some sort of disability their lives are going to be affected in a negative way,” Broverman added. “Nondisclosure shows those of us with visible disabilities that we’re not worthy. Nobody wants to be me.”

Instead of hearing that Broverman found our nondisclosure disappointing, I listed my “disabling” symptoms until they added up to something concrete — beyond painful joints and permanent organ damage, I mentioned daily episodes of double vision and visual scotomas from neurological involvement, arthritis in my feet, and the mental exhaustion of never knowing what I will face each morning. Afterwards, defensive still, I dug up studies showing that lupus is a leading cause of work disability in the United States, accounting for about 20% of the more than 1.5 million Americans with a work disability, as well as a loss in work hours that cost the nation nearly USD \$13 billion annually, in addition to negatively impacting an individual’s work, quality of life, self-management, and self-efficacy (Agarwal and Kumar 429). Listening to the transcript months later, I was embarrassed by my defensiveness.

The truth is, Broverman was right about the stigma around disclosing disability. When an HR manager told me — about twenty-three years into my career as a journalist — that I should seek long-term disability benefits for a particularly brutal exacerbation of my chronic condition, I replied, “But I’m not disabled.” I was fighting to hold on to a job

and I thought being called disabled was meant to put me in a box. Even when I was temporarily approved for Canadian Pension Plan disability support payments and disability benefits from my workplace insurer, I still could not accept the label, or its attached stigma. And not because I did not want to be associated with journalists who use mobility scooters or need text magnification equipment, but because I feared that accepting that description of my predicament meant I would never be permitted to do my journalism job again.

Broverman also spoke to the resentment and misunderstanding that exists between people, not just journalists, with visible and invisible disabilities. “A lot of people with visible disabilities are jealous of people with invisible disabilities because they can pass, or at least hide it sometimes. Well lucky for you that you don’t have be a disabled person all the time.” It is true. Although there is no cure for lupus, sometimes my symptoms improve so I am only a visitor to his homeland, not an inhabitant. That said, he sees the disadvantages of invisibility. “I don’t have the situation where someone is questioning whether I’m really disabled or am I just saying that. It’s obvious,” he said, adding, “I am acutely aware that I have not experienced this loss since I’ve always had my disability.”

We both wondered what would happen if more journalists with invisible disabilities decided to disclose, rather than clutching their chronic condition cards close to their chests. Maybe in larger numbers we would not be erased from daily news organizations, resulting in disability diversity and more coverage of related issues. If journalists with visible, invisible, and episodic disabilities worked together to confront common issues, we might create more opportunities, accommodations, and understanding for ourselves, especially within the mainstream. As recent University of British Columbia

journalism graduate Bailey Martens, who suffers from complex regional pain syndrome and uses a wheelchair, wrote in *Canadaland*, “Meeting disabled journalists happens by chance: a shy DM on Twitter or someone spotted at a conference. There is no formal organization, pipeline, or even a group chat. Instead, we are left to navigate an often-inaccessible industry alone” (“How Disabled”).

Thesis Outline

Chapter 1 relates my diagnosis with an invisible disability while at Carleton University — as well as the experiences of other students with hidden disabilities, including visual impairments, multiple sclerosis, lupus, irritable bowel syndrome, and anxiety disorder. Do the ableist attitudes and structures that exist in daily news organizations begin in journalism school? In Chapter 2, I explore the macho, competitive environment at the *Toronto Star* and the “overcoming” archetypes that journalists with obvious disabilities must embody, from bullfighters to Supercrrips. I discuss one foreign assignment in Chapter 3 that convinced me I did not have what it took to be a *Star* man. Chapter 4 explores why journalists do not disclose their disabilities — unless they absolutely must — and the consequences. Chapters 5 and 6 trace my attempts to succeed, until I found a job that seemed perfect for my abilities and limitations. Many journalists with invisible disabilities cut side deals and find workarounds to succeed, or just get by, and I speak with several journalists in Chapter 7 about the arrangements they made with their managers as well as their own attempts at self-accommodation. In Chapter 8, I show how the lived experience of having an invisible disability can shape the stories we tell with powerful results. In Chapter 9, I describe what happened when I sought formal

accommodations to help me do my job that led to me quitting journalism. In Chapter 10, I explore the experiences of other journalists with disabilities who sought formal accommodations and speak with managers of daily news organizations, union officials and former journalists about the fraught process. This chapter included an examination of the use of “undue hardship” to explain why news organizations, as with employers of all kinds, say they cannot accommodate employees with disabilities. Through interviews with current and former journalists it also suggests that maybe it is their employees who are experiencing hardship that is undue. Finally, I look at how journalists with invisible disabilities are writing about their experiences in memoir fragments, personal blogs, books, and “one-offs” in legacy media to situate their expertise, even if it is on the fringes. I conclude with recommendations for more research and an action plan.

I am the first to acknowledge that this journey — from launch to leaving — could have resulted in four or more separate projects because the terrain is so fertile and unexplored. In many cases, I could have probed much more deeply than space and time allowed; there was almost no end to the interviews I could have pursued. I see this as a beginning of a quest that I hope prompts more research into how ableism infuses daily news organizations and affects journalists with invisible disabilities, as well as what can be done to support those of us on the fringes during a reckoning that is meant to bring the marginalized out of the darkness.

Chapter 1: Journalism School and Lessons in Pain Management

The Saturday night of Easter weekend, when I was nineteen, I sat before a Brother electric typewriter on the coffee table in my rented row house. The floor was so slanted that a beer bottle rolled quickly from the north to south wall, inspiring party games. I was putting the finishing touches on a second-year reporting assignment, a feature story about the euthanasia of an old, incontinent beagle that I had watched die by injection a few days earlier at the Ottawa Humane Society. I rearranged and retyped, trying to create a varied rhythm, driving the reader to the end, when the beagle's head fell limply on the metal table. I had cried girlish tears but could not decide if my weeping was reportable.

There were three other varsity athletes in our house: one Teresa and two Jens. Jen 1 was a volleyball player with big quads and a huge spike. Jen 2 was my soft-spoken teammate on the Carleton University women's basketball team and a second-year journalism student. I met Teresa, another player, over beers during Frosh Week the year before. She convinced me to try out for the team.

My health woes seemed routine at first. Like when my left arm — I am left-handed — went completely limp, leaving me unable to dribble a ball or take a shot. A few months into the second season, I was sidelined by a stress fracture to my tibia. The season ended with my failed hoop dreams, me never getting my game back, and a blow-up with my coach, who did not think I needed a cast for my broken leg.

In our townhouse, resentment ruled our interactions. There had been too many borrowed sweaters and misplaced scarves (Jen 1); too much pilfering of each other's stockpiles of bread, popcorn, and Kraft dinner (me). Too many bills unpaid (all of us),

including a dispute over long-distance calls to Toronto. No one laid claim to the late payment notices and the line went dead the day before Good Friday, as everyone but me departed for home. I fell asleep that Saturday night in a house without a dial tone feeling lonely, hungry, but hopeful that I had crafted an A-worthy story about a dead dog.

I have often thought back over the innocuous terrain of that day, looking for something to suggest what was to come. In a blog I kept many years later, called *The Sick Days*, I wrote about that weekend. I had not eaten. Anything edible inside our communal fridge did not belong to me. I craved baked goods, discounted and day-old, from the thrift bakery around the corner. “It was like having a beer store on the block if we were a house of eighteen-year-old guys with new fake I.D., instead of four girl jocks with no cooking skills and 4000-calorie-a-day requirements. I polished off the one crumpet in cellophane remaining in a cupboard, perhaps even mine,” I wrote (“One Morning”). That blog, which had 30,000 views before I mothballed it, is both an artifact and an attempt to make sense of what it was like to fall out of step with my classmates and my chosen career path.

On that Easter Sunday I awoke from panicked dreams of poorly written stories and failed foul shots to find myself entombed in a body bag of pain. I tried to wiggle my fingers, lift my arms, and then my legs. My head. How did that song go? *Head and shoulders, knees, and toes*? None of them could be marshalled into action. I scanned my body like a wellness guru seeking mindfulness; instead of achieving stress reduction I was assessing damage. Each attempt was answered with a muscle-wrenching rebuff. I could not break free of the pain.

“Jen? Jen? JENNIFER!” But my roommates were away for the weekend.

With a dead phone line, I shuffled to the corner store to call a friend for help, but it was closed to observe the religious holiday. My walk to campus health services, normally about thirty minutes, took me close to an hour. “Each slow step made me wince, then weep. I felt like the Tin Man in The Wizard of Oz. I needed an oil can” (“One Morning”).

A wary doctor did not feel the swollen, tender joints in my hands, wrists, or elbows. Nor did she rotate my head or lift my legs to watch me writhe. She did not even give me a gentle hug and tell me it was going to be okay, which is probably why I struggled on foot to reach her. Instead, she pushed a sleeve of slender blue pills into my stiff hands. “Just take one of these at bedtime and relax a little.”

I limped home with my first diagnosis: stressed-out university student. My notes from that day recall I hid the pills in a sock where Jen 1 would not find them, wolfed down a bowl of Jen 2’s Corn Pops, then crawled into bed. I hoped to awake to find this was just a strange glitch and not an insurmountable obstacle to my ambition.

Ableism 101

It is not easy to fall ill as a young person filled with dreams, competing for their fulfillment. The cutthroat environment in Carleton University’s School of Journalism made my already worrying episodes seem career-ending. Since the day we had started J-School, we were warned that half of us would not make it to second year, and by the end of the program, only a quarter would graduate. Our professors were mostly chest-thumping, ruffled-suit-wearing men who set the standard for the hyper-masculinized profession. They bombarded us with advice. Do not miss a deadline. Beat the

competition. Push yourself to the limit. Get ‘em!

Semesters came and went; my condition worsened. I was suffering from pain, fatigue, and fear; fear of what was happening to me and fear I was not fit to be a journalist, at least not the version presented at Carleton. Admitting to my classmates or professors that I was faltering, mysteriously, seemed both weak and reckless when my peers were positioned as rivals.

When I was an undergraduate student at Carleton in the 1980s, there was no discussion of difference or diversity in culture, gender, ethnicity, or abilities. There were some racialized journalism students, but almost no disabled students, at least that I knew of. The 2005 Canadian Association of Broadcasters (CAB) report found the number of persons with disabilities enrolled in broadcasting or production-related educational programs was extremely small — fewer than 1%. The report’s authors put a positive spin on this miniscule proportion, writing the “significant demand for skilled employees means that persons with disabilities may represent a largely untapped pool of talent for the broadcasting and affiliated production sector” (CAB 2).

The prototype for a successful journalist is a hard-driving white male. As I discussed in the introduction, there are few openly disabled journalists working in daily news organizations. Based on the scant information available and interviews I conducted, journalists with invisible disabilities tend not to disclose to employers. In addition, there is very little coverage of disability issues in mainstream media, which advocacy groups and journalists with disabilities have long complained about, as Jones showed in her 2012 literature review (“Literature Review” 92; Boyer, ctd. in Jones, “Literature Review” 84), as well the CAB report (6). With so few working journalists with disabilities, who pushes

for stories about these issues? It is a circular problem. Looking back, I wonder how much the minimizing and marginalization of journalists with disabilities takes root in journalism schools, following a script set by daily news organizations?

Representation of racial identity and diversity entered the curriculum at Carleton's journalism school while I was a master's student, including a full course dedicated to the topic. Not so with disabilities, which impact more than 22% of the population (Morris et al. 4). A recent Carleton journalism graduate, whose irritable bowel syndrome (IBS) sometimes keeps her on the toilet for five hours straight, said during our interview: "Journalism schools should implement a curriculum that encourages accessibility rather than one that stokes fear and inadequacy. What's wrong with teaching us that it's okay to have a disability in school and it's okay to need accommodations instead of creating a culture where we feel we must hide?"

Along with IBS, D. also suffers from an anxiety disorder, which stems largely from fear of her condition interrupting an interview or interfering with an assignment. She said journalism schools could help change a culture that currently erases students with disabilities by showing that a more accessible industry is not only possible, but necessary. "Why not let us, the disseminators of information, be an example to society?" These are important questions that journalists with disabilities have long been afraid to ask out loud. To make up for lost time, I have dedicated considerable space in this work to their stories.

Secrecy and Silos

At Carleton so many years ago, I also felt isolated. It has taken me forty years to

find out I was not alone. I first came across Sheyfali Saujani's name — new to me, or so I thought — in a 2021 article in the *Canadian Journal of Communication* describing a “disabled journalists roundtable.” Organized by Saujani and Brock University's Chelsea T. Jones, the panel briefly explored her experience as a journalist at the Canadian Broadcasting Corporation (CBC).

Saujani has a visual impairment and is legally blind. She was a chase producer for radio programs like the CBC Toronto's *Metro Morning* and *Cross Country Checkup*, working for the first twelve years of her thirty-year career without any formal accommodations that would have made reading less difficult and painful and her situation less isolating. “It's likely there were other people with invisible disabilities around me, but no one talked about it back then,” she told the roundtable participants, adding, “I wonder what my life and career would've been like if I'd had a chance to meet other people like me, facing similar issues to the ones I faced, which I'd never articulated in my time” (Jones and Saujani 103).

Retired from the CBC in 2019, she is a PhD candidate in the Department of History at the University of Toronto. When I reached out to her, I learned we had more in common than I imagined.

A refugee from Uganda, Saujani arrived in Canada in 1972 with her family. Later, at sixteen, she was diagnosed with genetic macular degeneration, which means she has no distance vision and must use her peripheral sight, relying on a magnifying glass or thick lenses to see the world around her. To read, she holds the text a few inches from her nose. A lover of stories and writing, she applied to Carleton. “I recall this awkward meeting between my mom and the director of the school. She told him. ‘My daughter has a

disability, what can you do for her?’ And the director responded, ‘What do you expect us to do for her?’”

Saujani urged her mom to “please stop talking” about her vision challenges. She got the message. “Expect nothing and don’t ask for help. The director was a decent person who was a product of his era,” recalled Saujani, who had internalized the prevailing “medical model” of disability, which views disability as a deficiency or abnormality, instead of the “social model” that frames it as a difference, just as a person’s gender, age, or race is a difference (Gill 50; Goering 134).

“I was in denial about my disability at that point,” Saujani told me. “What could I do? I’m already brown, so no way was I going to make an issue with my disability.”

As she unspooled her story, she mentioned she had also attended Carleton’s J-School. I began to recognize details. In a second-year television class, she was assigned to a group of four students to produce short news items. She was returning from the cafeteria when she heard the others in her group talking about her in the stairwell. “They couldn’t stand my attitude, all my opinions. They didn’t want to work with me,” she recalled. “Then one said, at least I’d be good for carrying equipment. I was livid.”

Saujani said she refused to be a baggage porter for anybody and quit the group. Instead of failing her, the instructor paired her with a top student to produce a same-day piece for the class newscast. “It was about a local bookstore. I don’t remember its name,” she told me.

“Octopus Books,” I said, jumping in.

She had been paired with my then-boyfriend on the project. Saujani and I had been classmates. She did not remember me, either. “Who the fuck is Shelley Page?” she

said, laughing, assuming I was preppy (I was not), went skiing on winter break (I did not), and flew to the Caribbean for spring break (I wish).

Eventually we surfaced in each other's memories. She recalled me as tall, a wearer of long, sweeping skirts like a Victorian equestrian. I remember her in the phone room in Carleton's St. Patrick's building, holding a phone book inches from her face. She was funky, alternative. Saujani admitted she had "a big fat chip" on her shoulder and spent her time at the campus radio station or theatre group instead of with her classmates. I was in the early phases of an autoimmune disease and was caught up in my own struggles.

"We were isolated by the fact that identifying ourselves as persons with disabilities would have cost us professionally," she said, before listing the words that shaped her disability identity during that period: Burdensome. Unwelcome. Scapegoated. Separate. Different. "Like why the hell would I even want to be any of those? As a student with a disability, I'm distancing myself from whatever that identity is because I don't want to be any of those things, right? There's a certain kind of self-hatred. You're denying all the stigmatized aspects of this identity in a way that is contributing to the stigma."

Those are weighty issues to stuff in your suitcase and carry off to university. How can you build a community of support when its potential members hate themselves? Meanwhile, the journalistic identity is strong, unstoppable, competitive. For a person with some sort of disability, it is self-preservation to deny these stigmatized, different, and supposedly deficient parts of ourselves. It means we cannot bring our full, lived experience to journalism school, or later, to work in a newsroom.

I did not have to look that hard to find others at Carleton who were also hiding or minimizing multiple sclerosis, mental illness, chronic Lyme disease — afraid they could not live up to the profession’s standards, as reinforced by the school.

In April 2021, I interviewed Diane Sims from her hospital bed in Stratford, Ontario, where she was suffering from an irreversible bowel obstruction and had been told her life was ending. She and I crossed rocky paths at Carleton, where I had lupus and she had multiple sclerosis (MS). At seventeen, when she was diagnosed, doctors told her she would be bedridden by twenty-seven, dead by thirty-five. “And I thought, ‘Fuck you,’” she recalled.

“Those two words, that defiance, framed my attitude forever.” Like a motto to be embroidered on a pillow, she took the phrase with her as she went off to Waterloo University for religious studies and then to Carleton University to earn a one-year bachelor’s degree in journalism. Arriving at Carleton, Sims was legally blind in one eye and would eventually lose half her vision in the other. She also had sporadic numbness in her feet. “I am kind of bull-headed and some say I’m the most determined, tenacious person they’ve ever met,” she said, whispering her answers over Facebook Messenger’s video chat from her hospital bed. “Funny though, even though I had this ferocious attitude, instead of seeing me as a bulldog, I became a liability.”

At Carleton, Sims recalls confiding her disability to a television professor. “I was unsure about my eyes, being behind the camera. I didn’t know if I could do it. He said it was okay, that I was pretty, and he put me in front of the camera.” She also told her radio instructor because splicing tape was difficult. “I was very worried about succeeding

because I wanted to be a journalist, I wanted to do this so badly,” she said. “But they didn’t seem to think I had much of a future.”

Like me, she overcompensated and hustled to build a portfolio of clippings. She was hired at *The London Free Press* as a summer student. At that first job, she was “chastised” for daring to think she could work as a journalist with MS. “After I was hired, I stupidly thought that being honest was the best policy [...] But one senior editor — this old fart — said, if you tell anybody, any employer that you have MS, you will never work again.”

She thinks being disabled made her lose her sex appeal in the newsroom. “They’d found me attractive and then they must have visualized me in a wheelchair or something. It was the worst thing I could have said,” she recalled. “I had been getting some good assignments and then suddenly I was on rewrite [adapting wire stories]. They put me in a box, and they stuck me at a desk.”

Reflecting on what the editor said, Sims told me: “As much as I despise that man for saying that I think he was telling the truth. And that is such a sick commentary. Journalists are supposed to reflect and report on what’s wrong, what’s right, what needs to be exposed, and you don’t need to be perfect to do that.”

When she applied to become editor at *The Manitoulin Expositor*, the owners took no issue with her MS. “They were really good, down to earth people and they didn’t care if I walked with a cane. I excelled at the job. I loved it.”

Sims went on to work for CBC Radio North, as a stringer for the *Toronto Star*, and as well as a regular columnist for numerous northern newspapers. She returned to Carleton a few years later to do a master’s in journalism, with greater aspirations. Maybe

Parliament Hill, or feature writing. Her master's thesis covered the effectiveness of press councils. As her illness worsened, her disability became more obvious, and she was hospitalized. Applications for journalism jobs did not result in interviews. Word got around, she guessed.

She became assistant editor of *Legion* magazine, speechwriter for federal and provincial cabinet ministers, and then corporate editor of a Crown corporation, where she developed ovarian cancer and, later, breast cancer. While on long-term disability, she became a disability rights activist and eventually wrote five books, three published internationally, donating the royalties.

Sims, like Saujani, believed in the medical model of disability. MS was her problem to solve, not the responsibility of Carleton or *The London Free Press* or subsequent employers to offer help or accommodations.

When I think of Diane Sims and Sheyfali Saujani, I think of their hard-earned wisdom, marginalized voices within journalism's ableist environment, incubated at journalism school. They both spoke of having no one within the journalism program with whom to discuss their concerns; no one to help reimagine what success could look like. We were all at Carleton together, alone, no way to find each other or form any sort of community.

Did the university have any responsibility to create an environment where discussing, admitting, or mitigating disability — or learning to report on it — was acceptable? Encouraged? Supported? At the time, I did not think so. Other students I interviewed view disability through the social model. For them, society must adapt.

Carmela Graziani remains upset and wistful about the opportunities lost to her,

which she attributes to the journalism program's failings. She has severe asthma that has meant countless trips to the emergency department for treatment and hospitalizations.

"When I got to Carleton in 1990, I was not prepared for the amount of second-hand smoke on campus. You couldn't get away from it and I got very sick."

She described having to cover events in smoky campus bars and a church basement. "I was in constant negotiation with my classmates." She offered to edit the stories for broadcast in exchange for not having to step into a smoky room. "I almost didn't graduate journalism because I got so sick." While a student at Carleton, she developed a severe respiratory infection and lost 40% of her lung function. "I went back to write that final exam knowing that if I didn't write it, I would have no degree. My career was over before it even started."

She and I debated how the university could be responsible for mitigating a societal problem, like smoking. She argued society must shift and accommodation is accommodation, no matter the condition. "People with disabilities have a right to go to school and pursue careers," she said, suggesting the journalism school could have created an environment where a student with lupus, MS, a visual impairment, or severe asthma could have requested more flexible deadlines, did not have to lug TV equipment around, or go to smoky venues. The journalism school could have created an environment where you do not feel like a failure if you cannot deliver on the hard news version of daily journalism that was celebrated.

"Absolutely the school is responsible for providing a safe place for students to work and prepare for the career," Graziani said. "I suffered a severe injury to my airways that put an end to my career, and it could have been prevented. What would my life have

been like for all these years if I had bylaws protecting me? Could I be working in journalism today?”

Graziani became a full-time anti-smoking crusader, using her journalism skills — doggedness, headline writing, chasing sources — to hold bureaucrats and politicians to account. In 2016, she received the Sovereign’s Medal for Volunteers from the Governor General for her work with the Ottawa Council on Smoking or Health, where she “tirelessly advocated for greater public education and a smoke-free Ottawa.” Due to her efforts Ottawa’s Smoke-Free Bylaws went into effect on August 1, 2001.

She recalls returning to Carleton to speak to fourth-year journalism students about her activism. A student raised her hand to confess she had asthma and thanked her for fighting for the smoke-free bylaw. “Think of what that level of protection did and how many other people can now pursue that degree who have lung disease compared to me, who was not protected.” She still finds her experience hard to accept. “There was a time where I couldn’t even drive by campus because it was just so upsetting to me to think of all the opportunities that I lost.”

A 2016 study noted that while “little is known about media workers and students with disabilities” they are an important group to study “because they work and learn in a field that has presented primarily negative representations of people like themselves” (Sgroi 65). In interviews, three male students with visible disabilities said they had a “supportive postsecondary environment” but “limited accommodations, minimal job seeking support, and no preparation for discrimination they would go on to experience in the media industry” (Sgroi 64, qtd. in Ellis 20). This study noted the need for more research to fill this “significant gap.”

Job Hunting

At Carleton, six months after my Easter episode, as I bashed away on a typewriter reshaping an earnest diatribe for the campus student newspaper *The Charlatan*, I noticed a stiffness in my fingers. Within an hour, the joints of my wrists, then elbows, were swollen and painful to touch. I could feel “it” spreading to my *Head and shoulders, knees and toes*. Rob Longley, a student sports reporter (who now covers sports full-time for the *Toronto Sun*) drove me to the hospital. I hoped catching “it” in action might provide clarity.

Alone in the emergency department, curtains drawn, my body was leaden. I was so cold. The resident who first examined me asked if I was depressed, anxious, or suffering from a breakup? Not recently, I mumbled. He felt my joints, moved my limbs, then he and a nurse jabbed the needle up and down my arms, leaving bite-like bruises, before hitting a rich vein in my right ankle. My gathering friends told me later that he approached them in the waiting room to ask if I had any psychological problems. They looked at each, as if considering for the first time why I had random pain, fevers, and sore joints, then firmly said no.

After a night in the hospital, where I saw two psychiatrists and one rheumatologist, I was discharged with a tentative diagnosis of “fibro-myositis,” which seemed to me like a made-up word, but described an overall pain and stiffness of the joints. They gave me some free samples of Naproxen, an anti-inflammatory, and another complimentary sleeve of sleeping pills (Page, “Emergency Pit Stop”).

There is no way I would confess this worrying episode to my male journalism

professors and so struggled on, holding in my heart the hopes of landing a summer reporting job. Knowing I was expected to be fearless; I instead became fearful. I aped my classmates and applied for summer student journalism jobs across the prairies and British Columbia, because as a westerner I had lived in those provinces. All yielded rejection letters except my application to *The Province*, a daily in Vancouver. The city editor liked stories I wrote for local papers in Port Moody and Maple Ridge, and that I had worked for a local politician as an office manager during an election campaign. When I was hired, I felt like I had won the sweepstakes.

But within a month of being hired (this was near the end of third year), I began to wonder if I should rescind my acceptance. Not only were my joints sore, especially in my legs, but I also felt like a vice was clamped on my heart and squeezing my lungs. If I coughed or sneezed, I squawked with pain. My roommate Laura, also in J-School, speculated that if I walked more quietly my legs would hurt less. The clomping of my boots on the stairs at night irritated her. My thirty-minute walk to campus followed the edge of Dow's Lake, passing elegant 1920s mansions. By March, I could not make it without resting against a thin tree trunk surrounded by melting snow. I finished my exams, somehow.

A few days later, back in my hometown of Coquitlam, B.C., I unspooled my story to our family doctor. I kept waiting for him to scrawl a prescription for sleeping pills, but instead he listened as I detailed the advance of my pain, from joints and muscles, to chest, lungs, and heart. He probed the tender joints at my ankles and elbows; pressed a stethoscope again my heart and lungs. Then he leaned close and said, "I think you have lupus."

Lupus, what an awful name for a disease. If I felt relief at a diagnosis, I truly cannot remember. I had held my chin up for so long that I was numb. Much later, I documented this appointment in a blog post titled “Who’s Afraid of the Wolf?”

“You either have pericarditis or pleuritis,” my doctor added, explaining that inflammation of the connective tissue surrounding my heart or surrounding my lungs could cause intense pain upon breathing, laughing, crying. The business of life was hurting me. He did not share any prognosis or even suggest lupus was a serious illness. I did not know I had received a life sentence of sorts, diagnosed with a hidden disability that I would have to carry with me for the rest of my life as I struggled to find my place as a journalist. Later, I wondered how I acquired the disease. There were many potential autoimmunity triggers in high school, including a very bad case of chickenpox, then Epstein-Barr virus and mononucleosis. Before starting university, I also received the measles, mumps, and rubella (MMR) vaccine, also accused of triggering lupus flares. Who knows?

I told the doctor I was supposed to start my first job as a daily newspaper reporter the following week. He never told me not to. Instead, he put me on 20 milligrams of prednisone to help arrest the inflammation, booked a chest X-ray and an emergency appointment with a rheumatologist. He also sent me for blood tests to confirm his tentative diagnosis.

On a Monday morning at 8 a.m., my mom drove me forty-five minutes to the downtown Vancouver offices of *The Province*. I shuffled into the building, trying not to pant, and after writing one-thousand words for a sidebar that should have been four hundred, I slipped out to rejoin my waiting and saintly mother.

As I later explained in my blog, I had no idea how to act. “Should I tell people my problems? Or would that make me seem weak? If they knew I was sick, could they send me home? Maybe I should be sent home? Would my diagnosis taint me for my dreamed of future as a journalist?” (Page, “Getting the Scoop”). With so many unknowns I busied myself writing about allegedly psychotic polar bears at the Vancouver Zoo and a drug addict who hung his baby upside down out a window in Gastown. Each assignment brought new challenges because I could not easily walk a block or dash up a flight of stairs.

The rheumatologist’s review of my blood tests found I had an extremely high level of anti-dsDNA antibodies — produced by the immune system when it is failing to distinguish between “self” and “non-self.” I had lupus. The X-rays showed I also had an inflammation of the outer lining of my lungs, called pleurisy, as well as an effusion, which is a build-up of fluid in the pleural space. Worse, I had had this inflammation for so long there was scar tissue surrounding my lungs.

He prescribed 80 milligrams of prednisone, assuring me it would make me feel better. He also told me not to read anything about my illness because all medical textbooks were out of date. When I eventually found a dusty textbook in *The Province’s* resource library, I learned that lupus had a five- to ten-year survival rate after diagnosis. “I almost blacked out as the weight of that prognosis flattened me. By refusing to share this information, no matter how outdated, the doctor left me to process the possible prognosis alone. Anyone would eventually go looking in an old textbook, especially a young journalist. I suddenly felt like a fool,” I later wrote (“Getting the Scoop”).

If my determination to keep working seemed odd, it was fuelled by a kindly if

patronizing medical professional keeping me clueless. I started the summer as a pain-wracked neophyte and finished as a slightly seasoned reporter, forced to think about her own mortality. I was healthy once, and then for my entire adulthood I have not been. It has made me hypervigilant yet risk tolerant. I try to control my diet, sleep, and supplements, but because I am always worried my life might end too soon, I chase my dreams with even more determination.

I arrived to complete my fourth and final year at Carleton, a changed person. I had a cushingoid, puffy face caused by the high dose of prednisone, bright red cheeks that suggested a lupus rash, anxiety, and embarrassment. I resigned from my paid assistant news editor position at *The Charlatan* but kept my job as a teaching assistant for a second-year television class. During the year, I twice developed pneumonia. I once went to a party and spent most of it in a bedroom with my head tipped back, blood pooling in my ears from the nosebleed because my blood was not clotting. No more parties. My skin started ripping. When my then-boyfriend pulled me backwards onto our couch, my belt dug into my hips, opening large gashes in my skin. When I phoned my rheumatologist in a panic, she asked, “Didn’t anyone tell you that prednisone makes your skin really thin?” She reduced my dose to 60 milligrams to prevent more stretch marks (Page, “Prednisone 101”).

By March, prednisone tapered to 20 milligrams, I could breathe without pain, although not deeply. Sneezing still hurt like hell, which my rheumatologist blamed on my scarred lungs. I could glimpse my cheekbones. I was getting better.

Still riding high on the wings of prednisone, I photocopied my clippings from *The Province* and applied to be a summer reporter at the *Toronto Star*, the most competitive

reporting program in the country. I made the short list. When I was interviewed by the *Star* editors, I did not tell them I had lupus because I truly believed the worst was behind me. I also knew that if I did, I would not get the job. I had internalized the message from journalism school that reporters must be invincible. Over the previous year, I had at least proven resilient, I just was not sure they would see it that way.

Back to the Future

Are my experiences, and those of Sims and Saujani, relevant today? That is a question I explore as part of this Scholarly Personal Narrative. I told my story in 2020 to fourth-year journalism students at Carleton and afterward several came forward to disclose their disabilities and dismay that this was the first time disability issues had been discussed — in the last class of the last semester of their last year. These students, almost four decades after I graduated, wanted their differences acknowledged, even considered assets, in utter defiance of the prevailing mainstream daily journalism ethos. They argued they had more empathy, insight, and resilience because of living with disabilities. They saw representation as a human rights issue, and several — in essays for a fourth-year class where I was a teaching assistant — wrote about their commitment to reporting on disability issues. Reading the essays, so hopeful and courageous, made me cry.

Journalism schools turn out people who will go on to shape what others think about disability. What journalism students are taught matters because it is perpetuated. American media and disability scholar Beth Haller writes “media content is shaped by dominant societal beliefs about disability that come from the power of the dominant able-bodied culture” (Haller, *Representing Disability* iii).

Would changing journalism to put an emphasis on disability make a difference in students' lives and how they approach their work? It is a question that students and recent graduates I interviewed asked, and was explored in 2016 by Shawn Burns, a journalism lecturer at University of Wollongong in Australia. He cited the bold move by Christopher Callahan, dean of the Walter Cronkite School of Journalism in Phoenix, AZ, to embed the National Center for Disability and Journalism at his school, wanting to instill the value diverse news coverage beyond racial issues (Burns 222).

In his research, Burns explored if even minimal in-class exposure to disability influenced how journalists tackle the topic. Each year for five years, he ran one three-hour disability reporting class for his broadcast journalism students that explored the representation of people with disability (PWD) in media. Of the forty former students surveyed about the three-hour disability module, the majority (77%) strongly agreed that they were conscious of the way they represent PWD in their work and were prepared to challenge colleagues about representation of PWD (224). Burns concluded:

“Overwhelmingly, it shows that diversity studies, particularly disability studies, have a place within journalism curriculum” and that shining an “exploratory light on an aspect of news media coverage that is often dismissed as political correctness or ignored completely” is impactful (228). “This snowball, formed within one class, in one subject, and in one university, has shown itself to affect those who took part in its construction well beyond the bound of the classroom (223),” he wrote.

I was grateful to see the snowball I tossed in one classroom grow after speaking to students about struggling with lupus while at journalism school. A recent graduate who

identifies as a member of the BIPOC community, wrote an essay thanking me for my presentation and disclosing she also has lupus. Here and elsewhere, she is identified as B.

“I was completely caught off guard. It was so shocking because I knew that this was a conversation that we needed to have. I just didn’t think we’d ever have it at Carleton,” B. told me. “Because it’s not been addressed in four years, I just assumed I’ll graduate and that’ll be that. This won’t be a conversation that we ever have.” She said she appreciated it was coming from “someone who’s had that lived experience.”

At Carleton, B. kept her lupus hidden, concerned about how being a person of colour with a disability would impact her. “One of the very real fears or challenges for students of colour is we’re scared of just being seen as an example [...] Being seen as that student of colour who has these issues and who needs extra accommodations. I’m not sure I wanted that,” she told me. “At the start, I would often tell the professors that I might not be as responsive in class because I’m not feeling well. But the professors never asked if I was going through anything or if I’d like to discuss it. And I never bothered mentioning that I had lupus. I went to class because I needed the notes and the content. But I was rarely a participant.”

The COVID-19 pandemic, declared in early 2020, disrupted work and home life, and our collective ideas about physical health and psychological safety. A knock-on effect made students more likely to discuss their lived experience in relation to their practice as journalists and influenced how professors acted towards them as individuals with unique needs. “For the first three years, it was our number one goal in life to be a particular version of a journalist who is an observer or someone who’s questioning things, but you’re not a part of the community,” she observed. “With the pandemic,

journalists objected and said ‘No, our first responsibility is to ourselves as people.’ I think that’s what’s changed,” she said, noticing that during the pandemic professors increasingly asked if she needed help or needed to talk. “Hopefully that’s a practice that should permanently be in place, and not just for people with disabilities or chronic illness.”

The late Clark Edwards, a former journalism professor at Pittsburgh’s Duquesne University, argued in 1992 that “journalists are promoting journalism using stereotypes.” He wrote about TV ads portraying journalists “charging up a flight of stairs [...] in a scene reminiscent of a *Rocky* movie, or “jumping from a news cruiser with walkie-talkie in hand and running through traffic toward a police car,” (Edwards 85). Equating “physicality with journalism [...] may have been an easy image to focus on and once it may have been a useful image. Now, the stereotype is conveying a wrong message to disabled young people who might consider a future in journalism” (86).

He argued: “There is a serious need to examine the number of newspaper, radio or television journalism jobs that actually require this stair-dashing, running individual, as opposed to the intellectually able editorial writer or editor, the creative page-designer, infographics- creating journalist, phone-beat reporter, TV producer, radio or TV anchor” (86). He added: “We could better define all the complex roles of journalism. We should depict successful ‘journalists’ doing their jobs, including those who use wheelchairs or crutches or canes” (86). To Edwards’ suggestion, I would suggest we also portray successful journalists with mental illness, autoimmune disease, cognitive, and neurological disorders, among other invisible disabilities.

Edwards noted that disability had been left out of the push within journalism to

include and promote the rights of racialized groups and women. “Journalism, both education and the profession, was at the cutting-edge of integration in the racial civil rights movement. Both are active and publicly expressive in the battle over gender equality. Both, however, seem reluctant and silent concerning the disability movement” he wrote (85). He called out the considerable “money, energy and time recruiting ‘minority’ students” to university journalism programs and questioned if the same effort is put into recruiting disabled students. “This raises the question about how equally an entire class of people has been considered” (87). Important questions that resonate forty years after they were asked.

Journalism schools will have to meet the needs and expectations of increasingly vocal students who want to be recognized and accommodated for their diversity, including disabilities. Whether legacy media is open to embracing this aspect of their diversity, often associated with weakness, as Saujani and Sims pointed out, is a more difficult question to answer and one that requires further examination. In the following chapter, I explore working in Canada’s most competitive newsroom and how prevailing stereotypes informed their employees’ disability identity, including my own.

Chapter 2: Bullfighters and Supercrrips in Hemingway's Long Shadow at *The Toronto Star*

"I've got a very special mentor for you," the head of the summer intern program told me. Excited, I wondered if I would be coached by *The Toronto Star's* legendary feature writer Lynda Hurst? Or Queen's Park Bureau Chief Rosemary Speirs? Or maybe the intimidating and demanding editor Mary Deanne Shears? There were so many women I admired at the *Star*. But no. Apparently a male editor had made a special request for a "sweet young thing."

"He's never had one before," the program head joked. Now he would have me.

I juggled a lot of fledgling identities that summer. I was not just a cub reporter, or bait for seemingly lecherous editors, or a young feminist. I was also the not-so-proud owner of a newly diagnosed chronic illness, then said to have a ten-year life expectancy, which would certainly jeopardize my future in the intern program, if not my career as a journalist. I did not disclose these details, though the program head already knew I had some sort of "condition" and once asked how I was "feeling." Telling him or others about lupus's vise grip around my lungs, its clenched fist around my heart, would give me no advantage and likely harm my reputation. Or so I thought. I had no idea how my invisible disability would affect my career. Being known as a "sweet young thing" in the most competitive summer student program in the country seemed bad enough.

I needed a role model.

My mentor turned out to be Foreign News Editor Dennis Morgan. He struck me as quick witted, acerbic, and aggressive. He was about forty-years old, compared to my

twenty-one. He had a limp and a shrivelled right arm, which I later learned was a result of childhood polio. I would proudly hand him my raw copy, and he would take a vicious red pen to it, eviscerating flabby sentences and gouging holes in my approach. I explained, panicked, that I needed to increase my output because I had already been sidelined writing fluff for a special supplement while many of my fellow interns had a dozen or more bylines. Morgan assured me, in his Welsh accent, that there were no jobs except those promised to three second-year interns, said to be golden boys. Besides, Morgan said, even if there were jobs, he was not sure I was *Star* “material.”

I came to dread my meetings with him. His nickname was The Poison Dwarf, which seemed particularly cruel. That is how it was in newsrooms. Come prepared to be mocked for any perceived weakness. Morgan minimized his disability, although it clearly pained him and restricted his mobility. Instead, he compensated for the lasting effects of polio with bitter-tinged bravado, boasting he could type faster with one hand than anyone in the newsroom. Even his insistence I meet him for a drink, which I evaded, was mostly posturing. A car nut, later that summer he launched the paper’s Wheels section — almost entirely on his own, and in his spare time. In a tribute after Morgan’s 2007 death from a heart attack at age sixty-three, Canadian racing champion Scott Goodyear described him as having “a strong voice, a decisive, almost confrontational, manner, and what seemed to me to be a steely determination to ignore any potential handicap deriving from his obvious disability” (Cosgrove).

Dennis Morgan was the first person I encountered at the *Star* with an obvious disability. I never told him about mine, which might have made all the difference. Our match, mentor to mentee, could have been a stroke of genius arranged by the paper. A

journalist with a lifelong disability, who had started as a copy boy and climbed various metaphorical ladders, dispenses wise nuggets to a cub reporter struggling with a new and fast-developing disability that is mostly invisible. Few people would notice my shuffling limp or clumsy arthritic hand gestures. Morgan might have coached me in resilience, survival, and seeking accommodation. His mentorship could have helped define my career. Instead, our brief pairing reinforced my belief that whatever my physical challenges, I had to overcome if not overcompensate for them.

I cannot go back and interview Morgan, and it is unfair to psychoanalyze the dead (unless the subject is Ernest Hemingway — see below), but he had much to overcome in the macho dynamics of the news organization, as Goodyear posited.

Since its founding in 1892, the *Star* has been the largest and most influential daily in Canada, and a coveted destination for budding reporters. While I was starting my career there, some stand-out journalists with visible disabilities were also launching their careers. In this chapter, I consider the roles they were expected to play, from macho strivers to saintly Supercrips to the working wounded, and what we can learn from them today.

The brilliant photojournalist Paul Watson, who was born without a left hand, was a metaphorical bullfighter cut from the same cloth as Ernest Hemingway. The self-described “one-handed rebel” ran toward countless conflict zones, goaded by *Star* management. Barbara Turnbull, who had been shot in the neck at age eighteen during a robbery, severing her spinal cord and rendering her a high-level quadriplegic, started as an intern when I was at the paper. When she died at age fifty of pneumonia in 2015, the headline of her *Star* obit read: “Star reporter Barbara Turnbull overcame debilitating

injury to carve out a superlative career.” The story was a masterwork in the “overcoming” narrative that news organizations use almost exclusively when writing about the disabled. Helen Henderson was a pioneering business journalist who developed multiple sclerosis; it began as an invisible disability until she needed a cane and then a mobility scooter. She created the first disability beat in Canada and became a champion for Canada’s disability community. I would also include Dennis Morgan, my mentor, in this group of Supercrrips and bullfighters, since he worked so hard to make his colleagues see past his withered arm and bum leg, oozing aggression and championing masculine pursuits like automobiles and hyperbolic skirt chasing.

These were my role models, journalists compelled to exhibit superhuman bravery, strength of character and talent, all while overcoming real and perceived physical or mental differences. The men had to be especially masculine, while the women had to be overcomers as well as champions of a greater cause: disability rights. Just “living with” disability was not an acceptable option within the daily newsroom. The *Star*’s ethos, employment, and attitude toward disability no doubt influenced a generation of journalists and shaped the cultures of other news organizations as its alumni moved on. After examining the cases of Hemingway, Watson, Turnbull, and Henderson, I consider the influence on a junior reporter like me, newly diagnosed with a potentially fatal and debilitating chronic condition.

Setting the Standard: America’s Macho Icon

News organizations are steeped in masculine heroics, but none as much as the *Star*, where workaholism and risk-taking are celebrated, even today. Carleton Journalism

Professor Brett Popplewell, writing in *The Walrus*, made an example of “*Star* man” Daniel Dale, best known for his “doggedness” in fact-checking former U.S. President Donald Trump when he was the paper’s Washington correspondent. Dale, now with CNN, embodied “the stereotype of the muckraking workaholic who sacrifices health, relationships, and pretty much everything short of life itself in order to chase down the next scoop,” wrote Popplewell. He tied Dale to a long line of heroic journalists bred by the paper, including Watson and Kathleen Kenna (who also worked at the *Star* while I was there, and later, in 2002, was severely injured during an ambush while covering the war in Afghanistan). In addition to the defining attributes shared by Popplewell, *Star* public editor Kathy English added “courage” and “persistence,” as well as a “refusal to be stopped until they [reporters] have answers citizens need. Great reporters have drive and determination — day after day, even in the face of opposition and obstacles” (English).

I blame the idolization of Hemingway, whose legacy loomed large and cast the model for daring and bravado. Based on what is now understood of Hemingway’s varied and complex disabilities, including PTSD, brain disease from multiple concussions, and mental illness, his hiring by the *Star* could have been an example of a legendary writer earning respect from his editors as a journalist with invisible disabilities. Maybe, in an alternate history, they stepped in to protect a shell-shocked Hemingway from running toward danger. Instead, they dined out on his hunger for conflict while he soldiered on. Little was known about what was going on inside his brain; and it is not often discussed, even today, and especially at the *Star*. I could find no articles mentioning Hemingway and PTSD or his history of concussions.

After World War I, in 1920, the future winner of the Pulitzer Prize and the Nobel Prize in literature landed a job at the *Star*. As a European correspondent until 1924, he travelled extensively — ten thousand miles in one year, some on the Orient Express. “The *Star* gave [Hemingway] the keys to the world,” said another former foreign correspondent Bill Schiller in *The Hemingway Papers* in 2012 (Cooke).

While writing for the *Star*, Hemingway first witnessed bullfighting, which became a lifelong passion, along with other tough-guy pursuits. He went on to become “America’s macho icon,” according to grandson John Hemingway, perceived as the living embodiment of male stereotypes — “in equal parts drinking, hunting, war, and womanizing.” He died by suicide in 1961 at age sixty-one.

At the time, few understood why a man who had achieved so much in life would end it so abruptly. In recent years, literary critics, academics, psychoanalysts, psychiatrists, and Hemingway’s own family have analyzed his so-called madness. Many now identify the complex invisible disabilities he suffered, including mental illness and PTSD. Psychiatrist Andrew Farah said several severe concussions over Hemingway’s lifetime — the first in Italy during World War I — caused chronic traumatic encephalopathy. Bomb blasts and blows to the head led to “paranoia with specific and elaborate delusions,” dementia, and the final violence of his suicide (Smith).

Some of Hemingway’s difficulties, including undiagnosed mental illness and PTSD, likely manifested before his time at the *Star*. In 2009, historian Peter Moreira wrote in *Military History* about the wounded Hemingway limping into the newsroom, telling war stories and looking for a job.

The tall, beefy lad with a limp showed up at the *Star Weekly* in January 1920 and

started telling tales about fighting with Italy's famed Arditi commandos in World War I and suffering wounds from mortar explosions and machine-gun fire. The guy must have sensed the features editor's incredulity, for one day he showed up with a small cardboard box. It contained two medals — the Croce di Guerra and Medaglia d'Argento al Valore Militare. (Moreira)

Editor Greg Clark lifted a silver medal from the box — Italy's second highest award for valor — and read *TENENTE ERNESTO HEMINGWAY* etched on its edge. Clark, a veteran of the 1917 Battle of Vimy Ridge, offered young Hemingway a job and would learn later that the daring scribe had been a Red Cross ambulance driver on July 8, 1918, handing out cigarettes and chocolate to Italian troops, when a muzzle-loaded Austrian trench mortar nearly hit him. A bomb exploded about three feet from his teenage frame, burying Hemingway in dirt. When he came to, an Italian soldier between him and the explosion was dead, while another lost both legs. "Finding a third, badly wounded soldier nearby, Hemingway hoisted him on his shoulders and, though injured himself, started for an aid station," Moreira wrote. Subsequent machine-gun fire caught Hemingway in the right foot and knee, but he ran with the soldier to the nearest trench. According to Moreira, contemporary medical accounts recorded 227 shrapnel wounds in the writer's legs, noting that after his wounding in Italy, Hemingway suffered chronic nightmares and insomnia.

The author of *For Whom the Bell Tolls* was recently featured in *Phallacies: Historical Intersections of Disability and Masculinity*. Contributor Carolyn Slaughter's "Ernest Hemingway, the Man, the Girl, and the Genius" explored the possible genesis of his risk-taking macho behaviour, including a "full-bore diagnostic list:"

Oedipal complex, bipolar disorder, narcissistic personality disorder, alcoholism, psychosis, delusions and paranoia, impotence, chronic death wish, gender identity issues, self-image issues, latent homosexuality, spousal abuse, physical and emotional abuse [...] He was constantly running off to war as a correspondent and getting as close as he could to the front lines. And yet, there are also witnesses to his bravery under fire or his way of putting his own life at risk to help someone else — but surely these were death wishes too? Few could discount his real courage in situations where he found himself in tremendous pain, even of his own making. And still he lived, too afraid to die in any way that would remove the hero epitaph from his obituary or reveal him as a man who, like his father, had taken “the coward’s way out.” (Slaughter 6)

Slaughter added, “He was going to cement his reputation as the greatest living writer even if it killed him” (8), the implication being that childhood trauma and his war wounds birthed a death wish. Ken Burns, co-creator of the three-part documentary *Ernest Hemingway*, has contemplated the writer’s first brushes with madness: “Does it start when he’s nearly killed in World War I, and comes home and can’t sleep alone, and his sister sometimes comes and settles into his room, and he has suicidal ideations? Does it come after his father [dies by suicide]? When he begins to believe his own PR?” (Daley).

In other words, what pathologies underlie these risk-taking behaviours? These are provocative questions considering his lionization within the *Star*, which celebrates risk-taking and the sacrifice of personal health and safety.

Men with disabilities, not just journalists, have long struggled to reconcile masculine identity with disability stereotypes. As Asch and Fine observed in a ground-

breaking 1988 essay, “Having a disability [is] seen as synonymous with being dependent, childlike and helpless — an image fundamentally challenging all that is embodied in the ideal male: virility, autonomy and independence” (qtd. in Kinder 94). For men with disability, these stereotypes provoke an almost hyper-masculinity. Harlan Hahn, an American political scientist with post-polio syndrome and the first scholar to offer a comprehensive interpretation of disabled masculinity, argued that disabled men embrace masculine traits like independence and bravado instead of identifying as disabled (Shuttleworth et al. 176). Kathy Charmaz writes that men with chronic illnesses, like men with visible disabilities, must reconcile masculine identity with disability identity. She argued chronic illnesses often undermine the sense of status and privilege afforded by masculinity, writing, “illness can reduce a man’s status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity” (Charmaz 268).

Paul Watson offers some insight. He was a second-year summer intern — one of the golden boys guaranteed a job — when I joined the paper as a first-year intern. Watson wore his death wish on his shortened and pinned back sleeve, frequently boasting he would be a war correspondent long before any of us emerged from the *Star*’s suburban bureaus. He was right. He is best known for winning the 1994 Pulitzer Prize in spot news photography for his photograph of a U.S. soldier’s body being dragged through the streets of Mogadishu by a mob of jeering Somalis.

Back when we were newbies, I knew Watson as a gifted writer and a drinking buddy who had war lust. While he was working as a general assignment reporter, he saved his money for a working holiday in a warzone. His first vacation was to Eritrea. “It was just

the sort of obscure place where I could test myself and see if I was fit to be a foreign correspondent,” he writes in his 2007 memoir, *Where War Lives*, in which he also recounts his struggles with PTSD and chronic depression. Watson’s goal for that first reporting adventure was to contact Eritrean rebels in Sudan, who took him on a harrowing journey into the mountains, as Ethiopian bombs fell, and he suffered from malaria. He returned from his “vacation” to Toronto with enough pictures and notes to freelance a few stories for the *Star*, but was soon back on the midnight shift, “on the far edge of the newsroom, longing for the sounds of mountain wind, spoons against tin plates, and rebel laughter in African darkness” (Watson 86). He began planning his next vacation to Angola and after that, Somalia. The *Star* finally put him on a plane in 1991 to Baghdad on the cusp of the Gulf War.

All these years later, I remember his nonchalance in speaking about his hunger for danger and his indifference to death. In his book, he explains how, as a youngster, he began taking outsized risks to divert attention from his one-handedness. He would stand at the head of the stairs in his childhood home, back turned to the bottom, and teeter at the top, threatening to topple backwards.

Walking the razor’s edge soon became a habit, a game that I could win, and get attention on my own terms. I guess that just felt better than the troubled, misty-eyed stares, the nosy questions from complete strangers who stopped my mother to say how sorry they were and to ask, “How did it happen?” (62)

That question haunted Watson. *How did it happen?* “And each repetition fixes in your mind that you are different. That you sometimes scare people [...] whenever strangers looked my way, I could tell from their piercing stares that the deformity was what they

saw. It took longer for them to see me. Some never did” (63).

Some have quibbled that missing a hand is not technically a disability, suggesting it only requires a workaround — learning to type and take pictures with one hand — but that is a simplistic view of a lifelong disfigurement. The question of whether missing an appendage constitutes a “real” disability reminded me of a headline highlighted by disability studies expert Tanya Titchkosky in a *Kidzworld* magazine: “No arms, no legs, no problems.” As she points out: “To see ‘no problems’ while perceiving ‘no arms’ or ‘no legs’ does require some work. It requires the work of translating ‘no arms’ into something disconnected from the environments within which arms appear, environments that are set up as if there should always be arms, and always two” (Titchkosky 187)

Watson overcame his one-handedness to write and take photographs as well as or better than any other war correspondent of his generation. But his risk-taking begot serious mental health problems. His PTSD, diagnosed after reporting on the 1994 Rwandan genocide, does not have a straightforward workaround. He writes vividly about the expectation that reporters be “tough-skinned, inured to the madness that surrounds them” (Watson 140). He also describes the antidote for that pressure, a kind of reckless self-care that also conforms to male stereotypes: “If a construction worker drops a beam on his foot, he sees a doctor, goes to rehab, gets workers compensation, and heals. If a war correspondent fries a few circuits, he sedates himself with whatever booze, drug, or quick lay is at hand and gets ready for the next deadline” (140).

PTSD is a condition sometimes acquired by journalists in the line of duty but is not in the scope of this thesis. That said, it is another disability journalists struggle to get recognition and accommodation for, as noted in Chapter 10 with regards to the CBC.

From the beginning of Watson's career to his resignation, the *Star* capitalized on his compulsion to overcome — if not overcompensate — at the expense of his mental health. He resigned from the paper in 2015 over its “refusal to publish a story of significant public interest” — on the search for the lost ships of the 1845 Franklin expedition — an allegation the paper denied (Daro).

As for Dennis Morgan, he not only strove to be the ideal *Star* man, but he also modeled — whether he knew it or not — how to overcome physical deficiencies to earn respect, launching the new Wheels section on his own. In this way, he was an influential mentor. He drove me to work harder, encouraging me to find ways to get more, better bylines. That summer, still hyped up by an elevated dose of prednisone that kept inflammation under control, I worked from home before my afternoon shifts, researching stories that I would later pitch when the workday began. Some were colourful gems that showcased my writing, others were desperate ploys to get a byline on A1 (which sometimes worked). Somewhere along the way, Morgan told me he changed his mind about me and promised to help me get a job. Overcompensation was elevating my game.

Saintly Supercrrips

In 1983, a teenage Barbara Turnbull was shot in the neck during a convenience store robbery in Mississauga, the bullet severing her spinal cord and rendering her a high-level quadriplegic. She went on to graduate with honours from Arizona State University's journalism school as class valedictorian and was hired full-time as a staff reporter at the *Star* in 1996. Before that, she and I worked together in 1989 and 1990, when she was a summer intern and I was a general assignment reporter.

When Turnbull died in 2015 from pneumonia, the *Star*'s obituary celebrated her accomplishments in helping her colleagues forget her disability, her wheelchair, and her pitiable fate (Grewal and Hong). The qualities ascribed to Turnbull in the obit include strength, bravery, vibrancy, feistiness, and determination. Much is also made of her befriending able-bodied people in the newsroom, and that she worked hard to make them comfortable by downplaying her disability. "The miracle of Barb was you lost the chair. A whirring, lumbering, 300-pound contraption," one colleague and close friend was quoted as saying. "Yet if you knew her, it disappeared. Gone, in the glow of a sublime spirit." Another colleague lauded her for making others comfortable. "She used positive language, the language of the able-bodied, so that she was not set apart. Because of that we didn't set her apart. She walked to work. She had lunch with you. The relationship was collegial, not dependent."

Star managing editor Mary Deanne Shears, who had hired Turnbull, added: "Little did I know then of her strength, her bravery, the depth of her independence, her writing talent and her vibrant personality."

While the obituary says much about Turnbull's "overcoming," and the deep love and admiration her colleagues had for her, it also reveals an ableist mindset that elevated her to the newsroom's Supercrip. Even the *Star* editorial board weighed in after her death, inadvertently revealing their low expectations for people who are not seen as normal: "If all she had done was go to work and do her job, Barbara Turnbull would have been an inspiring example of courage in the face of enormous obstacles" ("Barbara Turnbull").

A super cripple, or Supercrip, is cast as a hero of a different kind. If *Star* men with

disabilities — visible or invisible — sought admiration by being hard-bitten, macho risk-takers, the women were valued for being caring, overcompensating for their own disability while also championing others.

Supercrips simultaneously demonstrate and diminish the worth and value of people with disabilities by serving as tropes. The identity is explored by Ann Schmiesing in *Disability, Deformity, and Disease in the Grimm's Fairy Tales*: “The supercrip ... represents overachieving, over-determined, self-enfreakment that distracts from the lived daily reality of most disabled people” (Schmiesing 112).

“The most common and most repetitive contemporary representation of how to solve the problem of disability — overcome it,” wrote Titchkosky, associate professor at the Ontario Institute for Studies in Education, University of Toronto. She added, “disability is not regarded as an ordinary and common fate of all, but instead it is regarded as an exceptional circumstance and a unique problem against which ‘special’ people can show their spirit” (181). Beth Haller, assistant professor of journalism at Towson University, wrote, “the power of the Supercrip is a false power. People with disabilities are put on pedestals because of their inspirational quality in doing ordinary things, which is actually a patronizing way to laud people, imbued with charity.” Presenting someone as inspirational is just another way of pitying them for the “tragedy of their fate.” Through this gaze, any person with a visible disability who does any basic task becomes inspirational. Anything outside of daily life, like competing as an alpine skier with missing limbs or performing the duties of a journalist while paralyzed, is the stuff of Supercrips.

Titchkosky writes that disability is perceived as negative and therefore individuals

who meet the demand to be positive are heroic. “A defining feature of the overcoming story is that the disabled other is made into a kind of ableist opportunity. Putting pedal to the metal, able-ist ‘can do’ values shine forth as if they are merely normal and even natural” (184). In other words, any concept of disability as an extension of the universal human condition, one as flawed and unique as every individual person, is erased by a culture that celebrates being “normal.” Titchkosky has also examined the prevalence of the overcoming narrative in news stories, such as one about a boy who “despite having no legs, plays football, runs track, and has even competed in several triathlons,” (*Kidzworld* ctd. in Titchkosky 187-88) adding that it is “as if the demand ‘Respond. Respond well!’ emanates from the spirit of mind situated in the impaired body, as if it has nothing to do with able-ist realms of normative values within which all people find themselves” (188).

The Supercrip that Turnbull’s colleagues saw is different from the anxious intern who entered their newsroom in 1989 and who wrote in her memoir, “I felt a little faint. That night I didn’t sleep; I lay in bed and fretted ‘til dawn. What on Earth have you gotten yourself into, and how are you going to pull this one off?” (Turnbull 149).

She wrote about the joy of seeing her name in her first byline, instead of a headline about being shot, and how “rewarding” it was. Proof of something she had done as opposed to something done to her. A story in the employee publication “mortified” Turnbull when it described how she “impressed everybody with her writing ability and dogged determination” and use of a mouth stick to type. “First of all, no other summer student was ever mentioned like this, even those returning for a second year. Secondly, there was absolutely no relevant reason to describe how I typed, except perhaps to inspire people and show how ‘brave’ I was supposed to be. There was no denying this was

different treatment — tokenism, even — and I was devastated” (150).

Even while producing good work, she “still felt inferior whenever I compared myself to my colleagues.” And she feared some colleagues “felt my disability and the publicity were the only reasons I was there, and I began to wonder if they were right” (152).

In those early years, she was very sensitive about her status as a person with a disability and a victim — “I feared I was considered a token” — and avoided writing stories related to wheelchairs or disability. When readers called with related tips, Turnbull referred them to the reporter who wrote the disabilities issues column in the Life section, Helen Henderson, who had MS. “I passed on some good, worthwhile news stories. I also carried a permanent chip on my shoulder,” Turnbull wrote (153).

She eventually grew to see her disability differently — as expertise. Or maybe she could not avoid expectations that she become a champion for her kind. She took on stories about related issues and prided herself on accuracy after being the subject of many errors in coverage surrounding her shooting. As is expected of a Supercrip, she lobbied for better accessibility, as well as better legislation. In the *Star* obit marking her death she was cast as a champion of disability rights, as though it all came so easily, as opposed to being born of a crisis of conscience, which is arguably a more interesting story.

In the 1980s, Henderson was diagnosed with MS and her role transitioned from pioneering female business reporter to the Life section, with its less demanding pace. She had “the slow kind of MS,” Henderson told an interviewer in 2010. She eventually used a cane, then needed a leg brace, then used an electric scooter. “So, my evolution as a disabled person and as a journalist ... was slow,” with the *Star* following her lead in

learning about accessibility and accommodation (Jones, “Dropping the Disability Beat” 332).

“The idea for a disability beat began brewing as her job shifted into the Life section, and she became increasingly aware of the ways in which her unfolding disability was surfacing in the newsroom,” according to Chelsea Temple Jones, an assistant professor at Brock University specializing in critical disability studies, who wrote a 2019 academic article about the long-term prognosis for the disability beat in news organizations. Her interview with Henderson formed the backbone of the article. When Henderson pitched a beat, it was rejected, and she was told to write a weekly, unpaid disability column in her spare time. “So, she wrote, knowing that she had to earn a beat rather than demand it” (331). Jones wrote, “although Henderson was not the only reporter with a disability in the *Star*’s newsroom, her push for a disability beat left her playing a dual role: She was a disabled reporter who covered disability” (332).

One of Henderson’s first features, published in 1991, told the story of a blind woman who “dropped off the edge of the world and fell to her death on the tracks of Lawrence West subway station.” It provoked disability activists to advocate for safer, more accessible transit in Toronto (Jones, “Dropping the Disability Beat” 336).

Henderson’s role as a columnist and feature writer focusing on disability issues was eventually formalized. Among other interventions, Henderson’s advocacy work led to stop announcements, request-stop buttons, and the uniform-length subway trains in Toronto’s subway system. As she went on, she expanded the column’s scope, also focusing on mental illness and aging. She made it her job to make sure disability stories did not disappear over seventeen years of weekly columns (336).

Henderson was also an overcomer and took her role as a disability rights champion seriously, explaining that journalists must “carry the fight” for reasonable disability representation into each newsroom (Jones, “Dropping the Disability Beat” 337). The last of her columns appeared online in 2012. She died in 2015 of lung cancer, one month before Turnbull. Henderson was portrayed as Supercrip in her staff-written *Star* obituary. She was remembered as a “champion for disability rights” who was “strong-willed” and “courageous,” adding that “[t]hose close to her say she faced her own health issues with grit, walking with a cane for many years before her condition required her to use a wheelchair” (Krishnan).

I remember Henderson as one of the women who had been shifted to the Life section for one reason or another; usually mothers who needed to leave early to pick up their children. I regret not having known her, beyond a hello as we passed each other in the newsroom. She, like me, had a chronic disability that relapsed and remitted, until in her case it led to permanent visible disability. I wonder what would have happened if she had been my mentor, instead of Morgan. If I had been honest about my chronic condition, she might have coached me how to disclose to my bosses and to use what I know to tell meaningful stories. She might have been the perfect mentor had I not been preoccupied with my own overcoming narrative. If I boldly disclosed, would it have jeopardized my chances at being hired full-time? Would I have then been relegated to the Life section to write social justice features and as my health declined, becoming a champion for others like me? Perhaps that would have been a better outcome for my long-term health.

I could not imagine becoming a Supercrip because I do not think it is a role that is embraced consciously, but instead foisted on you by others’ ableist expectations that you

overcome and overcompensate; showing you are useful by championing causes that might reduce the societal burden of people with disabilities. In addition, when your condition is entirely invisible, I imagine it is much harder to wear the Supercrip mantle because no one knows what you are overcoming. Worse than being a Supercrip is being branded a malinger.

When I was in that newsroom, I was undercover, intent on faking normalcy in the hopes I would be noticed only for my accomplishments.

During the final week of the summer internship, I was finishing up an assignment in a suburban bureau when City Editor Lou Clancy called to offer me a job. One of the golden boys had apparently started golfing during his shifts because he was so certain he would be hired. He was out; I was in. I was elated and terrified. It had been sixteen months since I was diagnosed with lupus and put on a mind-boggling dose of 80 milligrams of prednisone, the potent anti-inflammatory. I owed a lot to that secret sauce, and to my overcompensation, which pushed me to work harder than what ailed me. How else to explain winning a job?

In the almost five years that followed, first in the East bureau and then based at One Yonge, I struggled to keep pace and figure out my place. I slowly tapered off my prednisone, and a more realistic version of me emerged, one that hobbled in pain and dealt with bouts of pleurisy, chronic asthma, and persistent lupus migraines that lasted for weeks. Once I was hospitalized; another time I took vacation during a bout of pericarditis. Throughout, I consistently re-evaluated my career path as I covered labour disputes, drownings, teen prostitution, drug use at rock concerts, demonstrations outside abortion clinics, and the import of my assignments at the *Star* increased.

Identity, Expectations and Gatekeeping

I was not brave or confident enough to share my struggles beyond a few close friends. And I certainly did not think to sit down with Henderson, Turnbull, Watson, or Morgan to seek their advice on meeting expectations in the face of uncommon struggles, in large part because I could not yet imagine that I would face a lifetime of disabling illness and the topic seemed taboo. I mostly observed the lessons they lived from afar. Jones interviewed Turnbull and Henderson about their experiences before their untimely deaths. In contrast to their public personas, the journalists with disabilities that Jones interviewed said they felt like “tokenistic representatives of disability,” the “go-to” disability advisors in the newsroom, whether they embraced the role willingly. Turnbull told Jones: “I don’t think disability. And it’s not an area that I have traditionally been interested in covering [...] sometimes I feel like I’m betraying the disabled population because I choose not to write many stories that have to do with disability. But I always felt living it was enough.”

Jones’s 2012 literature review found underemployment of disabled journalists in Canada, paltry coverage of disability issues, a dearth of disability activists as sources, and biased language in news content. She argued an unfair burden befalls the very few openly disabled journalists to mitigate these issues. Jones writes, “journalists — especially journalists with disabilities working in sometimes unaccommodating newsrooms — unfairly shoulder much of the responsibility of representing others with disabilities through their work.”

This expectation and burden are felt by many openly disabled journalists. In 2011,

Saburah Murdoch, a journalist with TAR syndrome who used a wheelchair, wrote that journalists with disabilities face “daily accessibility obstacles and social stigmas, and have to prove themselves as ‘competent’ and ‘useful.’” Murdoch added: “Too often, they cover disability issues — whether they want to or not.”

In May 2021, Tara Weber, western bureau chief for BNN Bloomberg appeared on a panel with racialized journalists — she is white and uses a wheelchair — to discuss how to bring equity, inclusion, and a culture of belonging to Canadian journalism. Her appearance came ten years after she told a student reporter that she had no plans to become an advocate (Murdoch). Weber expressed to the panel regret over her initial resistance, with an explanation. Logistics and time management are a challenge for her, she explained, as she navigates unfamiliar buildings while on assignment with her wheelchair. She described hunting down security guards for keys to service elevators or loading zones. When the elevator in her office building broke down, she had to be piggybacked up and down the stairs by colleagues. Instead of drawing attention to her struggles, she kept her head down. “We always try to excel and not make ourselves look bad when we’re from an underrepresented group,” she said. “You don’t want to be pigeonholed or put in a box” (Walrus, 00:20:04–00:22:30). Weber’s additional workload comes from juggling time, energy, and logistics problems, as well as the shrinking of newsrooms, which helps explain why there’s less time to become an advocate. “It’s challenging to exert any more of yourself to helping others, “ she said (00:44:40 – 00:44:55).

Numerous racialized journalists have complained about the “invisible workload” of being an activist and internal resource for white colleagues. Vicky Mochoma wrote in

2017 of being a “diversity mascot,” while questioning whether this is a good long-term plan. She said: “An institutional, editorial and business priority cannot sustainably be one person’s unpaid and undervalued job.” Denise Balkissoon, formerly an editor and columnist at *The Globe and Mail*, wrote about this burden in “I Tried to Talk to My Bosses about Racism at Work”: “We organize workshops, sit on committees, and respond to white colleagues’ inquiries — which are well-meaning and even intelligent, but also labour, for which we should be recognized and paid.”

Journalists with visible disabilities also have an “invisible workload” that comes from being the diversity resource, as well as the champion, for their differences, which they must also overcome. They bring these extra expectations to work and then must excel in a can-do, macho environment.

The barriers broken by Helen Henderson, Barbara Turnbull, Dennis Morgan, and Paul Watson are immeasurable, but they did not demonstrably pave the way for others like them. The disability column at the *Star* ended with Henderson’s retirement. I am told no other quadriplegics have been hired as journalists at the *Star*. In fact, I interviewed several recent journalism graduates with visual, hearing, and mobility impairments who not only were not hired by the paper but were questioned about how they had managed to work without driver’s licences.

Meagan Gillmore, who is visually impaired and cannot drive, was still hopeful she would get hired as an intern at a major daily because she had won a North America-wide student journalism prize. She called the head of the *Star*’s intern program, and asked, “I don’t drive, what do we do about this?” The editor reportedly said to mention her visual impairment in the cover letter, and if she stood out, they would interview her

despite the deficiency. She is still waiting for his call. “I heard the flipping *Toronto Star* doesn’t need everyone to drive. Reporters take taxis everywhere,” she told me. Freelancer Aaron Broverman, who has cerebral palsy and uses crutches and a mobility scooter, has been questioned during job interviews about how he will get to breaking news when he cannot drive. He applied for a job as an intern at the *Star* in 2007, even though a posted job requirement was a driver’s licence. “I thought I could convince them I didn’t need one.” He told me he is disappointed with the *Star*’s lack of disability diversity. “They got rid of the disability beat when Helen Henderson retired and then never found anyone else to do that column again. If you’re looking to save money, disability seems extraneous,” Broverman said.

In November 2021 the *Star* dropped the driver’s licence requirement for 2022 student intern positions, and Bailey Martens, who uses a wheelchair, announced she had been hired as a 2022 intern (Martens, “New year”). Amid the efforts to increase representation of marginalized groups, the *Star* and other newsrooms could do well to remember the ground broken by Turnbull and Henderson and build on the legacy of these exemplary journalists.

Chapter 3: Prison, Prednisone, and Other Lessons from the Star

A suburban monster, he overpowered her from behind and dragged her into the backyard of her parents' Scarborough home. There, after viciously raping her for almost an hour and strangling her with an electrical cord, he left her tied to a fence with her own belt like a dog. The details in the press release were spare, stark. The victim was 19; I was not much older. I quickly typed up the brief and filed it ("Police Search"). I trembled as I typed, my mind dancing from the victim to the imagined rapist to the clock's long hand hopping past six. Deadlines were very hard for me then, whether I was writing about a brutal sexual assault or a motion on garbage pickup at Scarborough city hall, my part-time beat in the *Star's* East bureau.

I was hot, then cold; wired then weak. I no longer responded to tight deadlines like my colleagues, hunched over keyboards nearby. I strained to focus my thoughts. Sometimes tears welled in my eyes for no good reason. Or because a nineteen-year-old girl had been tied to her parents' backyard fence. I had no control over how I responded to stressful situations ("The Mantra"). My daily prednisone dose, at 5 milligrams (down from 80), was finally at the level where my adrenals, sitting atop my kidneys, were supposed to kick in and start producing cortisol again after high doses of artificial steroids had left them dormant. From my erratic emotional response, it is clear my stress-regulating hormones were still out of whack, leaving me chemically unable to compose myself.

Did my overreaction to most circumstances mean I was not ready to drop my prednisone even lower? Would I get sick again if I did? Was that inflammation I felt in

my right pointer finger? My left elbow? WAS I GETTING SICK AGAIN? I had so many questions. Calls to my rheumatologist's office only irritated his receptionist, who promised to take a message.

As mentioned in Chapter 1, I wrote some of these details almost twenty years ago and then published a personal blog in 2015, like what Callison and Young in *Reckoning* called “speculative memoir fragments” that journalists use to situate their experience of marginalization (99). I explore this format in-depth in Chapter 11. In this work, I supplement details from my blog posts with added relevant details to capture the uncertainty I felt working in daily news with a debilitating and possibly fatal invisible disability. I share only the low points, which make it all seem awful, when working at the *Star* was a lot of fun, filled with competition, parties, pub nights, dancing (arthritically), and hanging out with droll and daring journalists. Discussion of white blood cell counts and complement levels obscures the many good parts.

The Show

One of the last stories I worked on from the East bureau before I was transferred to general assignment at One Yonge was about the Scarborough rapist, who had struck again (Thomas). I was relieved to escape the hunting grounds of the sexual sadist and murderer later identified as Paul Bernardo. His despicable deeds would haunt journalists for decades, hobbling some with PTSD and addictions.

Once downtown, like most *Star* women, I was expected to have a writerly touch and be ruthless. Mostly, I exhibited this at large scale events, shouting from behind velvet ropes. When the G8 leaders met in Toronto in the spring of 1988, I trailed the Summit

wives, including Mila Mulroney (Brian) and Nancy Reagan (Ronald), and yelled questions at them. “Hey Mrs. Reagan, what have you been discussing?” resulted in “It’s mostly ‘Girl Talk’” on A16. Then the Italian prime minister’s daughter went missing for forty-eight hours. As she entered a formal dinner, I demanded to know where she had been. “I’ve been shopping! In Yorkville! SPORTSWEAR!” she shouted back. A10! (DiManno and Page).

When the Queen Mum attended the Queen’s Plate in Toronto, I was again assigned to be side kick to famed *Star* columnist Rosie DiManno. We figured the Queen Mum must have placed a bet on a horse and even though commoners are not allowed to talk to Royals, DiManno gave me a hard elbow and I shouted as Her Highness passed, “Hey, did you win?” Startled, she responded, “I’m afraid not.” Front-page headline: “Queen Mother backs a loser at racetrack.”

I was assigned to cover marathon swimmer Vicki Keith’s attempt to swim across all five Great Lakes. With seven editions of each day’s paper, I filed constant updates from dawn to midnight, on Keith’s incremental progress across Erie, Huron, and finally Superior, where I swam with her in the frigid waters and fittingly, the headline on the story I wrote declared me “No Wimp” — the ultimate compliment. Cell phones the size of winter boots were a recent technology, often without a signal, so I used a ship-to-shore radio to file. Then the city editor went on summer holidays, leaving his crusty deputy in charge. As I prepared to head to Chicago to document Keith’s Lake Michigan crossing, he grumbled about me being “too young” to be gallivanting around North America following the “dyke mermaid,” as he dubbed her. I convinced him to let me go, but when we were delayed for three days in a small Michigan town because of engine problems in

her chase boat, he ordered me home. Trying to piece together a ride back to Chicago was the most dangerous assignment that summer, including huge swells and inflatable boats running out of gas.

Once back in the newsroom, a more senior editor sent me back to Chicago even though I had literally missed the boat. I sat on the beach waiting for Keith to arrive. All of this — constant deadlines, chasing stories over unforgiving terrain, and the inconsistent, subjective whims of various editors — is standard operating procedure for a gumshoe reporter at a huge daily newspaper; none of it was good for my health. The job has likely gotten more difficult since then, with demands on reporters to shoot video and post tidbits of their stories on multiple social media channels. “We referred to it as JAFTA or Just Another Fucking Thing Again,” Kathy Viner, formerly of the Canadian Media Guild, told me about the increasingly challenging reporter roles. “Every year something else got added to the job description and it was absurd for a perfectly healthy journalist, never mind somebody who was not perfectly abled. That’s the challenge with journalism, it’s the feeding of the goat, it never stops.”

The excitement was also part of the attraction. Yet, over the course of the Great Lakes conquest, inflammation and pain randomly seized my joints. Perhaps it was a result of round-the-clock deadlines. Or the sun. At that point, I did not know that sun exposure flared lupus in many people, including me.

During Keith’s butterfly stroke double-crossing of Lake Ontario, I struggled to climb in and out of the inflatable boat that followed her. When she landed at Toronto’s Cherry Beach, I had to wade to shore with my RadioShack laptop over my head. I could

hardly move through the polluted water. In retrospect, the triggers — carelessness, ignorance, unrelenting deadlines, contempt for at least one editor, and in some ways Keith, who was arrogant — seem obvious, but I had been in no position to turn down the assignment. Finally at my desk in the *Star* newsroom, I wrote the final words on Vicki Keith's conquest. "Five down. None to go." My hands looked like a boxer's ("Vicki's Victorious").

It was hard to process these symptoms and the shock I felt at having the wolf slink back into my life; whopping doses of prednisone had not obliterated the yellow-eyed ever-hungry creature that was stalking me. On some level I understood that lupus was a lifelong companion, but the original 80 milligrams of prednisone had been a huge hammer. Now, with my dosage lowered, I focused on figuring out how to be sick at work. This remains my greatest challenge. If you come into a workplace with an obvious disability, some physical limitation that could be accommodated with a certain kind of desk or adaptive technology, employers generally know how to help you. Whether they want to is another matter. But with a relapsing and remitting invisible disability, people must first believe you are unwell; not just faking symptoms to get out of work.

At twenty-three, new to all this, I had no idea if I should work during a lupus flare. I probably needed an occupational therapist, social worker, or medical specialist to tell me whether to take a break or shrug it off. Or a mentor. I did not know if the *Star* newsroom held colleagues who were mentally ill, had ulcerative colitis, or rheumatoid arthritis. In retrospect, I wish I would have sought advice from Helen Henderson, who at that time had multiple sclerosis that relapsed and remitted. She sat close by, but she was not yet writing her disability column, so I did not know to seek her out. Meanwhile, I

already knew what Dennis Morgan, my mentor from the summer intern program, would have me do: suck it up and work harder.

Eventually I got an appointment with a new rheumatologist and gave another vial of blood. He found extremely high levels of the rare anti-double-stranded DNA antibody (anti-dsDNA) found in about 30% of people with lupus and less than 1% of healthy people. My white blood cells were abnormally low, another indicator of active lupus. My level of complements — a group of proteins that protect the body against infection — were also low, indicating they had been used up by the inflammation. If he had not seen me sitting there, in my plaid blazer, skirt, and work flats, he said my blood work suggested I should be bedridden. He concluded that the stress and excitement of my reporter job was good for me. In essence, he told me what I wanted to hear, not what I needed to hear. A few weeks later, the inflammation spread, and I was once again diagnosed with painful pericarditis, inflammation around in the lining of the heart. It coincided with a trip home to see my parents. I spent my so-called holiday in bed pumped with more prednisone.

What a Pill

My former colleague and friend Rita Daly, who worked at the *Star* for thirty-two years and covered multiple beats and held multiple editor positions, was among the first journalists to develop repetitive strain injury (RSI). Stepping away from her education beat when typing became too painful, she immediately felt she was doubted. When I interviewed her for this thesis, she described a “traditional male-dominated news culture” where “weakness was viewed with disdain” and “some editors believed that berating and

yelling at reporters made them stronger, more hard-nosed and so made them work harder.”

This climate made it difficult for women with children as well as journalists with disabilities to get workplace adjustments and flexibility, she said. “The attitude was if you showed up for work, you were a body in the newsroom able to take on assignments.” She said one editor confided, “if you can’t function 100%, stay home.”

Daly added: “There was no room for accommodation.” To deal with her RSI, she created her own, asking for a voice-activated computer and pitching a long-term project on domestic violence that went on to win a prestigious Michener Award, in the *Star* tradition of “overcoming” one’s perceived shortcoming.

Daly was the first colleague to whom I confided my health challenges. She was an incredible support, but she also recalled a huge fight we had after she commented on my changed appearance after prednisone had made my cheeks balloon. I was furious because people on prednisone are often irrationally furious; and because she had not noticed my struggles, only the unpleasant results of the treatment.

I confided in a few others, with mixed results. One day a new colleague noticed I was struggling to dial the phone (“The Wolf”). I told her I had lupus. She asked if it was some sort of “weird cold.” Her question made me instantly angry, maybe because she was unknowingly diminishing me. Suddenly I was regurgitating a medical pamphlet I had committed to memory. “It can kill you.” The bitterness in my voice surprised me. Although I knew almost no one had heard of lupus, I wanted to make her hurt like me.

A cold.

Trinidad or Bust

“Don’t forget to take their picture.” I heard these parting words from my editor as I hobbled out of the newsroom to catch a plane to Port of Spain, acting like a reporter capable of any challenge, knowing I was anything but. As I documented in “Reporting Behind Bars,” I was going to the capital of Trinidad to interview two teenage drug mules, imprisoned after an attempt to smuggle three suitcases of marijuana back to Canada. Both seventeen, these boys were sentenced to eight years in an adult prison, filled with murderers on death row. I was supposed to show up at the prison, say I was their cousin, get their story and a photo: proof of life for the front page.

The flaws in the plan were crater sized. Did I use my real name? What if the boys were asked to verify I was their cousin? And whose cousin was I, anyways? Both were named Wayne, but one had a last name too hard to pronounce, so I chose the other one.

In the prison waiting room, all eyes were on me, the only white woman. I told the prison official I was Wayne Galloway’s cousin, but I also wanted to see Wayne Wojcichowsky. I gave my name and ID. They searched my bag and did not take issue with the point-and-shoot camera inside. Two hours later, I was led to a room with a dirt floor and standing viewing cubicles. Within minutes, two confused teenagers were staring at me from behind bars. Visits were fifteen minutes.

I told them I was from the *Star*. I looked at the shorter blonde one. Galloway, I assumed based on photos I had seen. “If they ask, I’m your cousin.” He nodded. I could not pull out a notepad, so I leaned into the bars and tried to memorize everything the former suburban mall rats said.

“We said we didn’t want to take it, we’d get caught,” said Wojcichowsky. “The man pulled out the handgun and said we’d better take the stuff.” He told the boys they would not be searched and there would be no dogs inside the airport to sniff out the drugs. “They were covered in coffee grounds to hide the marijuana smell.”

The teens were escorted off the plane, bound for Toronto, just before takeoff. A top government official later boasted that a new team of sniffer dogs discovered the drugs. The teens were segregated from the rest of the prisoners. “We’re not safe in here.”

Down the corridor, a guard yelled, “Time’s up.”

I went to leave when I remembered the photo. No guard was watching that I could see, so I pulled the camera out of my bag and snapped a couple of pictures. Seemingly out of nowhere, two guards appeared and grabbed my camera — and me. I was hauled through prison corridors, an open courtyard, and up a staircase to the warden’s office.

To say I was scared would be insufficient. I had no clue what I should say or what the Waynes would say. If I had not taken the picture, I would already be in a cab heading back to the Hilton Trinidad.

Middle-aged and mustachioed, the warden came in holding my camera. I was young enough to be his daughter. “Who are you?” he demanded, from behind his desk.

“Wayne Galloway’s cousin.”

I made a split-second decision to hold onto the lie, even though I did not know the names of Galloway’s family members.

“Why did you take their picture?”

“Our family back home wants to see how they’re doing, make sure they’re healthy. I promised I’d take their photo.”

“I’m going to talk to the prisoners. See what they know.”

Suddenly the situation got real. Would the teens keep my secret? Or would decide lying would get them in more trouble? By blowing the whistle on me, maybe they would get extra prison rations?

As I waited, I took a mental inventory of my aching body. I could tell I was having another lupus flare right there in the warden’s office. If I had ever wondered what kind of extreme stress might trigger a flare, I had my answer. Unexpected imprisonment. If I was there for a longer stay, I was in trouble. Journalism 101: bring your life-saving meds with you when you sneak into a prison on assignment.

I could hear the warden climbing back up the steps. I began to consider what would happen if I ended up in custody without prednisone. I had no idea if lying about your identity to a government official was an offence.

“They confirmed your story.” *They said I was Cousin Shelley?* I stifled a nervous laugh. “But I still don’t believe you.” I had absolutely no idea what to say, so I started to cry, pleading to be set free.

Girlish tears for the win.

As I waited in line at the airport, sniffer dogs explored the deep recesses of passenger luggage. I hugged mine tight. As I flew home, I told myself repeatedly that I would never again go to a foreign country on assignment. I would never run toward danger to try to prove myself or fit an expected mold. What I needed to overcome was my belief that I needed to overcome. My story ran on A1 in June 1989 (Page and Gould).

Remembering a Massacre

The assignment editor told me the killing in Montreal had begun around 5 p.m., and within twenty minutes, twenty-seven people had been shot or stabbed. All the dead were young women; fourteen of them. He told me to get to the airport, and my stomach fell as though I was on the down slope of a rollercoaster. I could not imagine a scenario where I told the assignment editor that I felt poorly so count me out. I flew to Montreal with a photographer. A few hours later, the paper sent another female reporter, also in her twenties. None of the male reporters working the night shift could say more than *bonjour*. I had been taking weekly French lessons at Alliance Française.

When I arrived in Montreal four hours after the killing had ended, yellow tape wrapped L'Ecole Polytechnique like a macabre Christmas present. It was past the deadline and there was not much for me to do, other than grab a few quotes from lingering onlookers to file to the *Star*'s news desk, then return to my hotel. By this time — five years into my illness — I was used to struggling through the pain of inflamed joints and hardened muscles. A shower always made me feel temporarily better. Afterward, I climbed under the covers to watch the CBC's *The National* coverage. Only men were quoted: Eyewitnesses. Professors. Police. Survivors.

I awoke the next morning to frigid weather and unanswered questions of who the killer was and why had he targeted female engineering students. My joints were arthritic, worse than the day before. I decided to quadruple my dose of prednisone, hoping it would dampen the inflammation. But I could not find the bottle. In my race to the airport, I had forgotten to pack my pills.

If I went off the prednisone cold turkey — say because I forgot a bottle somewhere — I could suffer adrenal failure. Symptoms could include abdominal pain, confusion, coma, dehydration, dizziness, fatigue, headache, high fever, loss of appetite, low blood pressure, profound weakness, rapid heart rate, sluggish movement and vomiting. I had been warned never to skip a dose of prednisone. My then-boyfriend, who worked as a journalist in Ottawa, agreed to make the two-hour drive the following day to bring me half a bottle I left at his place.

I raced to a press conference at the Montreal police headquarters where the identity of the killer was disclosed, along with his hit list of feminists. I hailed a cab to the suburb where he grew up; learning he had been beaten by his father, liked to play war games, and had been turned down by the military. I helped brand him as an abuse victim instead of a murderous misogynist (Armstrong and Page).

By late afternoon, I could no longer take notes because my fingers were so stiff, knuckles inflamed. I hobbled into a drugstore and begged the pharmacist to give me a handful of prednisone tablets to hold me over until the next day. I showed him my deformed hands and my *Star* identification. Wordlessly, he put five prednisone tablets into a small envelope. Later, I washed them down with coffee and filed a story about the killer's background. There was a vigil being held by young feminists, but the news desk was not interested. I returned to my hotel room to await my prednisone package.

On CBC's *The Journal*, Barbara Frum, one of Canada's most respected journalists, questioned a panelist while refusing to admit the massacre was indeed an act of violence toward women. "Why do we diminish it by suggesting that it was an act against just one group?" Frum asked. She seemed puzzled that so many women insisted

the massacre was a result of a society that tolerates violence against women. “Look at the outrage in our society,” Frum said. “Where is the permission to do this to women?” She dismissed the actions of angry feminists. “If it was fourteen men, would we be having vigils? Isn’t violence the monstrosity here?” (Page, “How I Sanitized”).

I did not question how I was covering the story, or the anti-feminist sentiment expressed by Frum. I just raced from coffin viewing to memorial, filing front page stories. I remembered one sentence I wrote about the memorial with pride: “They stood crying before the coffins of strangers, offering roses and tiger lilies to young women they never knew” (“Thousands Line Up”). Years later, I would see it as an example of everything that was wrong with my coverage.

The *Star* entered my stories, among others, in the spot news category of the National Newspaper Awards. We did not get a nomination.

Twenty-five years later, in a remembrance I wrote for the *Ottawa Citizen*, where I spent the bulk of my career, I expressed regret that I portrayed the dead engineering students as sleeping beauties who received flowers from potential suitors. I also expressed regret that I did not acknowledge the buildings they would not design, the machines they would not create, or the products they never imagined. “They weren’t killed for being daughters or girlfriends, but because they were capable women in a male-dominated field,” I wrote in 2014.

I almost never used the word *feminist*; I never profiled the achievements of one of the slain engineering students or the obstacles she toppled. I never interviewed a single woman who was angry, only those who were sad. Why? No one told me what not to write, but I just knew. In the same way, I knew not to seem strident in a workplace where

I laughed at sexist jokes and waited until a certain boss had gone for the day before ripping down *Penthouse* centrefolds taped to the wall near his desk (Page, “How I Sanitized”). My attempt to revise my account would win a National Newspaper Award in the short feature category in 2015.

After covering the massacre, I applied for beat reporting jobs — environment and labour — in hopes of managing an area of expertise and therefore my schedule but was turned down. Had I disclosed my invisible disability, I might have been given a more manageable job than general assignment reporter; shuttled off to the Life section with Barb Turnbull and Henderson to follow their admirable leads. I will never know. Worries about my long-term health and fear of having to overcompensate for my chronic illness led me to a seemingly abrupt decision. When my long-absent boyfriend was permanently posted to Ottawa (from Saskatoon), I decided to move to that city to be with him. I would like to think I am not the type who would quit a dream job for a man (or for a relationship that in the end was short-lived), but that is what I appeared to have done. I could not imagine the job changing, so I had to. I applied to do my master’s in international relations at Carleton University, making the bold decision to turn my back on the impossible, unforgiving grind that is daily news journalism.

But as it turned out, I was not yet done with journalism.

Chapter 4: The Disability Disclosure Conundrum

My job interview for the role of science reporter at the *Ottawa Citizen* included props. I unfurled a list of twenty story ideas, drawn from reading *Scientific American* and *Discover* magazines and Gary Zukav's 1979 brain twister *Dancing Wu Li Masters*. Two male editors scrutinized me from behind a desk heaped with newspapers as I chatted with enthusiasm about Olbers' paradox. From their expressions, I doubted they stayed up nights wondering why the night sky is black, even though it is filled with stars, but I found the question fascinating. I hoped my excitement (and extensive hobby reading of popular science) would impress. A friend had told me about the opening. I was determined to get a beat reporting job that had so far eluded me at the *Toronto Star*. Focusing on issues and institutions related to a specialty subject could mean slower pacing and greater control over my work schedule, which in turn could help me get my career-crushing condition under control. As far as beats go, science seemed to lack the urgency of city hall, courts, or cops (climate change and finding a cure for cancer aside), and I had a genuine interest. I also had symptoms of active lupus during my interview, mostly unrelenting fatigue, and arthritic joints, but I believed confessing would ruin my chances of employment. Besides, I had no idea what my actual obligations were, legal or ethical, to reveal a significant health challenge.

Michael Lynk, an associate professor of law at Western University, told me during my research for this project that when disability has a direct bearing on a particular job — like twenty-twenty vision requirements for pilots — disclosure is mandatory for applicants; otherwise, it is a “don't ask, don't tell” situation. Where is the

line in potentially gruelling daily journalism, especially with representation at stake, which surely complicates matters? And where does a chronic illness fit in? I had no one to ask. But I was pretty sure I could report on science, so I could see no advantage in sharing my woes. I did not, and I got the job.

I had to fess up much more quickly than I expected. My first week, I was sent for a routine pre-employment medical exam to make sure I was fit to work. I told the doctor I had lupus. While I typically do not look sick, a blood test could reveal neutropenia and leukopenia — chronically low numbers of white blood cells — which left me highly susceptible to infection. If the doctor requested more sophisticated tests, she might also find extremely high levels of anti-double-stranded DNA antibodies, suggestive of more serious lupus, such as lupus nephritis, which can lead to total kidney failure and be the dividing line between serious and devastating disability. As far as I knew, my kidneys were not yet involved.

The doctor asked how lupus impacted me on the job, and I told her the truth: I never called in sick. Whatever she found in my blood, she told the company I was fit to work. I have always wondered what would have happened if she decided otherwise, as I had already quit my *Toronto Star* job to be there. Maybe they would have axed me at the end of my probation, claiming incompetence instead of protein in my urine?

Unlike journalists with an obvious disability, I was able to hide my invisible disability at three different news organizations, starting at the application stages. I made the decision to pass as hale and hearty, while living with the ache of not fully showing up to a job you love. The following quote from researchers Jain-Link and Kennedy hits

home: “If you’re hiding a disability, the daily grind of early mornings, deadlines, and office politics is compounded into a far heavier burden. You live in fear of being discovered. You work overtime to mask your authentic self.”

Were there others like me, hiding essential parts of their identities for fear of reprisal? My thesis research began as a quest to document my experience working with a nagging chronic illness, then to see who else was out there, and find out if the culture of daily news made them reticent to share. I have come to realize I was not alone. Fears of “disclosure” haunt all workplaces, but especially daily news organizations, where competition, survival of the fittest, and old-school convention frame disability as a weakness. “They’re worried they won’t get good assignments anymore, or they’ll be forced out, or won’t be on the career ladder, or they won’t get to go to Queen’s Park or Afghanistan,” explained Kathy Viner, who worked for twenty-eight years with the union that became the Canadian Media Guild, acting as lead union staff representative at CP and Thomson Reuters (1996–2011).

Many of us fear the consequences of revealing our invisible disabilities with good reason, especially if they are mental health related. Former *Ottawa Citizen* crime reporter Aaron Sands, received the Goff Penny Memorial Prize for Young Canadian Journalists while he worked there, has been on long-term disability since 2003 for intractable depression, as well as post-traumatic stress disorder. He traces the PTSD to being beat up by two bikers while visiting the home of a murdered elderly couple. The entire time he was covering the crime beat he sought counselling through the paper’s employee assistance program “just to cope with the content of the work I was doing, because there

were a lot of tragedies,” he told me. When he asked for access to more counselling after his allotment ran out, his supervisor “laughed in my face and said: ‘That’s the job, boyo.’” He says a more senior editor told him, “Put on a helmet. Life is tough for all of us.” Sands still resents how dismissive his supervisors were when he disclosed his mental health challenges and asked for help.

In this chapter, I document the previously untold disclosure stories of six journalists with invisible disabilities as they hunted for jobs or tried to advance careers. Four are women, two racialized, including a student, and three are unnamed for fear of reprisal. The Ethics Review Board at Carleton agreed with this concern, and counselled anonymity to prevent social or economic harm that might come from disclosure. Journalists who have already shared parts of their story publicly are named. These journalists have worked at the *CBC*, *The Toronto Star*, Postmedia, and *The Globe and Mail*, among others.

A senior manager with an autoimmune disease requiring hospitalization has hidden her disability in job interviews and from certain employers. She said she is not alone. “There are a lot of people in the media with what I’d call hidden disabilities, some of them minor, some of them major, who wouldn’t dream of telling their bosses,” she explained. “And to be honest, I was thinking, *Is this ethical?*” But she justified her non-disclosure: “We all believe we can do the job, that we are going to find ways that will be different from what a fully able-bodied person would do.”

A recent journalism graduate did not disclose having lupus to her professors or prospective employers. As a woman of colour, she thought it would be another strike

against her. “When you’re already kind of scared of taking up too much space, you wonder, ‘Do I want to disclose a disability that is going to make my identity more complex to understand?’”

Another recent graduate with irritable bowel syndrome (IBS) and an anxiety disorder lets prospective employers know about her disability, which can cause her to collapse from pain, because she does not want to get hired on false pretenses. She has struggled to find work but will not hide her disability. “I want to be honest. People have things wrong with them. We have to fight the ableist attitudes in journalism.”

Dave Brown, who has 10% vision and is the face and voice of Toronto-based Accessible Media Incorporated (AMI), applied for multiple internship roles out of broadcast college without disclosing he was legally blind, confident he could fulfil the job requirements and fearful he would not be hired if he was transparent.

Steven Ladurantaye, a reporter, editor, and media executive, recently disclosed he has bipolar disorder in his *Broken Brain Journal* after a meteoric climb through several media organizations and an “epic flame out.” In an interview, he said a “mean-spirited” culture that mocks anyone who seems deficient makes it “challenging to be honest about your struggles,” especially for those starting out. But he recently decided to lay it all out in his online journal, consequences be damned.

I also interviewed Jan Wong, the well-known former *Globe and Mail* journalist who was fired after she went on sick leave for an episode of clinical depression. She went on to publish, in 2012, *Out of the Blue: A Memoir of Workplace Depression, Recovery, Redemption and, Yes, Happiness*. Wong encouraged anyone suffering from a hidden disability to keep quiet about it until you have been hired and passed your probation,

“otherwise you won’t get hired.” The former foreign correspondent told me: “I would not advertise it because I don’t have any faith in management.”

When news organizations are missing an entire sector of the population — or inadvertently forcing a group of workers into hiding — they fail to represent a significant portion of audiences. Callison and Young called out legacy media for erasing Indigenous journalists and people of colour from news organizations. In their important 2019 book, *Reckoning: Journalism’s Limits and Possibilities*, they rightly criticize legacy media’s idealized “view from nowhere” that reinforces the false god of objectivity, upholding “white masculinity” and maintaining “social orders” while ensuring the “structural subordination” of racialized, gendered, and Indigenous groups (5). They urge journalists, especially those who are gendered, racialized, and Indigenous, to seize the “view from somewhere” and boldly locate themselves (17; 208). Although they did not include journalists with disabilities in their argument, which largely focuses on the impact of colonialism, I believe much of what they observed is also relevant to us.

While Callison and Young call for better representation of marginalized groups within daily news, I explore whether and why journalists choose to disclose disabilities at all. And, whether a culture of non-disclosure leads to a culture of non-accommodation and ultimately, erasure of disability. Aaron Broverman, a freelance journalist with cerebral palsy specializing in personal finance, told me disclosure is essential for representation: “Imagine what would happen if everyone disclosed their disability. It would change the culture and the coverage.”

The Statistics Behind Disclosure

A 2019 study from the New York-based Center for Talent Innovation (now Coqual) on disabilities and inclusion” among white-collar workers found 30% of the professional workforce in America fits the federal definition of having a disability. Of those, invisible disabilities account for 62% of all disabilities among white-collar workers. The majority keep their status a secret. According to study authors Jain-Link and Kennedy, only 39% of employees with disabilities have disclosed to their manager. Even fewer have disclosed to their teams (24%) and human resources (21%). As the authors point out, because so many disabilities cannot be seen, the onus is on workers to decide whether, when, and with whom to share their disability status.

Deciding whether to disclose a disability at work is a complex and often fraught process. A 2021 study conducted by the Toronto-based Institute for Work & Health (IWH) found half of the 896 Canadian workers with chronic health conditions surveyed had not disclosed to their supervisor (Gignac et al. 642). “It wasn’t disclosing or not disclosing that mattered as much as the reasons why people were making their decision,” said lead investigator Dr. Monique Gignac, who explained workers regularly assess their situation to determine what they have to gain or lose by sharing personal health information (IWH).

Those who did not disclose thought they could get by without making a big deal of their disability. Some felt private health information was not an employer’s business, while others feared being sidelined, passed over for promotion, or given differential treatment, among other reasons (Gignac et al. 643). Those who did disclose were more likely to live with both physical and mental health conditions, report more work-related

stress, and were more likely to have changed jobs because of their disability. They are also more likely to report having a more supportive environment and longer tenure, though with higher rates of absenteeism (642).

The risk of being fired or not hired was the top reason not to disclose, mentioned by 73% of respondents to a 2014 Cornell University study. Other reasons given for not disclosing include: concern the employer might focus more on disability than abilities — 62%; the risk of losing health care — 62%; a fear of limited opportunities for promotion — 61%; concern supervisors might not be supportive — 60%; or the risk of being treated differently by a supervisor or co-workers — 58% (von Shrader et al. 244). Among individuals with very apparent disabilities who had disclosed in their current or most recent job, 51% did so during the recruitment process, 34% during the interview process, and 15% after being hired. Among individuals with less apparent disabilities, fewer disclosed during recruitment (39%) or the interview process (25%), with most waiting until they had been hired (36%) (249). Importantly, 80.3% of respondents indicated they had disclosed their disability in either their current or most recent job (244). Of those who disclosed, nearly a quarter reported long-term negative consequences related to their disclosure (252).

We already know (from Chapter 3) that news organizations are competitive workplaces that celebrate macho heroics. Below, I explore how that culture impacts disclosure rates in daily news.

Disclosure in Journalism

Studies are scant but telling. Journalists with disability, whether living with

visible, invisible, or episodic conditions, seem to be missing from news organizations. The UK-based charity Leonard Cheshire Disability reported fewer than 1% of those working in media identify as having a disability; the national average for the UK population is 13%. Closer to home, a 2007 CBC employment equity report showed 1.8% of employees self-identified as having a disability; by 2020, that number increased to 3.4%. There are few if any other studies about the number of journalists with disabilities working in daily news. News organizations I contacted, including CP, *The Toronto Star*, Postmedia and *The Globe and Mail*, did not respond to requests to provide those numbers.

Whether 1% or 3.4% have self-disclosed within a Canadian news organization, these numbers are a fraction of the 30% of disabled white-collar workers in the national Talent and Innovation study (Jain-Link and Kennedy). Or the 80.3% of respondents in the Cornell Survey who reported they had disclosed their disability in their current or most recent job (von Shrader et al. 244). Or the 20% of working-age Canadians with a disability (Morris et al. 7). And it is fewer than the 13.2% of workers who self-identified as having a disability in 2020 at Microsoft, where company-wide initiatives encourage disclosure and improve workplace accommodations (Microsoft).

Terri Monture, staff representative, human rights and equity, at the Canadian Media Guild, which represents unionized CBC workers, said many workers at the Canadian broadcaster are afraid to disclose for fear of being penalized in some way. The number of employees with a disability working at the CBC is thought to be much higher than the 3.4% who self-identified in the 2020 Employment Equity report. “The rest are in hiding,” Monture said.

In interviews, CBC's diversity and inclusion leaders agreed that employees are reluctant to reveal invisible disabilities and that increasing disclosure would ensure workers can bring their full identities to their roles, improving representation as well as the broadcaster's workplace culture.

Rachel Desjourdy was hired in 2021 to lead the Canadian broadcaster's national accessibility efforts. Speaking about all workplaces, not just at the CBC, she said, "employees are worried if they disclose, they're going to be made a case study, like 'here's this person with a disability that's part of our team.' Then they'd be recognized with that filter instead of by the merits of their work." She added that in most workplaces, "A lot of people are really worried about the repercussions. What does it mean for me, for my career?"

Instead of disclosing, workers try to hide while overcompensating in their role, and that creates a "negative feedback loop," she said. For example, a person with an invisible disability might be making more "independent effort" to maintain a level that is perceived as the same performance as their peers, explained Desjourdy, adding, "they might be expending 30% more energy to work around the barriers, rather than figure out adjustments where they can perform at 100% and give 100%, instead of 130%."

She described the negative consequences for workplace culture. "There is a lot of hidden labour that goes on behind the scenes, whether it's masking or self-accommodating, which helps everyone maintain the status quo. And if you're not disclosing, your managers don't know, there's no trust, and things don't change."

Unlike most other news organizations, the CBC must adhere to the federal *Employment Equity Act*. Desjourdy said the Act's definition of disability, used for CBC's

workforce reporting data, includes some weighted terms. To self-identify as disabled, employees must agree that they are “disadvantaged” in the workplace. “I have had a disability my entire life but cannot say that I consider myself disadvantaged at work. There are barriers, yes, but the notion of disadvantage causes me to hesitate before self-identifying,” explained Desjourdy, who has a master’s in critical disability studies. When people don’t disclose, it leads not only to under reporting but also a “narrow portrait of who actually has a disability in the workplace.”

Jovane Drouin, CBC’s director, Equity, Diversity and Inclusion (EDI) and Engagement, cited the employee resource group Abilicrew, created in June 2016 to support employees with disabilities within the English broadcasting service. It led to an increase in disability self-identification for those who consider themselves be at a disadvantage within the workplace: to 2.5% (2016) from 1.7% (2015). As of 2020, the proportion of employees with disabilities self-identifying increased to 3.4%.

“Even though our numbers are very small, it’s still a very big jump when we have been static for so many years before,” Drouin said. Within the national broadcaster’s French service Radio-Canada there is no employee resource group to support employees with disabilities, and no similar increase was noted in the number of workers with disabilities self-identifying. “So, creating an employee resource group certainly helped move that needle; and we saw a direct correlation between that and the Abilicrew bringing more conversations into the workplace,” he said.

The broadcaster knows it has workers that will not disclose, although just how many is unclear. CBC’s goal is to have more than 8% of its workforce self-identify as having a disability on their annual cultural surveys, according to Drouin, who said that

target is based on external labour force standards. To achieve 8%, he said that CBC will likely have to add another question to the survey to better capture the make-up of its workforce, pointing to the approach the Royal Bank of Canada (RBC) has taken.

RBC now asks its employees two questions on their self-identification survey: (1) do you identify as having a disability, and (2) do you consider yourself disadvantaged in the workplace due to the disability? As a result, the percentage of workers with disabilities jumps significantly when the notion of disadvantage is removed. RBC reported to the government in 2018: “7.1% of RBC’s employees identify as having a long-term or recurring physical, mental, sensory, or psychiatric or learning disability; however, only 3.7% consider themselves disadvantaged in employment because of their disability (RBC 2).

Drouin added: “The notion of disadvantage is one that we believe we should not have in the definition. It’s a personal choice to identify as having disadvantages,” said Drouin, noting that this is the view of his team and not necessarily the view of CBC/Radio-Canada.

To Disclose or Not: Journalists Share Their Stories

Disclosing is fraught with uncertainties, especially in a newsroom culture built on notions of invincibility. There has never been a public forum for journalists to share their anxieties around disclosure. The following six stories are drawn from dozens of interviews I conducted with journalists about their difficult disclosure decisions, among other issues, including the pervasive silence around disability issues, confusion around their rights, and uncertainty about the consequences.

“I’m thinking, how much does this factor into my hiring or my promotion ...”

As a veteran journalist who has been managing editor, department head, and reporter at various Ontario-based news organizations, A. weighs the pros and cons of disclosing her autoimmune disease in every situation. “What you call macho white culture, which is a good way to put it, I just call it competitive culture. If somebody is out for a day or a week or they don’t feel well, our newsroom culture tends to just snowplough over them.” She changes tactics depending on whether she feels secure, her boss is empathetic, or she thinks her role might be eliminated due to cost savings or a change in ownership. When she was first diagnosed with sarcoidosis, which causes profound fatigue, breathing difficulties, and muscle soreness, she was hospitalized and then took sick leave for eight months. It was a “long road back,” but she was in a secure position in her news organization, and she disclosed her condition to the Editor-in-Chief. Although she said he was usually “the least empathetic person,” she found him “very helpful.” She left her job some months later, the result of a misunderstanding with the paper’s owners over how a certain article was to be treated. She thinks sarcoidosis contributed to her confusion during the incident, “because I was still in recovery mode, and I didn’t realize it at the time.”

Since then, she has been more judicious in disclosing her hidden disability, including in interviews for a senior editor position at a new outlet. “I did not tell them, even though I was suffering from a number of symptoms. I wondered what would happen if I had an attack,” she said. She got the job and was confident she could find a workaround for any difficulties. “I have always found ways, as one does, to do the job

and get rest when I needed to. I would put in a good, honest, fairly exhausting week and then I would just collapse for an entire weekend. But I never told my bosses.”

A. believes people with invisible disabilities have figured out workarounds for their conditions, but these adjustments are hard for some editors to accept in competitive news culture. She said she knows many journalists hiding indivisible disabilities who have “really figured it out over the years,” and managers “aren’t taking into account that it can be managed.”

Since her diagnosis, A. has tried to evolve from being task oriented to more human with her own employees. “I can’t ask them if they’ve got a particular illness, but I can ask them if there is anything bothering them or if they need support.” She also wrestles with her own hiring choices: “I would be lying if I said that having a disability isn’t a factor when you’re thinking about hiring the person,” adding, “You can’t ask if someone has a disability, but sometimes people tell you, which is honest and very honorable. And in that case, I’m thinking, ‘how much does this factor into my hiring or my promotion of this person?’”

A lot must happen to make it safe for candidates to disclose, she said. “The applicant would probably have to see it modeled or know someone working there already with some kind of disability that everyone knew about and was comfortable with.” She also says the “tough guy culture” might have to go. “We’re seeing it in journalism schools. There is a whole generation of new journalists who don’t want to be tough like that, and I think that’s a good thing.”

“As a person of colour, I won’t give anyone another reason to think I can’t perform.”

We both have lupus and although there are more than three decades between us, not much had changed. This is what B. thought during a guest lecture I gave to her fourth-year journalism class, where I described how I struggled to cope with my ever-evolving and worsening autoimmune disease. I had not told my professors about my condition or how much I needed help because I worried the admission might harm me. I just could not predict how.

“I was sitting there listening and thinking, *this could be me*. It was actually shocking,” B. told me later in an interview. “I just didn’t think we’d ever have the discussion about ‘How to deal with having a disability’ or ‘How we cover disability.’ It just hadn’t been addressed in the past four years.”

She travelled far to come to Carleton and thought she had left her chronic condition behind, a bad dream from childhood. B. had been a sickly child, with random inflammations that had no obvious explanation. Her foot would not work one day, an arm would not cooperate the next. Sometimes swelling and pain would go away overnight, or last for several weeks. She suffered fatigue and random stomach pains.

A CT scan during high school finally revealed inflammation of the kidneys and liver. Her parents sat B. down and told her she had lupus, cautioning her to avoid the internet, rife with misinformation, in the same way I had once been warned not to look at medical textbooks. “They told me I shared something with Selena Gomez,” a teen star she grew up watching on the Disney Channel, who has lupus. “They told me, as religious

parents usually do, to be grateful that it wasn't something worse. That God never gives us more than we can handle.”

B. planned on becoming a journalist (not a pop star) and hoped to leave home to attend journalism school. “I didn't know what this diagnosis meant for me or my plans.” But it took a lot of convincing for her parents to let her go to Carleton, several hours away by air. Once there, she never informed the administration or her professors that she had a chronic autoimmune disease. Few of her friends know, even today. Those who do — like her first-year roommate and emergency contact — saw her when she experienced flares of her disease, mostly during stressful events, like when her dad had a heart attack.

She had a few rough years, and her grades slipped while she missed classes to deal with lupus flares, marked mostly by fatigue and pain. Because she had not shared this, she had no accommodations from the university that might have brought relaxed deadlines or a modified workload. As an ambitious student and talented writer, falling behind was difficult. She had an acute flare days before a crucial interview for a scholarship.

“There was absolutely no way I could get up,” she recalls. She sent an email of apology in place of attending the interview. “It looked bad, but I absolutely had no choice.” She says the professor who helped set it up seemed “angry.” She realized she had to disclose that she had lupus and was experiencing a particularly debilitating flare. “He told me I should have disclosed sooner, but I didn't want to,” she explained. “As a person of colour I won't give anyone another reason to think I can't perform.”

While she keeps her diagnosis mostly to herself, she noticed during the COVID-19 pandemic her professors had been more empathetic in general. “A lot of times before

when I told professors I was not feeling well, the expectation was I should be getting a doctor's note. But you can't go running to the doctor all the time with a chronic illness," she said. "This past year, if I was not feeling well, professors asked what they could do to help, or would I like to talk about something?" She mused, "Maybe this should be a practice that's put in place for the future."

As for now, she said, even with greater transparency around other identities, "your pronouns, whether we belong to the Queer community or we're BIPOC," that same transparency has not occurred for people who may have disabilities or chronic illness. "Until we know we can disclose our disabilities safely, journalists won't disclose."

"You've really got to read the room before disclosing."

Steven Ladurantaye recently disclosed his bipolar disorder diagnosis and long-standing depression on a subscription-based newsletter, *Broken Brain Journal*, on the platform Substack. He figured he could take the risk: "I have the privilege of having a career and achievements and three NNAs [National Newspaper Awards] that allows me to say I am a little crazy, but I'm better now."

He told me a newsroom culture of "beer swilling, X-Acto knife-fighting guys that rewards bad behaviour" would not be kind to a newbie. "If you're a student or just starting out, I worry that what makes you different or less productive in a newsroom could be used as a weapon to beat you over the head with," he says. "You've really got to read the room before disclosing."

Ladurantaye also lamented that not much has changed in news organizations over his twenty-year career and admits to his own previous bias against people who were

ailing. “You can tell your boss that you need time off and you’ll get it, but it’ll hurt you, in the way your colleagues perceive you,” he said. “Everyone, including me sometimes, is rolling their eyes at somebody who has been off for six weeks with clearly a pretty severe case of depression or anxiety or some other disability.” He recalled a former editor “literally standing on a desk and screaming at us to file. He humiliated you in front of people. If you made a mistake, he’d call everybody over to look at it. And that was just kind of accepted.” Ladurantaye deadpans that the culture has improved. “People now know better than to scream at you across a newsroom.”

As to the risks of disclosing his bipolar disorder, diagnosed in 2020, he had no choice after he left his head of news and current affairs role at a broadcaster in Scotland, which put out a press release saying he was dealing with mental health issues (see Chapter 11).

His *Broken Brain Journal* is intended to offer “insight, updates and hope” so others find help for mental illness. But it is also an attempt to explain his erratic behaviour, when he cycled between hypomania and depression, and he thinks his colleagues “must have thought I was hyped up on coke for the last twenty years.”

He said he had no choice but to write about his ordeal with a stigmatized mental illness that may make it hard for him to re-enter the daily news business if he so chooses. “I think one of the benefits of flaming out absolutely completely is that you don’t have as much at stake,” he told me. “This attempts to explain a lot of my behaviour and be a voice for those who have these problems in various forms but can’t write or figure out how to work a website. And I can do all these things and be outspoken.”

He said he takes the approach that you should be open about an invisible

disability. “I take the tack that if I was suddenly in a wheelchair, I wouldn’t pretend I wasn’t in a wheelchair,” so he is upfront that he has a disorder, which “isn’t my most defining feature.” He now explains to colleagues that “some weeks I get an awful lot done, but there are definitely days when I just want to nap on the couch. Now let’s deal with it.” He hopes the news business can change so veterans and novices alike can be welcomed.

“I just figured, as long as it was my issue to deal with, I’d be fine.”

With his mellifluous tone and enthusiastic charm, Dave Brown fronts his eponymous current affairs show on Accessible Media Inc. (AMI), which reaches thousands of mostly visually impaired listeners. It is hard to believe that a decade earlier, in 2011, Brown was applying for radio jobs in small towns across the prairies without disclosing he was legally blind, with 10% vision.

He elaborated on why he was trying to pass as fully sighted during a 2020 roundtable of visually impaired journalists: “I know that sounds like really terrible leadership from a disability front, but this comes down to a little bit of privilege because of the vision that I have,” he said. “I can kind of live my life in two camps, with a foot on either side, and I’ll only really lean on my disability when I absolutely have to, when there’s no workaround to be found” (Jones and Saujani).

In the past decade, he has gone from fearing his disability might hinder advancement to embracing its opportunities. “Why did I not disclose?” he pondered in our interview. “Maybe it was my ego or my subconscious? Or I thought it didn’t matter. Maybe I thought it might stand in the way of getting a job.” If he got hired at one of those

small-town radio stations, “I would have needed a driver’s licence, and my vision would have mattered,” he pointed out.

“Being an albino, as soon as my sunglasses come off, it’s extremely clear that there’s something not right with my eyes. So, I just figured, as long as it was my issue to deal with, I’d be fine,” he said. Even though he wasn’t “loud and proud” about his disability after graduating from Algonquin College’s radio journalism program in 2010, people did notice. After he completed internships at various radio stations, CBC Radio One in Ottawa needed a traffic reporter — and to increase its diversity by employing people with disabilities. “They told me, ‘We think you’re our guy,’” and offered Brown a nine-month contract. He held the role for three and a half years.

He has come to realize that “although there might be a perceived impediment to disclosing disability, it can actually open doors for you.” If he had been “more comfortable disclosing,” he said, there would have been many more opportunities for him, “which really runs counter to the narrative that sometimes gets presented, which is that disability is a hurdle.”

Brown appreciated that the CBC put him on their morning show as a traffic reporter and provided technology to accommodate his vision needs. “It was super significant to have somebody on air every morning on a popular radio show who has a disability. That’s a huge step.” But Brown started to notice he was “bumping into a glass ceiling.”

He said: “My colleagues thought I was a good traffic reporter but pointed to the fact that I didn’t have the regional experience — two years in Sudbury, another year in Kitchener — that would give me the experience to help me climb the ladder.” His peers

were getting new opportunities, whereas “I wasn’t even being interviewed.” He had to think of his career. “What is the development path for blind traffic reporter Dave Brown? Is traffic my job for forty years?”

He reluctantly left to join AMI in 2015 as a bureau reporter in Ottawa. Since then, he has hosted *AMI This Week* and produced stories and documentaries for the network, eventually being offered full-time duties at *Now with Dave Brown*, AMI’s flagship show, which he hosts daily. “It’s freeing and challenging,” he said, noting he appreciates not having to hide certain parts of his identity, and embraces his leadership role in the disability community. However, he regrets a blind journalist could not find growth within a mainstream news organization.

“I’m too honest, and if they don’t like all of me, what can I do?”

When dealing with a spastic colon related to her irritable bowel syndrome (IBS), D. sets her laptop on a chair in the washroom so she can finish her assignments. Sometimes the pain causes her to pass out and she calls out to her wife to catch her before she hits the floor.

D. always hoped there would be a workaround for her very hidden disability until she arrived at journalism school and tasted the culture that celebrated high stress with little compassion for human weakness.

At age thirty, she is a mature student attending university for the first time; the first person in her large extended family to do so. She decided to become a journalist to combat the fake news that became so prevalent during Donald Trump’s presidency. But what she calls the narrow and ableist views of journalism culture have made her

reconsider her career choices. “I find it heartbreaking and scary, to tell you the truth.” She felt from the onset that she could not do the job as she encountered it at journalism school. “I’d have five things due in three days and I didn’t know how I would do it. That anxiety would anger my IBS. I started to realize this was more than a little issue,” she recalled. “I don’t blame the professors. They’re trying to prepare us for the world. I blame the culture.”

I mentioned to D. that she should follow *Globe* political reporter Kristy Kirkup on Twitter because she tweets fairly frequently about having Crohn’s disease and being immunocompromised in the time of COVID-19 (“I’m 34 and take medication”). D.’s reaction? “Wow. I had no idea. It would have been nice to have learned about her in school.” D. urges journalism programs to acknowledge it is possible for budding reporters with health challenges to make meaningful contributions. “I wish someone would have talked to us about flexibility, invincibility, what’s possible,” she said.

Now that D. is job-hunting, she reveals she has IBS by including in her applications an essay she wrote about ableism in journalism and her own experiences with invisible disabilities. When we spoke in June 2021, she had received few responses to her many applications and wondered if it is because she had revealed too much. “I’m too honest, and if they don’t like all of me, what can I do?”

Having read her essay, I can attest she is an excellent writer. She will not remove it from her applications because she thinks it is imperative to tell the truth, even if it limits her opportunities and makes others uncomfortable.

“We don’t all have to be decapitating gladiators to be effective reporters.”

Jan Wong, a former journalism professor and China correspondent for the *Globe*, insists better disclosure practices for disability and illness will lead to much-needed representation of more minority groups within news organizations. And better content that speaks to a larger audience. Her empathy toward those with invisible disabilities is hard-earned, after she was fired from the *Globe* in 2009 during an episode of clinical depression. In an interview, Wong said, “If you want to cover a diversity of issues, you have to have a diverse newsroom.”

Wong was a tenacious, driven, gutsy, unsparing, and award-winning reporter whose reputation preceded her. She observed the Tiananmen Square massacre. She went undercover as a maid earning minimum wage. She smuggled a pair of box-cutters aboard four Air Canada flights after the 9/11 attacks to test Canada’s airport security. She became instantly infamous for her weekly “Lunch With” column, inviting celebrities or celebrity hopefuls to dine and then hoisting them by their own petards. In September 2006 she produced a morning-after feature on the Montreal Dawson College shooting that left the gunman and one student dead. In her piece, a combination of reporting and analysis, she linked the incident to two other Montreal school shootings, including the 1989 Montreal massacre, noting that in each instance the perpetrator was an immigrant or son of an immigrant marginalized in a society that valued “*pure laine*,” which Wong defined as francophone slang for old-stock Quebecers.

An entire province, then the House of Commons and Wong’s boss, turned against her. Quebec Premier Jean Charest called the article a “disgrace” and demanded an apology from Wong to all Québécois, while the House of Commons unanimously passed

a motion requesting an apology for the column. In response, *Globe* editor Edward Greenspon published a column saying Wong's opinion had no place in the piece.

In the face of vitriol and personal attacks, Wong descended into a clinical depression and, unable to work, went on sick leave. The *Globe's* insurer, Manulife Financial, repeatedly denied that she was ill and hence entitled to sick pay. The former superstar had been cast as a malingerer who was having a snit. Ordering her back to work, her employer withdrew her sick pay and negotiated her dismissal with a monetary settlement.

The experience enlightened Wong to the plight of journalists with mental health challenges and other invisible disabilities. "News organizations don't like weakness, so journalists with disabilities must hide their situation to get in the door, and not tell anybody until they pass probation," she said. Her advice: produce great stories, pass probation, disclose disability if you dare, get into management, and then start hiring other people with disabilities. She likens this prescribed path to the advancement of women in media, who started out in lifestyle sections in the 1970s, then became news reporters in the 80s, before climbing the managerial ladder through the 2000s, roughly speaking. First women without children ascended, then women with children. More recently, it is racialized women seizing a few senior editorial roles.

Wong predicts journalists with disabilities will be the last to be welcomed into newsrooms. "It's going to take a while to have enough disabled people in the core. And then moving up and then fighting for the top job," she said.

At the same time, she urges daily news organizations to include disability in their scope of diversity as they seek new hires. In other words, don't just hire racialized

journalists; hire some with disabilities. “Until I suffered from depression, I had not really known anything about it. It was a hidden topic and not covered. If we had been much more open in the newsroom to having people with chronic depression, chronic pain, stuff like that, we would have had better reporting. It would have served our readers better.”

After she left the *Globe*, Wong became a professor at St. Thomas University in Fredericton, New Brunswick, where she says she spoke openly about depression and its signs up until her retirement in 2021. She encouraged students to lean on their differences, whether they were racialized or Indigenous, and pitch story ideas that celebrate those differences to help them stand out. While she thinks people with invisible disabilities should “hide” until they are hired, she thinks journalists who use wheelchairs or are blind should work to stand out — “make a lot of noise about it, get a lot of allies who are supporting you, and be right in [news managers’] faces about it.” Hopefully then, with a spotlight on them, they will make the right hiring decision, Wong said. She said she learned the stigma that can breed in the silence. When she was suffering from depression, her employer told her not to tell anyone she had depression and was on sick leave. “Everyone thought I was on a book tour. Nobody had any idea what I was suffering, and that’s how they wanted it.”

She said young journalists shouldn’t feel bad if they don’t fit the prevailing mold. “We don’t all have to be decapitating gladiators to be effective reporters.”

“I hear you are a faker.”

At the *Ottawa Citizen*, my health was fine at first. Then it was not. Something odd began to happen after just a few hours in the office: my face became bright red and hot to

touch. It was as though I spent a day at the beach instead of head down at my desk (Page, “Falling Apart”). Research would reveal that the UVA and UVB emissions from fluorescent lights triggers disease flares, especially in the kidneys of photosensitive lupus sufferers (Rihner and McGrath). The lights in my section of the newsroom had no covers, revealing the long, bare bulbs. But then I had no idea why my face was burning.

Meanwhile, intermittent fatigue became permanent, while the inflammation parked in the connective tissue of my joints. To take a cap off a juice bottle I had to turn to my desk mates, some of whom mocked me because they could not believe how weak I was. I had not fully explained to anyone what I was suffering. At work, anyone who watched me walk could see me wince in pain. I went to interview the Chief Scientist and acting head of the Canadian Space Agency, Alan Mortimer (he also had a PhD in medicine), and he asked me what was wrong. I told him I had lupus. I had to talk to somebody. He told me if I was having that much stiffness and pain, I probably needed better treatment. It was hard to disagree.

I interviewed Dr. Mortimer because Dr. Roberta Bondar was about to become Canada’s second astronaut and first women in space. I went to Kennedy Space Center in Florida to watch the lift off, and then Huntsville, Alabama, to the Marshall Space Flight Center where the mission science was monitored. I wrote eighteen stories over a fifteen-day period, and then returned for a routine appointment with my rheumatologist. Test results revealed my kidneys were spilling way too much protein, a sign of significant inflammation.

Three days later, I was lying on my stomach at the Ottawa Hospital as an X was drawn on my back to mark the spot for the biopsy needle. A nephrologist was going to

take a snack-sized bite of my innards: a moment of truth in the course of my chronic illness. They could then study what my disease looked like, at least in my kidneys. Until then, I could only divine the turmoil when it showed up as heat, swelling or pain.

About 60% of lupus sufferers have kidney involvement, usually lupus nephritis, when tiny filters called the glomeruli become inflamed or damaged. When this happens, the kidneys cannot clean the blood properly and the protein and red blood cells that normally circulate in the bloodstream are abnormally passed into the urine. One in five cases of lupus nephritis is severe, based on biopsy results. These patients are diagnosed with Class IV diffuse and proliferative lupus nephritis; the glomeruli are so hobbled by inflammation that it can lead to kidney failure.

Turns out I had Class IV lupus nephritis and was in danger of kidney failure. I was to be in the hospital for two weeks, and then on sick leave while I took high doses of chemotherapy and corticosteroids. I forgot to ask if I was going to die.

I also had no idea what medical information I was supposed to divulge to my employer. Where does an ailing twenty-six-year-old find out these things? Word spread from close friends to the newsroom, and colleagues from work started to arrive at the hospital with flowers and cards. *So, this is what happens when you tell people you're sick*, I thought. My face turned red, this time because I was embarrassed.

A collection of specialists did not chastise me for my desire to return to work quickly. Instead, I suspect they liked my spunk, which was in direct opposition to my need for rest but fuelled my long-standing career aspirations. The doctors all fed into my delusion that I could work full-time, all the time. No one ever told me to give it rest. Three months would be my target return.

I could not think of a single person who had gone on sick leave from the *Toronto Star* or *Ottawa Citizen* newsroom, except for stints in rehab for alcoholism, which was an acceptable occupational hazard. I fretted about what the City Editor would say about my kidneys succumbing to lupus and not excessive drinking.

Once alone, I yanked the hospital phone off the table and set it on my lap. I dialled the newsroom. In retrospect, I could have said I was sick and needed a few weeks off and provided a vague doctor's note. Instead, I was crying before Randall Denley even answered the phone. I told him I had lupus, but still downplayed the severity of lupus nephritis, and focused on my return to work. "I'm on lots of drugs. They will make me better. But I need time for them to work."

I said two months, shaving a month off what my doctors had suggested, even though my raging immune system was devouring my kidneys. I recall him being very nice and promised to get a friend to drop off my doctor's note (I never heard a word from HR about it or my leave). I think I apologized to Denley. "I'll be back later," I declared.

I had moved from being invisible to being seen, and I was not sure what that would mean for me. I had been pretending I was fine since I landed my first reporting job six years earlier. The jig was up.

Chapter 5: A First-Person Battle with Ambition

In the months after my return to work following sick leave for kidney failure, I tried to make my supervisors and colleagues forget I had anything wrong with me. Fuelled by immunosuppressants and manic from prednisone, I wrote furiously about scientific issues that confound scientists still: the quest to map the human genome, perils of genetic screening, discovery of pregnancy vaccines, the warming Earth, gender testing for elite female athletes, and the hunt for a gay gene. Some of my pieces were beautiful, mostly because I chewed over the opening paragraphs for hours, masticating each word, reading sentences aloud under my breath, tasting their rhythm. If I could not be a political reporter or a foreign correspondent, I could do this one thing very well.

When I reread my stories now, not a word is misplaced. Although I tried so hard to construct something perfect, it is not the work of a perfectionist. I did not fear failure or criticism or think what I wrote was not good enough. My work was created by someone seeking control in her life, when so much was beyond her influence. The one thing I ruled completely was word choice. If I did not get a revealing anecdote or a strong quote, I would call the subject back until I did. This I could manipulate and manage, and this is how I elevated my craft: control.

Hours would pass while I pored over academic papers and scientific journals like *Science* and *Nature*. My colleagues called me Dr. Page.

Following my sick leave, while on 30 milligrams of prednisone with an azathioprine and amitriptyline chaser, I was sent to cover the space launch of physicist Steve MacLean, a former national team gymnast, who in 1992 was to become Canada's

third person in space. I had covered astronaut Roberta Bondar's mission when my kidneys were already at stage four diffuse proliferative nephritis and my white blood cell count was in the cellar — although I did not know it yet. Covering MacLean's launch while pumped with a whopping dose of prednisone was like driving a convertible instead of pedalling a bicycle. I had fuel to burn. But the meds made me highly anxious. In Houston, home of the Johnson Space Center, there were moments I was scared to leave my motel room, afraid of the many pickup trucks, and the men driving them, with their guns mounted in back windows. When I did venture out, things went poorly. I went to a movie but left early, afraid there might be a shooting in the theatre. I fled the city on a day trip to Galveston, on the Gulf of Mexico, but, consumed with fear, did not get out of my rental car. I circled the coastal city several times, parking to stare at the ocean briefly through the windshield before heading back to Houston to finish reporting on the nine-day mission. The jittery prednisone energy, compounded with amitriptyline anxiety, was exhausting.

Weeks later, when MacLean returned to Ottawa for a welcome-back press conference, I stood up to ask him a question. I was in the back row, in an airport hangar filled with other journalists and dignitaries.

“Shelley, is that you?” he asked.

“Uh, yes.”

“I barely recognize you.”

All eyes turned to me, apparently unrecognizable because the prednisone had bloated my face. I looked like a big round head on top of a stick. I quickly touched my face, remembering, then stammered my question. Fat-face strikes again. Scientists,

especially physicists, are not known for their emotional intelligence, but I felt like I had been fat-shamed on a national stage. I had to laugh, even as my face turned the colour of a cherry-red lollipop.

I once flew to Sudbury to travel to the bottom of Inco's Creighton Mine to visit the future site of the Sudbury Neutrino Observatory, where a detector would look for subatomic particles. It was a four-minute ear popping elevator ride straight down, then a fifteen-minute walk through a mine shaft to get to the Observatory. The head of the Observatory, Art MacDonald, would go on to win the Nobel Prize in 2015 for his discoveries. The evening after my journey to the mine's bottom, I passed out in my hotel room, wondering why I had pushed myself to go. The simple answer: I liked my job and wanted to do well.

I also seized manageable opportunities. I became an instructor at my alma mater, teaching science journalism to fourth-year students; hosted "Science Watch" on CBC Newsworld, a brief spot about scientific discoveries; and appeared on panels to speak about improving science and medical journalism.

All of this was proof that I could find success within the limits of my health and the opportunities presented to me. But was I healthy during this period? I lived in a permanent state of immunosuppression from azathioprine and prednisone. These drugs made my kidneys temporarily safe, but outside of work I mostly lay on my leather couch, hobbled by fatigue and a chronic yeast infection. I caught pneumonia at least twice every winter, and battled shingles. And like almost everyone with a chronic illness with no known cause or cure, I was susceptible to the promise of alternative treatments. I had my jaw X-rayed to look for pockets of infection where I had my wisdom teeth removed a

decade earlier; then had my mercury fillings replaced with composite by a holistic dentist. I was tested for leaky gut, visited an osteopath, and underwent reiki and lymphatic drainage (separately). I took bentonite and caprylic acid oil to kill my candida. Each alternative practitioner I consulted had theories, but no experience successfully treating someone with stage four lupus nephritis.

At work, my frenetic and sometimes confrontational behaviour got me into trouble with my supervisor, who once accused me of having a personality disorder, instead of a reaction to mania-inducing amounts of prednisone. She threatened to put a note on my HR file for being insubordinate. I felt like laughing, crying, and punching her in the face. I was careful not to make a big deal out of my situation, which may have led people to believe it was a minor setback. Talking about my woes with my colleagues was tedious — even I needed a break from myself. Mostly, I found escape in the competitive, ribald, and darkly humorous banter of the newsroom.

I often wondered where others with invisible disabilities were hiding, and while it is possible many were keeping silent about what ailed them, some may have self-selected out of a journalism career. Authors Paul J. Donahue and Mary E. Siegel, in *Sick and Tired of Being Sick and Tired: Living with Invisible Chronic Illness*, explain how hard it is for young chronically ill people to plan for the future.

We all have dreams and with them, the natural tendency to hope and plan. These dreams form our identity and our view of ourselves as we launch into the world. *I will go to journalism school. I will get a newspaper job and travel the world. I will live near water. I will find a partner. I will have children.* Not all plans are attainable or practical, but we make them. And to make plans, it is necessary to think about the future, projecting

outcomes and consequences. According to Donahue and Siegal, living with an illness that is relapsing and remitting makes clear-headed choices about the future impossible. We fear we will not have the opportunity to follow through (Donahue and Siegel ch. 11). Even if we make choices, will we be healthy enough to see the results? The future is inhospitable.

I chased a beat reporting job at another newspaper, hoping it would give me more control over stress and demands. Weighing options, I could not predict the inherent stresses of that job, the negative impact of unguarded fluorescent lights on my health, a serious nephritis flare, worsening illness, or a recent break-up with my long-time boyfriend. All this left me with a feeling that I could not attain my goals, and that there was no safe path to choose. In the days before my kidney biopsy and subsequent increases in drug treatment, I was hobbling from sore joints, fatigue, and exhaustion. That had not been in my calculations.

Given these constant blowbacks, it is hard for the chronically ill to avoid “what if” thinking. *I cannot take this new job, because what if I get sick again. I cannot try to have kids, because what if my kidneys fail? I cannot find a new relationship, because what if my illness pushes him away?* All real possibilities, based on my track record. How do you not just give up? (Donahue and Siegel ch. 11).

Donohue and Siegel urge those with invisible disabilities and other chronic conditions to ban the “what ifs” from their minds. Unless you can concretely tackle the concern, stop fixating on a dreary future that may not even happen. They acknowledge this mindset shift is not easy: “clearing the mind of futile, troubling thoughts requires commitment and concentration.” As they write, “Our fears produce these troubling

thoughts quickly, push them to the front of our minds, and insist that we pay them close attention [...] We go over them and over them, as though we will obtain relief and arrive at answers” (ch.11).

“What if I become disabled?” does not lead to the purchase of crutches or the selling of a three-storey house to avoid stairs, as the authors write. And “what if I go blind?” does not lead to classes in Braille. It is impossible to find real solutions for hypothetical extremes. For me, wondering “what if my lupus nephritis makes me need a kidney transplant?” does not send me looking for an organ donor, but instead causes me to create a plan of action: watch my blood pressure, reduce my protein intake, eat less red meat, and watch for any signs of increased dysfunction in case I need to take stronger immunosuppressants. Whether the “what ifs” of worsening kidney disease and another lupus flare would make me abandon a career or life goal was a harder question to answer.

Instead, I focused on my work, which should have been enough. But the truth was, I did not have the heart for what I was writing about. It was difficult to devote all my brain power to deciphering new discoveries and telling stories about the highest, fastest, weirdest, newest to seduce a reading audience. This was not my imagined career as a journalist back when I thought I might be a foreign correspondent or a Parliament Hill reporter, or at least part of urgent conversations.

After five years on my science beat, I saw a new job posting at the *Citizen*, a columnist to cover Ottawa. Not its politics, but its people, including police, crime, and social justice; the hidden issues. I passed by the job board frequently, a beacon calling me back to my original career goals. My health sucked and there was no good reason to take a harder job. In fact, if I was thinking only of my health, I would have found menial

office work where I could put my excellent typing skills to manageable use. Many of my colleagues encouraged me to apply, likely because I never complained about fatigue or sore joints, so none understood that they were essentially daring me to take on something that I could not and should not do. The only devil's advocate was my inner, wiser voice shouting: "You can't do this. You shouldn't do this!"

In my application, I made a case for why I should get the job, leaving out the most obvious reasons why I should not.

When the column was offered to me, I found myself making promises to do a kick-ass job. It felt like driving through a busy, uncontrolled intersection. I had no idea what might hit me. It was thrilling.

In the months ahead, I wrote about teens squatting in the bush near Parliament Hill, murdered women and monuments memorializing their death, safe houses and child killers and developmentally delayed adults fighting for work. Without a strong opinion about anything, my columns were expository; I sought to reveal the heart of a situation through detailed behind-the-scenes reporting. Each column took a long time to research and write; it would have been much easier to dash off a strongly worded condemnation of a politician or policy, but that was not me.

Early on, I was invited to tag along with a woman named Susan McNab who was speaking to a group of high school students about the death of her son, killed by a drunk driver. She had just joined the Ottawa chapter of Mothers Against Drunk Driving. As much as she wanted to shock the students sober before they got into any car, she also needed to unburden herself of how she felt upon learning how her son died.

Her quest for justice for her son would consume me.

The August day Shayne Norris died he and his best friend, Sean, had chased each other on mountain bikes over curbs and along side streets. They were both sixteen. As Sean burned down a quiet street in Bells Corners, a car swung around the corner and almost slammed into him before speeding away. Stunned, he skidded to a stop and toppled off his bike. He fell to the curb and started to weep. Death had never seemed so close. Sean and Shayne, shoulders heaving while they both wept, talked of how badly they wanted to live. Life was awesome (Page, “Classic Case”).

“I’m afraid of dying,” Sean later remembered saying.

“Me too,” mumbled Shayne, who for once would make his 12:30 a.m. curfew. He leapt on his bike shortly before 10 p.m. to make the thirty-minute ride home to his dad and stepmom’s Kanata townhouse.

Less than a kilometre away, twenty-nine-year-old Serge Loranger sat in a dimly lit roadhouse surrounded by professional tough guys who earned their living as undercover cops with the local drug unit. Constable Loranger arrived at the bar at 4:30 p.m. and over the course of four hours drank nine glasses of beer. At about 10 p.m., he got into an unmarked OPP Ford Sable station wagon, and with his friend following in his own car, headed toward his Kanata home. He had to drive along Robertson Road, which begins as a busy byway through a knot of strip malls and doughnut shops and then becomes an unlit four-lane road punctuated with driveways to old stone farmhouses.

It was the same ribbon of road that Shayne had chosen as his route home.

That night, a cop in a car and a boy on a bike collided. So began a heartbreaking search for answers to how Shayne died, accountability, and justice.

What Shayne's mother, Susan, told the high school students is unforgettable, drawn from details in the coroner's report on her son's death. "I see is the smashed windshield and the tufts of light brown hair implanted in the molding. I see Shayne's running shoes on the side of the road. I see his favourite ball cap a few yards away from the shoes," she said, voice trembling. "I take another few steps and find part of Shayne's skull, then an arm, a leg, then much further out in the field I find the face of my Shayne staring towards the Heavens above" (Page, "A Mother's Mournful Screams").

She told the students how they handled her son's body, they "picked it up piece by piece, their stomachs wrenching at the heinous tragedy that lay all around them [...] Nine months later and no answers." This was the first of almost a dozen columns I wrote about the case. During the subsequent trial, the Crown prosecutor had to prove beyond a shadow of a doubt that Loranger knew he had hit a person — not a deer, as he claimed — when he failed to stop, or that he was willfully blind in not finding out. In the end, Loranger was acquitted of all charges relating to Shayne's death. There were just too many errors in the police investigation, too much doubt left on the table.

Afterward, Loranger was encircled by an entourage of officers and led out of the courtroom to a glass-walled elevator. As the doors closed and a wall of blue surrounded him, I tried to push my way in, leaning hard against his bodyguards while shouting questions. I was determined to ask him my questions. As I pushed, one officer, a special constable at the courthouse, hit and shoved me very hard several times, until I was sent stumbling out of the elevator.

The only article in the paper the next day with my name in it was about my assault. "Shelley got hit, and she got hit hard," it quoted a rival journalist. *Citizen* lawyer

Rick Dearden was also quoted: “Page was forcibly blocked from entering the elevator by courthouse security staff, then hit in the back near her kidneys.” Ottawa police chief Brian Ford added, “It should not have happened (“Police Probe”).

The *Citizen* story added that I had lupus and kidney impairment. I had never come out as suffering a chronic autoimmune disease before and felt exposed. The journalist writing the article asked if I minded mentioning this, as it seemed to explain why I went to the hospital and why this attack was notable. I reluctantly agreed.

I also decided to make an official complaint, in the hopes it would shine a light on the special treatment that Loranger had received, to the detriment of those trying to cover the story. But when two Ottawa police officers came to interview me in my home — to determine if charges against the special constable were warranted — instead of asking me questions about the incident, they encouraged me to drop the charges, saying that it was the easiest course of action, so I would not have my integrity questioned in a trial. They told me the special constable was a good guy, active in his church. They told me it was very common for women to reconsider their original complaints against their attackers. I was being intimidated into remaining silent. I was a journalist in a privileged position with a voice and a column. I thought of how other women, without my advantages, must feel when faced with this type of pressure.

A special prosecutor from Toronto was assigned to my case and after reviewing the file, assault charges were laid against the court officer. The special prosecutor told me that if the case went to court, I would indeed have a rough ride, just as the officers who came to my home had warned. The Ottawa police had not bothered to interview any witnesses, even though several journalists had witnessed the assault. Instead, my case file

was filed with eye-witness reports from more than a dozen officers who claimed nothing had happened. Their investigation guaranteed I would be painted as a liar. Loranger's special treatment would not come to light. The special prosecutor advised me that mediation with my attacker — sitting across from him so I could explain how I felt — was the best way forward. I chose that route, which ended in a public apology from the court officer who shoved me repeatedly, published in the *Citizen*. Instead of feeling vindicated, I was left with an intimate understanding of the justice system and regret that I had ever pursued Loranger into the elevator.

So, this is what it meant to be part of the conversation. The work was unrelenting, and I continued to write seven columns every two weeks. I was perpetually exhausted. I loved it but often wanted to quit. I was determined to make it a year. When a year passed, I aimed for two. If I made it that long it would not look like I had failed.

Once, a reader reached out to offer me counselling. He was affiliated with a funeral home and said he had noticed I wrote so often about grief that he figured I, too, needed support. We talked on the phone a few times, and I worked on distancing myself from everyone else's pain. All the while, I knew I could not be a columnist anymore. The intensity, the daily demands, taxed my depleted reserves. I could admit that to myself, but not easily to others. No one, my bosses, colleagues, friends, could see how hard it all was for me. If I bailed, would I be thrown into the general assignment pool? Surely that was worse?

Then I caught a lucky break.

Chapter 6: The Improbable Dream Job

When Neil Reynolds showed up in 1996 with a flourish of eccentric notoriety to overhaul the *Citizen* as its new editor-in-chief, he glided into his new office in a loose-fitting beige tweed blazer and closed the blinds on the huge windows through which we typically gleaned gossipy tidbits. For days, then weeks, like the seasoned alchemist of content he was reputed to be, he plotted our transformation behind cheap venetian shutters. He proceeded to shred us and our news judgement, product, and processes. People would be invited in, summoned really, to be told they were mediocre and then leave, demoted. Others would talk smart about geopolitics and be sent to Europe for a few months to investigate, only to return to be demoted.

Reynolds was dubbed “Bubbleboy,” not only because he swam almost exclusively inside his own fishbowl, but also because he seemed to be fuelled by better air than the rest of us at Baxter Road, the bunker-like headquarters built in the 1970s with the latest chemical innovations, including unscuffable carpets. How else to explain the aspirations Reynolds had for us, far greater than those we ever had for ourselves? “You will create literature!” he declared.

Reynolds had been Conrad Black’s pick to transform the *Citizen* after his Hollinger Inc., once the world’s third-largest English-language newspaper empire, bought a controlling interest in Southam, our paper’s parent company. His stated ambition, after buying the chain, was to get rid of the “overwhelming avalanche of soft, left, bland, envious pap which has poured like sludge through the centre pages of most of the Southam papers for some time” (“Black Vows”). That was harsh criticism, but it was

largely true of all the papers, including the *Citizen*. We had standout journalists, some of the most gifted and dogged I have ever worked with, but the paper itself had become lowbrow and unambitious, part of a trend of homogenizing the papers across the Southam chain. Our Arts sections had shrunk. The science and environment section I was hired to work for was axed. There were few investigations or special projects, which were usually meant to show a paper's heft and depth. We were mostly workaday journeymen. Jim Travers, editor-in-chief prior to the appointment of Reynolds, got the job after being a long-time foreign correspondent. From Africa and the Middle East he had filed concise, serviceable stories that could fit into any slot on the scant international pages of the hyperlocal *Owen Sound Sun-Times* or *The Kamloops Daily News*. He was solid, dependable, fair, and uninspired. He was a chum to many in the newsroom, and in turn we were loyal to him.

The paper's managing editor had been a librarian who picked up trends at editors' conferences. At one point, she ordered us to write using the "high fives" — a method promoted by American journalist and writing coach Carole Rich — where all stories had to include the (1) news, (2) context, (3) scope, (4) edge, and (5) impact. These so-called innovations in storytelling made everything bland, predictable.

Bland. That was the word Black sneered. We all knew he had a point, as much as his blistering appraisal stung. Because Southam did not have a Toronto presence, the *Citizen*, in the nation's capital, was the closest entity to a flagship and therefore Black's target. We might have been happy about Reynolds's arrival if we did not like Travers so much and were not so defensive about our mediocre product.

Reynolds was the antithesis to this sea of sameness we had been dog paddling in.

He did not want journalism to be narrowed by professional convention, but instead widened; for us to strive to create stories that were well-written, inventive, imaginative, and presented elegantly.

He had a track record of inspiring writers to seize the golden ring at small-town newspapers. As editor of *The Kingston Whig-Standard* for thirteen years, he produced a literate and worldly newspaper, gaining national attention with articles from reporters sent to China and Afghanistan. When he left Kingston for Saint John, New Brunswick, to become editor-in-chief of the *Telegraph-Journal*, he transformed the “thin, innocuous paper dominated by wire copy into a dynamic and controversial news source with strong local coverage” (Wahl). At both the *Whig-Standard* and the *Telegraph-Journal* he also created weekend magazines devoted to literary topics. Not only did Reynolds’s lofty aspirations for the newspaper chain match Black’s, so did his politics. A former leader of the Libertarian Party of Canada, Reynolds believed government had no place in the private lives of citizens.

In one of the few townhalls Reynolds held after his arrival, he explained that a newspaper’s role was to wander, whimsically and purposefully, back and forth between the lofty and the low. His pick for Sunday editor, David Warren, wrote that Reynolds believed a newspaper should “wander profanely into the sacred, and sacredly into the profane” (Warren).

We all feared an invitation to that glass-walled office. I had been watching Reynolds’s early moves, wondering where I would fit in the new *Citizen*. As city columnist, I did not expect to escape his overhaul plans, especially because I probably seemed like a left-leaning sob sister, but I did not want him to decide my destiny. I knew

I desperately wanted a job I could do, one that did not tax my health. Filing those seven city columns every two weeks while in a permanently immunocompromised state was extremely taxing. Beyond that, I was not an ideologue, so I could not knock off a piece about the funding of homeless shelters, or the lack of safehouses for women fleeing abusive partners, or whatever a left-of-centre columnist might think. I had to go meet the person living in the homeless shelter and talk to the woman hiding in a safe house. It was a slog.

During that period of severe immunosuppression, I had a way of hugging myself, with my arms wrapped around my torso, as though I was made of antique glass that might shatter at any moment. I held myself so very still to conserve my energy, which I doled out cautiously. Because I controlled my own hours, many times I would just go home to lie on the couch, willing myself to sit upright and perform the duties of a columnist. I went into the office because being in a newsroom doing purposeful work gave me energy, but the work I would do there would drain it just as quickly as it came. Yeah, a slog.

I longed for someone to think I was heroic for having dreams of being a successful journalist while having a serious chronic illness. I had no relationship with any editor, any boss, where a frank talk about my health and ability to do my job seemed possible. My plan had been to hold onto the column for two years, which I thought was a respectable amount of time, before asking to be moved to a different role. I had not planned to tell anyone it was my health that made the job so hard, or why I needed an out. I just hoped, maybe, I could find an easier position, like going back to science writing or covering the environment? When Reynolds showed up a few months before my self-

imposed two-year deadline, I stewed constantly about how to free myself from column writing and end up with a safe spot. I would not raise the issue of my health on first meeting for fear he would forever think of me sickly, which seemed much worse than being sickly, at least to me.

My rendezvous with Bubbleboy came unexpectedly, about six weeks after he had arrived. I assumed he would book an appointment, but he strolled out of his office and asked if I had some time to chat. “Now?” I looked around at my colleagues, who were trying to appear uninterested.

He sat across from me on one of the two leather couches in his office. When I explained I had been the paper’s science reporter, he leaned in. After I listed my previous stories about advances in genetic technology, the Human Genome Project, gender identity, privacy rights, black holes, and neutrinos, he cocked his head to the side and stared at me for a few seconds, as though reconsidering me, an actual science journalist who grasped big ideas. Sensing this, I mentioned I had written about unified field theory before but had failed to get a mention of the Schrödinger’s cat paradox into the paper, causing him to chuckle.

“What would you like to do next?”

So, there it was. He never mentioned there was anything wrong with my column, it was just a given that I would move on. I felt more upset than expected to. After all, I was poised to quit, and he was opening the exit door. But suddenly I felt I needed to defend my column. It was popular with readers. People liked my so-called take. I opened my mouth to defend it but stopped myself. Another type of survival instinct kicked in. I

told him I agreed it was time to move on, and that was what I was hoping to discuss, as though I was setting the agenda. “Maybe I could try writing features?”

He paused, considering. Not just anyone gets to be a feature writer at a Neil Reynolds’s paper. “I’m not opposed to this,” he said, pausing again. “No, I’m not opposed.”

We discussed what I would write about; less human misery and more science and other weightier topics. Very quickly, we agreed I would be a “columnist feature writer” who would get a headshot atop my stories. I could write what I wanted, when I wanted, and we would see if I rose to the occasion. He handed me a job I did not know was open, was not posted on the bulletin board, and had no specific prerequisites or qualifications. Very possibly a dream job. I was worried it was some sort of trap. It was certainly a test.

When I left his office, I struggled to make sense of my conflicted thoughts. I felt rejected. Yet, I was free. I had gotten exactly what I wanted, without even having to quit, or admit weakness, or failure, or hidden disability. My colleagues cautiously crowded around me to commiserate, assuming I had been demoted. I told them I had lost the city column, which confirmed their suspicions that the left-leaning were being sidelined. I held back in announcing that I was appointed feature-writing columnist because I was afraid there would be a stampede to Reynolds’s office as others demanded a similar job. How to explain that I had been promoted and that I may have gotten the best possible job for me? Meanwhile, I gained a bit of newsroom notoriety: I had lost the city column because I was too left and mushy for Conrad Black.

On March 3, 1997, an all-new *Citizen* greeted Ottawans, with a detailed etching of the Peace Tower on Parliament Hill on the paper’s masthead, meant to signal a new

gravitas. “Everybody who loves newspapers should be rejoicing,” wrote *Globe and Mail* columnist Robert Fulford a week after the relaunch (Wahl). Also, anyone who loves mosquitos. Reynolds’s wife, freelancer Donna Jacobs, dropped a series of articles for “mosquito week” that explored the rise of the insect and the likelihood that malaria might return to the capital.

On launch day I had a prominent feature on a “new breed of pilot” who learned to fly using a flight simulator and “whose white bedroom walls form the landscape of infinite destinations.” He had clocked 1,375 hours and made 2,620 flights — compared to a working pilot, who clocks just seven hundred hours a year. It was a well-written piece, but hardly the intellectual fare Reynolds was likely hoping for. I followed up two days later with a story about a new Ottawa-based treatment for eating disorders. Again, well-written but soft.

I worried I was already a disappointment. Then, on the third day, a colleague handed me a clipping from a local Catholic church newsletter that would cement my position as a feature writer and saved my health many times over. The clipping mentioned a long-time parishioner, now a comedian, who was performing a one-woman play that exposed her entire family as hidden Jews and her prominent eye-surgeon father, as well as her mother, as Holocaust survivors.

The comedian, Frannie Sheridan, then living in Vancouver, was funny, scattered, non-linear. She spoke of growing up in Ottawa and being forced to hide her identity as a Jew because her paranoid father thought Nazis hiding in Canada were out to get the family even decades after the war. I pitched an idea to Reynolds that was epic, and that

would take me to Vancouver, Arizona (where another family member lived), and then Austria.

In Vienna I met eighty-four-year-old Dr. Sheridan, who had returned to his birth name, Bernie Sigal. He sat on a bench wearing the yellow armband of the blind, arms resting on his white cane. His legal blindness was a difficult twist for the eye surgeon. After I introduced myself, Dr. Sigal threw down his cane and held up his trembling hands. “His arms, they were this big. He must have been a mechanic or a butcher,” he said. “He wore brass knuckles.” He seemed to be describing a long-ago attack that had occurred in Vienna at the medical school. As we spoke, much of his story was hard to follow as he jumped countries, decades, and identities (Page, “Our Father”).

Over several days of interviews, he talked of his duplicitous life, of masking his faith, with regret. “When you want to protect your children, you will do anything. Maybe I went too far,” he said. On other days he said defiantly, “I would do it all over again.” Then, an hour later, he claimed he was a perfect father to his happy, well-adjusted children. Shuffling down the street, white cane clicking against grey stones, he asked, “What do children really know about their parents? What are parents supposed to tell their children? Everything? Do you terrify them? What do you do?”

I wondered how I was going to write this story in a way that was understandable, that revealed universal truths about being raised by Holocaust survivors and still did justice to the paranoia, fear, and trauma.

I packed two books to help me with structure: *The Art and Craft of Feature Writing* by acclaimed *Wall Street Journal* journalist William E. Blundell, who had come to the *Citizen* to give us a workshop on feature writing. I also brought Jonathan Franklin’s

Writing for Story: Craft Secrets of Dramatic Nonfiction (1994). In the Vienna hotel room I scrutinized these writers' advice and poured every bit of my experience into the outline. Vicki Keith hallucinating as she swam for two days straight in Lake Ontario. The drowning death of fourteen-year-old Benji Hayward after he took LSD at a Pink Floyd concert. The abuse of teen prostitutes. Heart surgery on a seven-year-old boy. The research scientist who wrote poetry about his pigs. The experience of asking hundreds of scientists "And then what happened?" to tease out a compelling narrative to the point of discovery.

In mid-May, two months after I began researching, "Our Father," my 12,000-word feature was published in the *Citizen's Weekly* on Sunday. It took up ten pages. The story focused on Frannie's quest to expose a truth her father had long kept hidden, at first even from his seven children, whom he sent to Catholic school and mass on Sundays, and the profound consequences on the mental health of the family. Like many children of Holocaust survivors, who sort through their pain and confusion through the arts — theatre, writing, stand-up comedy — Frannie tried to heal the second-generational trauma, even though she did not yet think of herself as a Jew.

"Our Father" moved and astonished many in Ottawa, including former classmates of the Sheridan children and patients of their father. A Jewish synagogue and a Catholic parish came together to bring Frannie to Ottawa later that year to perform her one-woman play. Many of her estranged family members also came to see her perform, some who never forgave her for betrayal of family secrets. I spoke at the event, and then accompanied Frannie and her family to her mother's grave.

That one story enabled me to write whatever I wanted, working with former sports editor Lynn McAuley, who was appointed editor of the *Citizen's* weekly. A year after the paper's relaunch, the *Ryerson Review of Journalism* wrote an in-depth article about Reynolds and the new paper (Wahl). The author mentioned there were journalists who saw the "shakeup as an opportunity to try something new and have blossomed, particularly those now writing for the *Citizen's Weekly*." Specifically, me. "Reynolds [...] quietly tested everyone in the *Citizen* newsroom, even veteran reporters. Those who succeed, like Page, get to do almost anything they want: Page now writes features from home" (Wahl).

Years later, after Reynolds was long gone and Black had sold the newspaper, a few colleagues would complain to a new editor-in-chief that I had unfairly snagged a job that did not require working nights or accepting daily assignments and allowed me to work from home whenever I wanted. All that was true. A bit of luck and tenacity allowed me to hide in plain sight. Some colleagues cried favouritism. I called it functioning as a journalist despite my mostly invisible disability that dogged me daily.

Chapter 7: Off the Record: Workarounds and Side Deals

In daily news organizations, ableism rules. Cutthroat culture often will not acknowledge invisible disability, let alone provide official accommodations. Many journalists like me “self-accommodate,” working longer hours or bringing our own adaptations to work; others figure out “workarounds” that include cutting side deals with supervisors. The current and former journalists I interviewed, all of whom meet the 2019 *Accessible Canada Act* definition of disability, told me stories of behind-the-scenes negotiations needed to reduce barriers and adequately perform in their roles.

Some journalists bring their own adaptive visual technologies to the newsroom or, without driver’s licences, ask colleagues for a lift to assignments or pay for their own cabs. Others work quietly with supervisors to adjust schedules or assignments to be relieved of deadline pressure, without official approval from the organization. Sick days go unrecorded, episodes of disability undocumented. One journalist with repetitive strain injury in his wrists had his editor, a good friend, type his stories for him. Another journalist, with bipolar disorder, was highly productive during manic phases but explained he could not produce much during his low points, asking managers to work around his cycles. A beat reporter, with multiple sclerosis, cut a deal with her manager so she could work from home or get an extra day to produce a story, unlike her colleagues.

“We try not to be a nuisance, we oblige,” said Sheyfali Saujani, who worked at the CBC for twelve of her thirty years in journalism without asking for formal accommodations for her visual impairment. Instead, she found her own strategies to read scripts and computer screens, including holding the printed word inches from her face in

contortions that damaged her neck and back. “I hate to think how culpable we’ve been in our own erasure, and the downplaying of disabilities, just to not cause anyone any trouble,” she said, looking back.

What are the consequences of workarounds or side deals in daily news organizations, explored here in-depth for the first time? Some say these adjustments are the best way to keep an employee with an invisible disability working while avoiding long, drawn-out, and often unsuccessful attempts at official accommodations. By-the-books support involves HR, upper-level management, and even insurance companies, all of which is taxing, perhaps personally invasive, not necessarily effective, or ultimately successful. Others call workarounds a “conspiracy of silence” that exacerbate issues of invisibility, co-opting everyone involved to keep medical and disability issues hidden.

Rachel Desjourdy, the CBC’s accessibility lead on the broadcaster’s People and Culture team, said it’s common to see “masking,” “self-accommodating,” “workarounds,” and “job trading” among other strategies. “You see side deals happening, with employees covering for each other without the manager knowing.” And as she said in more detail in Chapter 4, all these off-the-books strategies hide disability and “nothing ever changes.”

Jan Ravensbergen, former president of the Montreal Newspaper Guild, saw lots of side deals and workarounds during his twenty-seven years of union work. Jobs are made easier, or schedules quietly changed outside official channels, as if “the injury or disability didn’t really happen.”

Ravensbergen told me, “It’s the equivalent of an NDA [non-disclosure agreement]. To deny what is invisible with a side deal is like *omerta*, it’s an Italian mob

expression for silence.”

He can see how and why this happens. “If you’re a manager, you can look in the mirror at night and tell yourself you’re doing the right thing,” he said. “They don’t want a big hassle, so there is an incentive to doing a side deal. If you’re the injured party, you just want to survive, so you take a side deal instead of fighting for official accommodations because you’ve got to feed the kids, car payments; you don’t need more trouble.”

But keeping it off the books leaves no record. “The next poor schlub who comes along with an invisible disability or invisible injury is left on their own; there’s no precedent for helping them. It doesn’t appear in their records. It’s buried. That happens all the time,” he said, adding that he left Guild leadership in 2007, and the situation may have changed. He speaks from his experience.

One top beat reporter I interviewed is in “constant negotiations” to get accommodations for her multiple sclerosis. Officially, she has none. “I find it really frustrating that I’m constantly telling people my private health information to get a workaround.”

I can confirm it is exhausting. I spent much of my career angling for a job that suited my invisible disability, while not making any official requests for my serious autoimmune disease. As mentioned in Chapter 6, after seven years at the *Ottawa Citizen* (I was there for a total of twenty-two) I convinced the new Editor-in-Chief Neil Reynolds to make me a full-time feature writer for *Citizen’s Weekly*, a long-form Sunday section that launched in 1997. When I began intravenous chemotherapy in 1999 to arrest lupus-induced kidney failure, I was lucky to have an accommodating supervisor. Allowed to

work from home when I was having an awful day, I could be productive, meet all my deadlines, and avoid sitting in a newsroom during flu season. I did not go to HR, having been warned by the newspaper guild that support was unlikely, even with a medical note from my rheumatologist. Instead, I worked around the system as best I could, despite rotten health.

Lynn McAuley, my supervisor at the *Weekly*, did not know I had a chronic condition until I had worked with her for many months. “When I look back, I think, ‘Wow, you did so much back then, so many stories,’” McAuley said. “After you told me you were receiving some strong treatments, we just went at a pace that would work for you.” McAuley left the *Citizen* in 2005, after twenty-two years, for the *Toronto Star*, where she was appointed Associate Editor. She acknowledged we had a rare situation. “I don’t think that all editors have that kind of luxury, nor do all writers. We had funds and a big staff that could cover any story if we needed to. Today, it would be a much more difficult thing to pull off and say we’ll just go at our own pace.”

To be clear, what occasionally working from home afforded me was the opportunity to lie on the couch, take a nap, or attend medical appointments in between interviews. I rarely took an official sick day, although I worked sick many days. What benefit did the newspaper get by McAuley granting me this flexibility? Productivity, loyalty, and access to my experience and ability. The paper’s management dined out on my many national journalism awards announcing them on the second page with congratulatory headlines.

McAuley added: “I don’t know why we pretend that we have these fully well-rounded people who can do anything. That’s just not true. I think that’s a fake construct.”

In addition to me, she said she has helped several journalists with invisible disabilities in both *Ottawa Citizen* and *Toronto Star* newsrooms who needed relaxed deadlines or off-the-book sick days. “They want it kept a secret because they think it will be held against them,” she said.

My efforts to “work around” my invisible disability are not unique, although the job I found may have been. Many journalists I interviewed used the same term to describe how they got by at work.

There are downsides to these strategies, which the journalists I interviewed readily acknowledged. By being obliging instead of demanding official support, we have participated in our own erasure, as Saujani pointed out. We have minimized our issues — and broader disability issues — so news organizations do not have to acknowledge us or create policies that improve hiring, inclusion, and accommodation. By remaining silent, we have also contributed to the myth that all journalists are hale and hearty, with perfect mental and physical health. Within this ableist culture we have helped impose, it becomes very difficult to “come out” as the anomaly to seek official workplace support within a system that does not see disability.

In this climate, back-channel accommodations become the norm, with no momentum or incentive to change ableist structures. In addition, unofficial arrangements can perpetuate unofficial hierarchies; the only journalists with disabilities who get support are those who curry favour or outperform. Those who are perceived to get “special treatment” are resented, especially if their disability is hidden, as eventually happened to me. Our supervisors are also put in difficult positions: they know private health information about us, their employees, and must decide whether to escalate to HR,

or quietly and unofficially accommodate at the risk of seeming to play favourites.

In this chapter, I share workarounds stories from five journalists with invisible disabilities, including one anonymously. A top beat reporter with multiple sclerosis (MS), has cut side deals with her supervisors to work through fatigue and intermittent mobility challenges at two separate daily news organizations. Former *Globe and Mail* medical reporter Paul Taylor told had colleagues who helped him do his job despite repetitive strain injury (RSI) to his hands and voice. Freelancer Meagan Gillmore brought “self-accommodations” to various newspaper internships to work around her visual impairment. And I further scrutinize my working relationship with McAuley, whose support enabled me to succeed. But first, I explore the experiences of my former Carleton classmate Sheyfali Saujani, who struggled for more than a decade at the CBC without any support for her visual impairment.

A Subculture That Sustained Careers

“I obviously couldn’t see well, but no one ever asked me if I needed help.”

After graduating from Carleton University in 1986, Saujani got her first journalism job in community radio by “semi-passing.” She did not loudly and proudly tell others she had genetic macular degeneration, and instead, stealthily used a hand monocular to see distances, reading the printed word wearing Coke-bottle lenses and holding text a few inches from her face.

“I was visible, but invisible. I obviously couldn’t see well but no one ever asked me if I needed help. So, I knew I shouldn’t ask for it,” she told me, adding that being a Ugandan refugee and racialized journalist also made her reluctant to draw attention to

any perceived inadequacies. Instead, she brought her own accommodations and overwork to every task.

With experience in campus and community radio, she got her first job at a CBC radio station on Prince Edward Island. When she was recommended for a job at CBC Toronto, her current boss said to her future boss: “You know about her vision, right?” Future Boss looked at her blankly, “like I was about to give some huge ideas about my vision for the CBC, and I blurted out, ‘I’m partially blind, I don’t have a driver’s licence, but I can do everything I need to do, as long as you don’t need me to drive.’”

Her life as a chase producer began. If anyone paid attention, they would have seen her leaning over the keyboard to stare at her computer screen or holding scripts to her nose. She excelled by making calls to potential guests for the flagship Toronto radio show, *Metro Morning*, as well as several national current affairs programs. “I had no problem sitting at my desk all day doing cold calls. I was really good at it and that’s how I hoped I was regarded,” she recalled. She worked ten to twelve hours a day (instead of a standard workday) because she “read a lot more slowly,” holding everything up to her nose. “You can only do that for a certain number of years before your body starts to say, ‘No!’”

Saujani never asked the CBC to make adjustments or reduce any barriers to help her do her job, although a senior producer once found her a larger monitor with a larger font. “I didn’t see anyone else asking for accommodations, so I just tried to fit in.” She knew no other employees with disabilities at the CBC, making her experience more isolating.

After twelve years and with significant neck and shoulder pain from all the adaptive contortions she made, she was mentally and physically exhausted. “Try holding your elbows bent with your hands five inches from your face for an hour. My body, my neck and back were in so much pain,” she recalled. The emotional stress also got to her, not just doing a job designed for someone with perfect vision, but also dealing with incidents of racism during a time of budget cuts and layoffs. All while hiding part of herself.

One day, while she was working as a chase producer for the current affairs radio show *As It Happens*, she ended up crying inconsolably in an editing suite, defeated. An editor came in to ask her how she was progressing with a story and “she asked me if I needed to go home.” Saujani left for almost a year. “It’s a moment I’m not proud of,” she told me. “I came here as a refugee, so on top of unresolved issues about the trauma of exile, I’d never dealt with having a disability, among other issues.”

On stress leave, she sought psychotherapy. “The big thing was coming to terms with my disability. I never named it. I’d never owned it. I’d never disclosed it,” she recalled. “This is a complicated thing about disclosure. Like everybody knew I was partially blind, but I never named it in a way that required accommodations.”

Preparing to return to the CBC a year later, she had a medical certificate stating she was “legally blind” and needed accommodations. She hoped that she would be able to end her painful workarounds, finally claim her disability identity, and find belonging at work. It did not go as planned (see Chapter 11).

“I’m the first to acknowledge I have a sweet deal.”

A top beat reporter in her city, C. would stand in the shower every day and repeat to herself, “Fuck my life.” She could not understand what was happening to her body and her mind, and no matter how many showers she took, the water pressure would not wash away the constant lower back pain and intermittent numbness and tingling throughout her body, especially her feet. Her husband was working out of town, so she had to walk the dog three times a day by herself. “I was exhausted and in pain, and I’d just stand in the shower and chant to myself, ‘Fuck my life,’ like it was my mantra. I popped Robaxacet and went to physio three times a week. But I thought it was depression, or that I was out of shape. Or lazy.”

As a reporter, she was still doing her job exceptionally well, with a nose for news, a collection of highly placed sources, scoops, and stellar writing. A battery of medical tests was inconclusive, so an MRI was booked. Almost a year later, she was finally scanned. When she was called into her doctor’s office to get the results she prepared for the worst: “I thought I had a brain tumour.” Instead, she had multiple lesions consistent with multiple sclerosis (MS) and was diagnosed with the relapsing remitting variety. Eighty percent of cases worsen to become secondary progressive MS.

She already had many side deals with her supervisor. Not just time off for her many physiotherapy and medical appointments, but also the ability to work from home. “I rarely stepped into the newsroom because I was on the road, or I filed from a coffee shop, or I was on the phone working sources,” she said. “I had the kind of job where the adjustments I needed were built into my work, and so people couldn’t see my struggles.”

After the MS diagnosis, C. immediately told an editor and her direct supervisor, both good friends. “This speaks to disclosure, right? I didn’t think through any of the consequences with regards to my work.” She was upfront with her supervisor about symptoms, including fatigue that sometimes causes her speech to be slow and slurred. “I would never do an interview in that state,” she was quick to add. As her condition progressed, if she had to cover a night meeting, she would start work the next day after noon to get extra rest.

She leveraged her friendship with her supervisor to work around the barriers to her beat. “I’m the first to acknowledge I had a pretty sweet deal. But I kind of feel I did great work and with it came trust.” She had no plans to go to HR or the senior managements to ask for an official change of duties or schedule, uncertain as to whether they would grant any. “I know some people complained about my special treatment, but they didn’t know what I was dealing with.”

Just as she was figuring out how to work with relapsing and remitting MS, her supervisor left, with predictable consequences. When people with disabilities are not accommodated with an official work plan, a change in management means renegotiating side deals, easily lost to staffing shuffles. Already, one manager was questioning why C. was slower than other reporter when she transcribed interviews or typed up her stories. “Her ignorance really pissed me off,” she said.

Then another news organization went after C., who wondered if she might have a more secure future because it was larger and had more opportunities. In an informal conversation, C. told the senior manager trying to recruit her that she had MS, so she could assess her options. “[The senior manager] was very clear that we would figure

things out. She described possible accommodations. Obviously, she was trying to win me over.” She told C. that her MS did not have to be disclosed to the corporate HR representative during the official interview, unless the number of stories she produced was “less than normal” or it had some other impact. “She said I was under no obligation to do so. So I didn’t. And you know, I got the job.”

C. wonders if disclosing her MS would have changed the outcome, but at the time of our first interview for this thesis, she planned to keep her health status to herself for a while longer. “I wasn’t diagnosed all that long ago and I don’t need everybody to know that about me. I don’t want people to see me as a stereotypical weak, disabled person, and I’m cautious about people knowing the truth about me.”

In November 2021, when I touched base with C., she had since told several supervisors — it is a large organization — about her MS. In part, she shared her diagnosis because she was worried “they’d think they’d hired a lemon,” she said. “I didn’t want them to think I was slow, but some weeks are more difficult than others.” In addition, she believed she needed to share her diagnosis to gain and maintain the “side deals” needed to excel in her role. “Sometimes I need to insert a second day into a deadline for a story, or not take calls late at night,” she said.

Her supervisors mostly understand her limitations, but when they are out of office, she finds herself in “constant negotiations” with replacements who probably don’t need to know her private health information. “I have to disclose to new people who can’t understand why I can’t work after 9:30 at night or need an extra day. I find that really frustrating,” she said. She is also worried about her reputation. “I have multiple identities,

many things I'm really good at, but the more people I tell, the wider the circle becomes, and I worry MS becomes my main identity."

C. is a woman of colour and has noted some of her colleagues are more concerned with her "visible minority status" than her disability identity. "It's a bizarre situation when you have co-workers who are really vocal about diversity, equity, and inclusion issues, but some of the things they're publicly against they're actually perpetrating against people with disabilities. I have to figure out how to navigate that."

C. remains hopeful. If she shares details of her disability with her supervisors, maintains side deals and workarounds, she feels she should be able to transition to other roles as her condition progresses. Formal accommodations through HR, she fears, would limit her advancement because she would lose flexibility. "I think there is a lot more negotiation ahead of me," she said.

"I was never accommodated. It really made me question my career."

Meagan Gillmore cannot drive, and she cannot overcome this for any newspaper editor who wants to hire her for her writing chops. Premature birth left her with retinopathy that classifies her as legally blind. As the second-ever Canadian winner of a major international student journalism prize, she has much to offer any prospective employer. If only she could get through the door without a driver's licence.

This problem could seem laughable in the early of 2022, after many journalists have spent almost two years working from home during a pandemic, with little need to go anywhere but the fridge. But for journalists with visual and mobility disabilities, not being able to drive keeps them out no matter how talented they are.

Often, driver's licences end up as an informal screening tool for would-be journalists like Gillmore. As Dave Rudin wrote in "Dude, Where's My Car?" for a 2017 issue of the *Review of Journalism*, "a driver's licence can often be the closest thing to a required document when seeking employment in the field." He highlighted the *Toronto Star's* posting for a summer intern program that bolded this requirement: "A full, unrestricted Ontario driver's licence is **required.**" It is worth noting that Rudin wasn't writing this piece because he was worried about the fate of young journalists with disabilities. Instead, he fretted about the increasing number of young people "expressing indifference toward driving," and that makes them unqualified to work at the *Star*. (As noted in Chapter 2, in November 2021 the *Star* dropped the driver's licence requirement for 2022 student intern positions).

Gillmore has always worried that not having a licence would stand in the way of her employment, despite her record of achievement. A piece she wrote for her university newspaper in 2011 was the unanimous winner of the David S. Barr Award (College Division) from the American Newspaper Guild, which recognizes student articles that promote justice. She arrives at job interviews with the prize, strong clippings, and tenacity.

"I usually wait until halfway through the interview after I've sold myself to disclose that I can't drive. Then you just hear the balloon deflate," she told me. "I feel like I am the perpetual runner-up on *American Idol*, and I just can't get the record deal."

A job posting for *Yukon News*, a twice-weekly community paper in Whitehorse, did not mention the need for a driver's licence. This seemed like her chance, even though Yukon is a remote place where driving could be a necessity (unlike urban centres, where

Uber and taxis are common). “I decided I’m not going to get mad at journalism for not hiring me unless I give them the opportunity to fully reject me,” she said.

In the interview she confessed she could not drive and required text magnification software. To her surprise, the interviewer upsold Gillmore on the walkability of Whitehorse, with government buildings and landmarks closely clustered. She got the job.

Almost immediately, she struggled to get to assignments, having to ask her colleagues for rides or stand back as others with driver’s licences were assigned instead. She wondered if she could succeed as a journalist in Yukon. “Being published once had felt like a medal around my neck; now, with every typo, it felt like a noose strangling me, killing the image I once had of myself as an accomplished writer,” Gillmore wrote in *The Walrus* in 2020 (“The Author”).

Gillmore leaned harder on unique strengths that come from living with a disability. “If I want a source to go there, I leverage my disability, build some empathy. I probably ask different questions than others. I also have received government social assistance in various forms, so I get the situation of living on disability payments,” she explained.

Later, she landed a job as copy editor for Brunswick News in Saint John, where she edited news stories and proofed pages for English-language publications across New Brunswick, no driver’s licence required. The challenge was getting Zoom Texts for low vision installed on her work computer. She made a request on her first day, and when she left three months later, the accommodation had not been made, though she had disclosed her visual impairment. “Like in the Yukon, sometimes I’d be called over to look at stories on screen before going to print, to read the headline. I’d always ask people to read the

headline for me. I was there from Victoria Day until Labour Day and never once was this rectified.” She could do her job because she has her own electronic eyewear with remote control and magnification.

Gillmore, an excellent writer, is also resourceful and tenacious. The gatekeeper stopping her entrance into the mainstream seems to be ableism. And why, to be accepted, does she have to bring her own magnifying glasses, make repeated requests for software, and beg for rides to assignments?

In addition to freelancing for Accessible Media Inc., she began the Master of Journalism program at Carleton University in 2021. When I spoke with Gillmore in November 2021, the *Star* had just dropped the driver’s licence requirement for 2022 student intern positions. “It’s about flipping time,” she replied.

“My editor would be my hands and type my stories for me.”

Paul Taylor had been *The Globe and Mail* medical reporter for many years when he developed symptoms of repetitive strain injury (RSI) in the mid-1990s, first in his hands and then, after switching to a voice-activated computer, his vocal cords, “which were fried.”

I am interested in Taylor’s experience for many reasons. First, he had numerous people help him work around the RSI in his hands; at home, his wife transcribed his interviews and at work his editor typed some of his stories, as well as lightened his workload and duties. While RSI is invisible and it certainly was disabling, preventing Taylor from fully doing his job, it is unique because it is understood as a workplace

injury, he points out. News organizations can be accommodating when injury prevention helps the bottom line in the form of fewer claims and better insurance premiums.

After developing repetitive strain injury in his hands, wrists, and arms, Taylor filed a successful claim with the Workplace Safety Compensation Board (WSIB). Back at work after treatment, he said he was quickly accommodated because his boss, Paul Knox, had a brother who had lost his career as a pianist because of RSI in his hands. “Because you can’t see RSI, management thinks you look normal and you must be a bunch of malingerers and fakers,” said Taylor. “But I was saved because of Paul. I would go out and report my story and then I’d sit beside him and he would be my hands and type my stories for me. This was the level of extraordinary support I got.” To be clear, this kind of help wasn’t an official accommodation, but a workaround to help Taylor succeed. The official accommodation was a voice-activated computer to replace Knox’s typing. Unfortunately, Taylor developed vocal strain that again jeopardized his career. “It was primitive technology and you had to speak like a robot,” he recalled.

His second claim to the WSIB was at first disallowed after a Board medical specialist, who did not even examine Taylor, said his vocal injury wasn’t work-related. Taylor was off work for seven months.

Once back in the newsroom, he was offered editor roles that did not require much speaking. For a time, he was the head of the *Globe* summer intern program. “A year earlier, I was doing award-winning journalism and suddenly I’m ordering lunches for the students,” he recalled. “I became the poster child for RSI, and I didn’t like being seen as a victim. But I knew I was lucky and had to suck it up.”

The paper's management made him the health editor from 1998 to 2013, but he did not have to do paginating or layout, tasks that typically come with the role and require a lot of typing. "So I think it's kind of an example of what can be done to accommodate people, the maximum amount," he said.

As a medical reporter, he also supported his paper's efforts to deal with an increasing number of cases of RSI that hit newsrooms in the 1990s and early 2000s, thought to be due to touch-typing and poor ergonomics. "I did research and could point the way to what treatments and clinics were useful, and they used those resources for others."

As for why his employer worked so hard to accommodate his disability, Taylor thinks that because he had won several journalism awards, "no one thought I was malingering, so I had the foundation that I was well respected," he speculated. "Does it make a difference that I'm a white male? I don't know for sure. I also had a sympathetic boss. If all those things had not been together, I might have been looking for a new job."

He said the newspaper understood this could happen to other employees, so they needed to take it seriously. "With this particular issue, a lot of people were vulnerable to RSI, and it could hurt their bottom line if there were claims and insurance rates went up," he said. To Taylor, it also shows what flexibility is possible when a daily news organization is motivated.

"It's a miracle I kept my dream job for so long."

Securing a job as a feature writer saved my journalism career. Following a two-year stint as a city columnist, my lupus was in constant flare. I worked with chronic pain,

dangerously low white blood cell counts, and inflamed organs. I was lucky to have an empathetic supervisor. I am grateful every day for the opportunities I had, including working with McAuley, who was insatiably curious and an excellent editor. I wrote dozens of mostly long-form features on local, national, and international issues: from street preachers near Ottawa's Rideau Centre shopping mall to whales in the waters near Bermuda being harmed by Navy sonar, to fans who travelled to Princess Diana's favourite haunts a year after her death.

When McAuley came to me in the wake of the September 11, 2001, terrorist attacks with an assignment to track the Canadians who had died, I felt it was my civic duty but feared it would make me sicker. I had guarded my health since recovering from in-patient intravenous cyclophosphamide I received monthly for a year in 1999 and 2000 to knock back my defective immune system, and as a result I had had pneumonia once or twice in each of the previous two years. But after the collapse of the World Trade Center's twin towers, few Canadian names had been released. McAuley wanted me to uncover their identities, find their families, and describe their last hours alive.

The assignment reporters claim to hate most is the "pickup," where you reach the relatives of dead loved ones at their most vulnerable and ask, "How do you feel?" One is hard enough. We did not know how many had died. Five? A dozen? If it was a multiple vehicle car crash, the newsroom would dispatch numerous reporters to divide and conquer the pain. I asked a few colleagues if they would work with me. None would.

I spent weeks poring over photos of missing faces posted to online message boards and church websites with fellowship in Manhattan's financial district. My goal

was to do one emotional phone call a day until I had found as many victims' relatives as possible. Three weeks into the hunt, I was diagnosed with "walking pneumonia."

My eight-thousand-word story ran six weeks later, on October 21, 2001, identifying twenty-three Canadian victims. A few days later, the government released an official list of twenty-five names (*National Post*). I had found all but two in that pre-Google era. As ill as I was, I have always felt incredibly proud of the very long hours I put into that piece, with support from McAuley, who allowed me to work from home and take breaks throughout. Ultimately, I wanted to trace the victims' last hours. It was my choice.

Over the years, at both the *Citizen* and the *Star*, McAuley has been a confidante for struggling journalists. After the suicide of award-winning *Star* reporter Raveena Aulakh on May 27, 2016, McAuley was drawn into the subsequent internal investigation, as both Aulakh's direct supervisor and her good friend. After her death, in a statement published in the *National Post*, McAuley said:

I tried to my core to help Raveena, as did many others, over many months and countless hours. Her death is a tragedy, and we continue to mourn her. She was a gifted and brave reporter and a good friend. I always understood that Raveena and

I spoke in confidence as her privacy was important to her. (Craig)

McAuley told me that the privacy of her staff has always been important to her. She has worked with reporters who suffered from clinical depression and bipolar disorder, as well as other invisible disabilities. In one case, she recalled, "We chose assignments very carefully because we didn't want to cause any triggers. We did find ways to work with the condition, where they could do certain parts of a job but not others."

McAuley said secrecy and stigma are often behind the need for silence, but silence can have its own consequences. “I worked with one reporter who did not want anybody to know that they were having really bad bouts of depression,” recalled McAuley. “One day it just came tumbling out. But I had to promise not to tell anybody.”

She debated what to do. “Because of what had happened with Raveena, I was in a terrible position. No one would ever trust me again if I didn’t respect their confidence, but I knew I would have to escalate.”

In some cases, she said she has warned the person about to confide in her: “If you tell me this, I’m going to have to do something about it. I can’t just keep it to myself.” In other cases, she enforces boundaries on someone who is not coping well. “I say, ‘It’s okay if you’re struggling. Take a few days or we can postpone the story.’” Some people don’t want her help. “They say, ‘I don’t want you to make these changes for me. I don’t think this is any of your business, okay?’”

Since Aulakh’s suicide, McAuley spent some “sleepless nights” wondering where the line is — when does her responsibility include official disclosure for the employee’s own safety? “It’s a calculated risk,” she said, with consequences involving lives and livelihoods: “The worst thing that can happen is that I lose this reporter and the *Star* loses their talent and I’m not going to do that.”

McAuley retired in 2020, but in her last four years at the *Star* she found an HR person she could go to, still in confidence, and say: “‘This is a problem. Here is how I want to handle it. Can you help me?’ And we always found a way to do what’s best for the employee.”

In her career, McAuley has worked with several editors who “just don’t believe in any accommodation bullshit.” They think, “That’s not what you’re being paid for and we’re not going to entertain any options,” she said. If daily news organizations offered official accommodations for invisible disabilities, a journalist’s work-life experience would not be left to the whims of disbelieving editors.

All these issues are worse for young journalists who live “contract to contract,” McAuley said. The pandemic, gig economy, changing media landscape, and a climate of uncertainty discourage the sharing of health issues because “there is somebody right behind you who could get your contract. You have no security that way.”

There must be a better way, beyond treating journalists like automatons. What are the solutions? Flexible, empathetic bosses who run news organizations with the understanding that yes, even enterprising journalists are flawed people, vulnerable and strong, fallible, and tenacious.

Some might think my feature-writing job, never posted, and the flexibility to be sick at work (and home), was unfair. For me, the alternative would have been to leave journalism, and I’m grateful I did not have to, at least not then. Reading this, many might conclude I was not fit to work anyway and should have gone on disability leave for my own good, at least until my health stabilized. Truth is, no matter how many cytotoxic drugs I took, my health did not improve that much. I was in a permanent and exhausting flare. One of the joys and challenges in my life came from reporting for a daily newspaper. That feature writing job saved my career, if not my life, at least for a while.

Chapter 8: Write What You Know

As I drove to meet Francine and Luc Parent at the small white bungalow where they lived with their two sons, I was unnerved to realize how close it was to the Ottawa Hospital's general campus, as well as the Children's Hospital of Eastern Ontario. They once told me that wailing sirens passed so frequently that it sometimes felt like they were living inside an ambulance. As I wrote later in the *Citizen*, "The Parents live near the hospitals, the great grey monsters, out of grudging necessity. Yet, no matter how close they are, they often seem like an eternal voyage away" ("Test of Faith"). The hospitals up the road were a frantic two-minute ambulance ride or a hard twenty-minute walk while pushing their sons' wheelchairs.

Over the next several months in early 1998, as I probed the impossible box this family lived inside, I would pass the hospital more than two dozen times, until my personal sorrows no longer surfaced. But that first time, I pulled over on a side street and rested my head against the car window. It was February, six weeks since the Great Ice Storm of 1998, six weeks since I had been hospitalized at Ottawa General. The cold glass was pleasing against my cheek, grown round and hot to touch from another dramatic increase in prednisone dosage. Underneath my winter jacket, my skirt and turtleneck felt too tight. My body insisted on reminding me of what might have been.

When I finally arrived at their home, Luc and Francine told me I was a rare visitor. Even their family and closest friends did not want to witness the scene inside, where two profoundly disabled boys, wearing diapers, reclined in huge wheelchairs parked in the living room. A familiar antiseptic hospital smell permeated their home.

It was hard for Luc and Francine to name what was wrong with their boys, it was so strange and rare. Alexandre Parent, the older at thirteen, was born without a cerebellum, the part of the brain that moves muscles and maintains balance. Three years younger, Benoit was born without a portion of the brain that joins the two halves of the cerebellum. Most often the boys were labelled spastic quadriplegics, although there was no accurate label for what they had, except “unjust, unfair and inescapable,” as I would eventually write (“Test of Faith”).

The community averted its gaze from the sadness within that bungalow. Neighbours later told me that pregnant moms or one couple who were trying to conceive would not cross its threshold, because the boys were a reminder of everything that could go wrong in the pursuit of parenthood.

Standing in their living room, it seemed rude not to meet the boys’ blank-eyed gazes. Alexandre had black hair and dark, unfocused eyes. He would have been a tall boy, but his crooked spine had been broken apart and shortened by doctors so he could breathe more easily. His hips seemed to belong to a boy running in the opposite direction. “He has more metal inside him than the Six Million Dollar Man,” Francine told me. Music or a warm hand on his face made him smile. When happy, he made an arcing *aaah* sound. A low, rumbling *arrgh* signalled pain or distress.

Benoit, also legally blind, was almost comatose during my first visit, a side effect of his seizure medication. Without it, he had dozens of seizures a day. Like his brother, he reacted to almost nothing, but at least he was not in constant pain from torturous medical interventions. Luc and Francine refused to submit Benoit to all the surgeries Alexandre had had, because they could not stand to see him also suffer.

Disability Stories

The case of another profoundly disabled child, Tracy Latimer, drew me to the Parent home throughout that winter and spring in 1998, almost twenty-five years ago. Tracy's 1993 murder at the hands of her father, Robert Latimer, was again in the news. Like the Parent boys, Tracy could not walk, talk, or feed herself. She had the mental capacity of a four-month-old and endured chronic excruciating pain from repeated surgeries to mitigate severe cerebral palsy. The entire country had debated the case since the day her father decided Tracy's pain was too great and that keeping her alive meant torture, pumping exhaust fumes into his truck's cab, where she was strapped.

Robert Latimer was convicted of second-degree murder, but the case was appealed; a new trial was ordered and he was convicted again, but with a much more lenient sentence, which was also appealed. That winter, when I met the Parents and their boys, several groups had applied for intervenor status to act as Tracy's voice, the nation's conscience, during the coming appeal of her father's sentence.

I hoped to understand why Latimer chose to kill his severely disabled child while other parents soldier on, never giving up their lonely posts. The topic was intellectually interesting to me as someone passionate about disability issues and medical ethics. Emotionally, I was conflicted. But when I sat in my car outside the Parent home searching for the strength to go in, I convinced myself I was the only one who could write this painful story. The chronic illness that had dogged me during my entire journalism career and was behind my recent hospitalization gave me the insight and courage to bear witness to their lives. At least, that is what I told myself.

All these years later, as I recall those months, it reaffirms to me the importance of having journalists with disabilities working in daily news. Few readers of the *Ottawa Citizen* would know I lived with systemic lupus erythematosus that attacked my brain and internal organs and made me prone to miscarriage and life-threatening pregnancies. My disability was invisible. But my own suffering compelled me to tell the stories of others with physical and mental challenges, perhaps to make more of us visible. I frequently wrote about multiple sclerosis, chronic pain, rare diseases, genetic illnesses, and people needing organ transplants. I preferred the messy, unrelenting stories of ill health over a calamitous car crash. I felt my perspective was important, in part because it was so rare.

The lack of disability diversity in newsrooms leaves gaps in perspective and, therefore, in content. Readers are robbed of insights that would shape both individual and cultural attitudes about disability. Chelsea Temple Jones, an assistant professor at Brock University specializing in critical disability studies, conducted a 2012 literature review of journalism and disability from a Canadian perspective. Her search found chronic underemployment of journalists with disabilities in Canada, paltry coverage of disability issues, a dearth of disability activists as sources, and biased language. An unfair burden befalls the very few openly disabled journalists who might mitigate these issues. Writes Jones, “Researchers suggest that journalists — especially journalists with disabilities working in sometimes unaccommodating newsrooms — unfairly shoulder much of the responsibility of representing others with disabilities through their work” (“Literature Review” 83).

While I would never be a foreign correspondent or a political journalist, as I once envisioned, I could sit with families like the Parents and learn their stories. First, I had to

pass Ottawa General, and the alternative life I left inside, to get to their front door. An incident prior to meeting the family all those years ago proved to me that personal experiences of disability can elevate a journalist's work. It can even help win the top journalism prize in the country.

The Ice Storm

Six weeks before I met the Parents, on a Monday just after midnight, the first drops of a record-setting rain began falling in Ottawa. It was early January. When the rain hit lower altitudes, it froze, cloaking trees, power and phone lines, sidewalks, and roads with a glistening layer of ice. By the end of that day, power outages had spread across the region and emergency vehicles slid through icy streets to reach the storm's first casualties. Weather experts predicted the situation would get much worse.

I was eleven weeks pregnant. *She* — I imagined a girl — was the size of a plum.

On the Tuesday I worked from home writing a feature, while many of my colleagues were out interviewing people shaken by the storm. Through the patio doors I watched as endless sheets of icy spittle fell. On television, news footage showed people, like cartoon characters, slipping on driveways and losing their footing on sidewalks. Fractured people, fractured trees. Then my power went out. Listening to branches snap outside, I began to feel cramps in my abdomen. I found drops of fresh blood in my underwear. An hour later, there was more blood.

The city was a mess. I would never get an ambulance. I used my cellphone to call my husband to tell him that I feared the worst was coming, the end of what had been a mere fantasy.

We agreed I would drive the fifteen minutes to Parliament Hill, where he worked as a journalist in the Parliamentary Press Gallery. Then he would drive me the rest of the way to Smyth Road, to the Ottawa Hospital. As I inched along, passing abandoned cars, I saw that every naked tree along the Ottawa River Parkway had been transformed into shimmering crystalline figurines. By the time I reached Wellington Street, my cramping had evolved into a pain I had never experienced, like knife hitting bone over and over, deep inside me. I wanted to stop but I did not want to be that woman stuck in my car, ice droplets falling all around, waiting hours for an ambulance to come.

The triage team expected to send me to the gynaecological care unit, but I was writhing in pain, flopping like a gasping fish, so I was wheeled away from the ice-storm casualties — broken limbs, carbon monoxide poisonings, housefire burns, electrocutions — to an observation room. The obstetrician on call gave me an injection of something that ended the contractions abruptly. I fell back, exhausted and limp, while the nurse pulled my sweatpants off and wrestled my legs into stirrups. The doctor bent down between my legs with some sort of contraption — chopsticks, for all I knew — to remove the embryo that was caught in my cervix and which my body had been vigorously trying to expel.

Afterward, I needed a dilation and curettage procedure to scrape out any biological remains from my uterus to prevent infection. It required anaesthetic, a surgical room, and a gynecological surgeon. But elective surgery was cancelled. The hospital had sent non-essential staff home as the thousand-bed facility began operating in emergency mode on a backup generator. I was the only occupant in a communal room with eight beds. As people suffering from burns, heart attacks, brain aneurysms, and bad falls

descended upon the hospital, I waited.

My rheumatologist, Dr. Smith, came every day to visit because his weekly rounds were cancelled. I have always wondered if he felt guilty for encouraging me down the path to motherhood. This is the thing about lupus: it wreaks havoc on every part of your life. While miscarriage happens to many women, for those with lupus, it happens repeatedly. If you can stay pregnant, you are at risk of kidney failure, preeclampsia, premature birth, and death. It can also make you far sicker than you were before pregnancy, because it destabilizes your hormones and immune system. Even in pregnancy, lupus teaches hard lessons that shaped me as a human being, and therefore my journalism.

After the procedure, I emerged from the hospital to see splintered trees, their broken limbs crashed to the ground. The storm claimed as many as thirty-five lives, injured 945, and resulted in the temporary displacement of 600,000 people who lost power from downed electrical systems. Had it also marked the end of my hopes for a certain kind of motherhood?

I thought that no woman who hoped to become pregnant again would spend time speaking to families whose children had been born profoundly disabled. It would be a courage-killer. So why was I doing this assignment? I already knew the answer. Walking into the Parent family home, I summoned the wisdom of accumulated losses to tell the story of what happened when they became Mother and Father, twice.

Bearing Witness

Luc and Francine agreed to let me attend the boys' school, where profoundly

disabled children were integrated with the general population. I also joined them at swimming classes and church. Many days I sat with the couple, probing their belief system, their relationship to each other and to God. I was so weak as my post-miscarriage immune system ran rampant that sometimes all I could do was sit and nurse a cup of tea, tape recorder at my elbow, while Francine and Luc recounted their story.

Had they been born a decade earlier, Benoit and Alexandre would have starved to death in infancy. Had they survived those first odds, they would have been bundled off to institutions to live drastically shortened lives out of sight. Babies born with their conditions can't eat without choking, at least not without certain medical advancements. Now the boys were kept alive with feeding tubes, oxygen tanks, surgeries, and repeated medical interventions, which caused intense debates among medical ethicists, doctors, and the disability community. I hoped to convey all of this in the article I was researching.

Luc and Francine wanted people to understand that medical interventions had rendered them full-time care workers who made daily life-saving choices for their children with almost no financial or emotional support. Each day, they were expected to choose life, instead of death, for their boys.

The loss of pregnancy hormones made me feel awful, weak. Lupus is thought to be estrogen fuelled, although how exactly is not understood. I had sore joints, weakness, sadness, pain. My body insisted on reminding me of what I should have had. There were outward signs if someone had looked closely. Stuck between my usual weight and the departed baby bump, I did not fit most of my clothes. And in those eleven short weeks, I developed a pregnancy mask above my lip, across my cheeks. The dark, freckled skin

was pronounced, like the remnants of a long summer without sunscreen. And when I laughed too hard, I peed myself. That was not often.

Fortunately, my job as a feature writer meant I could get by with sitting, thinking, researching, interviewing, writing. Some days, my only exertion was getting dressed and making it to the newsroom, and then moving my fingers vigorously over my keyboard. I had other assignments during that time, mostly shorter features, and the occasional column. When I look back through the digital archives, I wrote some of the best stories of my life while I was briefly pregnant and afterwards. That job saved me over and over again. If I had been a salesclerk or a doctor or an engineer or an interior designer, the physical demands would have kneecapped me. I hid so many of my frailties behind a desk and computer screen.

I shared some of my struggles with the Parent family, who in turn shared many of their own, so much more profound and devastating. It was an exchange with a clear understanding that their disclosures would end up in print, whereas mine were a reach across the journalist-subject divide. Some journalists say you should remain distant and professional during interviews, while I chose to carry my personal experience of suffering as an expertise. I agree with Callison and Young, who wrote in *Reckoning* that calling for lack of bias in reporting is a trap: “The insinuation is that those who are biased “lack credibility and/or should be ignored completely.” Often, “bias” is a code for difference among journalists — and not, as we argue [...] a recognition of situated knowledge or expertise” (11).

Luc Parent always revealed so much in our interviews, usually at the kitchen table when Francine was at work and Luc had a day off. She worked for a homecare

association, finding help for ailing people. He cared for disabled adults. If there was one thing Luc and Francine knew how to do it was look after people.

Luc told me he often thought about Robert Latimer. He said not only did he refuse to judge him, but he also understood why he had killed Tracy. His own boys' lives had been so painful, especially Alexandre's. He had his tendons cut from groin to ankles so they would not seize up; surgeries where a string of vertebrae was removed so the spine could not twist; sharp bones puncturing lungs and liver; failed operations to insert rods to straighten spines; and hip replacements.

When the boys were little, Luc would come home from work and lie under their cribs, weeping, mourning the loss of an idealized fatherhood — playing catch, taking them to Scouts, coaching hockey. Luc blamed himself for their plight, convinced his sperm had been damaged from the industrial-strength chemicals used to clean the fryers at Kentucky Fried Chicken, where he had worked for thirteen years. One night, when the boys were elementary-school age, Luc got drunk, shut the door to the garage, climbed into the car, and turned it on. Francine heard the engine running and pulled him out, scolding him to get his act together. Unlike Latimer, he planned to kill himself, not his children, with carbon monoxide

Francine, too, prayed for God to take her children. After a decade of doggedly working to prolong the two boys' lives, she had come to believe additional medical interventions were not in Alexandre and Benoit's best interests. She did not want her sons to die, but she also did not want them to continue to suffer as guinea pigs. Luc reluctantly agreed that going forward, they would withhold care. They signed Do Not Resuscitate orders. If their boys developed pneumonia or began choking or had many seizures, they

would not try to save their lives. They told me their motivations were the same as Robert Latimer's: love and compassion.

That decision would be tested soon after, on Saturday of Easter weekend. While Francine was out shopping for the makings of a modest Sunday dinner, Luc returned home to find a scene that he and Francine had rehearsed in recent months. Alexandre was purple. He was suffocating on his phlegm.

The nurse was hunched over him, thumping his chest, and suctioning his air hole, calling for help. Alexandre was dying. Luc froze, thinking through his next steps, hearing Francine's voice. *No intervention. No resuscitation.*

At first, Luc held back as Alexandre retreated from this world. Then, with panicked desperation, he burst forth, shouting: "No, no, no! Alexandre!" He grabbed him from the nurse and began shaking the wind into him. Then he ran to call 911, summoning one of the nearby ambulances.

I visited their home on the Tuesday afterward. Benoit was at school. Francine at work. Alexandre still in hospital. Luc was in the kitchen making a series of telephone calls. To a priest to arrange Benoit's First Communion. To a doctor to make an appointment. To a pharmacist to order several prescription drugs. Overhead, a chopper passed on route to one of the Smythe Road hospitals and he said a little prayer for the sick child or organ recipient waiting for a heart on ice to arrive. The ordeal of Easter weekend weighed heavily on him; both having almost lost Alexandre and making the split-second decision to save his life. There had been tension in the home ever since. He maintained Francine would have done the same thing. She was not sure.

Francine told me later that she had two thoughts about the resurrection of her son.

She was glad he was okay, but she wished Luc had not revived him.

Luc and Francine sometimes talked about trying to conceive another child and wondered if they gave birth to a girl, would she escape what Alexandre and Benoit had suffered.

“You could adopt,” I suggested, trying out my own emerging idea for how to form a family. Francine, by then, knew my health history.

“Are you thinking of adopting?” she asked me.

A week earlier, I had sat in the exam room at the Ottawa Hospital as Dr. Smith scrutinized the results of my most recent blood work. Nothing looked hopeful. His scrawled notes from the hospital stay said it all. I requested a copy from the hospital.

Lupus worse since miscarriage. Chronic fatigue. Poor sleep, sometimes just three hours.

Problems with vision. Walks stiffly. Shooting pain in feet. Painful lungs. Red face.

Rosacea. Heart burn. Upper abdomen pain. Raynaud’s syndrome. Increased prednisone:

30 mgs (I had been on 10 milligrams previously). Increase azathioprine. May need chemotherapy: Cyclophosphamide. Ativan for sleep.

“You can’t do this again,” he said.

I did not argue. I did not have the energy or the hope. Remission was elusive, impossible for me at the time. That night, as we sat on the couch in our family room, I told my husband what Dr. Smith said. I can only imagine how hard it is to have a partner who is sick all the time, and then to learn that your patience and kindness is rewarded with more loss. As sad as he was, he never made me feel bad or blamed me for this setback. When I suggested we think about adoption, because I always think of an action plan to solve the latest challenge, he asked to sit with this heart break for a few days.

In late April, we visited the suburban home of an adoptive mom, who lived there with her firefighter husband and her two-year-old daughter. Another adoptive mom was also there, with her daughter, also two.

The girls raced around the living room while we asked the moms about adoption from China. They explained unique paths that put them on the same plane to Beijing a year earlier.

Afterward, we climbed into our car, both afraid to speak, unsure of what the other was thinking. He spoke first. "I want to do this," I remember him saying. "I can imagine that being our life, us being good parents to a little girl."

We clutched each other, wordlessly imagining the journey ahead. Over coming weeks, we made an appointment with the local branch of an international adoption agency. We knew we needed to select a social worker, who would evaluate us as parents. I knew my health would be an issue and perhaps having lupus would disqualify me as a candidate for adoption. I hoped not. These days, 90% of people with lupus have a normal life expectancy due to improved diagnosis and treatments (Vrooman Durning).

I felt better that I had figured out a path forward. It might be a little different than that of my colleagues who I sat around the work lunch table with, as they chatted about the trials of parenthood, but it was the best we could forge, even if less travelled.

Benoit Parent's First Communion was scheduled for May, after Mother's Day, now that a priest had agreed to give him the sacrament of the Eucharist, the body and blood of Jesus Christ. Most children who grow up in the Catholic faith receive their First Communion when they are seven or eight years of age because this is considered the age of reason. Some priests told Luc and Francine that boys like Benoit were not capable of

reason, and it was pointless to put him through this ritual. But Father Rochon welcomed Benoit into the group of children who would receive the Sacrament without making a big deal of his differences.

I saw Luc and Francine one last time that Sunday of Benoit's First Communion, where he would receive the sacrament, a wafer dipped in wine to symbolize Christ's last supper. They took a front row seat in the church, with Benoit between them. Alexandre was too unwell to be there. They hoped Benoit would be awake and calm during the service, but the organ music was provoking seizures and his body was stiffening, eyes rolling backward. They tried to quiet him.

Luc and Francine pushed Benoit toward the front of the church and he suddenly relaxed. And as the priest spoke of the importance of faith, Francine thought of how God may have chosen her to take care of her two boys. Luc realized it was faith that got him that far with the boys, helped him stick it out. Tears formed in their eyes. Benoit seemed to giggle. *Bravo, Benoit*, they whispered.

"A Test of Faith" filled ten pages of the *Ottawa Citizen's Weekly* on Sunday.

Afterward, Francine and Luc's phone, silent for so long, rang out with calls from family and friends and the disability community. Some apologized for being absent for so long. The Ottawa Hospital invited them to sit on an advisory board to review medical care and interventions for profoundly disabled children. The couple felt they had added to an important discussion about the costs and benefits of using advanced technology to prolong the lives of children like Alexandre and Benoit. And Tracy.

My story won the National Newspaper Award (NNA) for Long Features.

By the time of the awards ceremony, almost a year later, I was receiving cyclophosphamide, an intravenous chemotherapy that treats lymphoma, leukemia, and ovarian cancer and in lower doses is used for severe forms of lupus that attack the kidneys. The short-lived pregnancy and its aftermath of roiling hormones had turned my body against me. My kidney function was declining, even as I readied for a trip to China to adopt a baby girl.

In my NNA acceptance speech, I spoke of how medical technologies had prolonged the lives of Francine and Luc's profoundly disabled children but also sanctioned their torture, sentencing their parents to being lifelong caregivers. I stressed these as important ethical issues for society to address. I did not "out" myself to the assembled journalists as a colleague living with an invisible disability, nor reveal the many times I had pulled over en route to the Parent home because I was too fatigued to mount their stairs. I did not say I once dreamed of being a journalist who travelled the world, chasing scoops or daily deadlines, but instead, now travelled the landscape of people's lives. I was not the story — even though it was my own story that enabled me to tell this one so well. My job required patience, calm, compassion, and craft, and the willingness to sit and watch and work to understand. I could do all that within my limitations. It also required insight into human suffering, and I had that, too.

Alexandre and Benoit both died of pneumonia, in 1999 and 2002, respectively.

My husband and I adopted two daughters.

Chapter 9: The End's Beginning: Seeking Formal Accommodations

Late summer 2008, and I was so happy. Looking back, I wish I had never taken a long, slow suck of that moment, as if jinxing it. We were swimming in Hotel Lake near my parents' place in remote Irvines Landing, on the Sunshine Coast of B.C. The deep mountain lake, with a motel and campground straddling its far edge, glistened near the end of a circuitous road that wound past mountains. My eldest, then nine years old, soared high from a tree swing before dropping gleefully into the lake. My youngest daughter, six, rode in a huge inflatable raft as I swam behind, propelling her with a vigorous flutter kick. With each kick-push, I overtook the previous decades of ill health, buoyed by joy, my unconventionally formed family, and a successful career. And a lifejacket that finally fit, the right dose of immunosuppressant drugs.

The following day I developed diarrhea, fever, chills. It felt worse than a flu, more consequential. My husband took me to a local doctor, who did blood work. My C-reactive protein (CRP), a marker of inflammation, was 180 mg/L. Normal levels sit under 3 mg/L. Triple digits can signal inflamed arteries, an imminent heart attack, or severe infection. The local doctor felt strongly I was having a lupus flare or that I had an ulcer, based on the stomach issues. There is a huge delta between those hypotheses. The urea breath test she booked showed I was free of ulcer-causing bacteria. She told me to ramp up my modest 5-milligram dose of prednisone, to 50 milligrams.

Later I stood by the ocean, a bottle of horse-sized prednisone tablets in hand, talking to my Ottawa-based rheumatologist on my cellphone. He did not think I was having a lupus flare. Recent bloodwork had been normal, which suggested to him I had

an infection. He cautioned me against increasing my prednisone dose, but I craved a jolt of energy because my uncle's wedding was the following day.

Back in Ottawa, I went straight to my family doctor instead of work because I felt so unwell. She gave me a note prescribing six weeks off while the anti-inflammatory knocked back my uppity immune system because she, too, assumed I was having a lupus flare. While I had missed a week of work here or there for pneumonia, this was the first time since 1992, when I was hospitalized for lupus nephritis, that I was ordered on sick leave for several consecutive weeks.

This was also the first time I was prescribed a huge dose of mood-altering prednisone as a parent and I felt like Shrek, a monster yelling at my girls to stop anything, everything, nothing. When I saw how scared they looked, I would melt, telling them: *When you see Mommy is going to lose it, run away from me.* Sometimes the girls told strangers in grocery store lineups that when Mommy gets angry, run away. This latest dance with prednisone seemed worse than others. I screamed at pedestrians walking too slowly across the street. In a movie theatre, I clenched the arm of a woman talking during the previews — the feature film had yet to start. She yelled that I was assaulting her; I was furious I might miss the commercials. The prednisone, meant to heal me, made everything worse.

Six weeks of sick days went by with no improvements. Sitting hunched forward in discomfort in my GP's office, I begged her to test me for everything. I had my blood scrutinized and my stool studied; I drank contrast dye so my abdomen could be scanned. I had an endoscope rammed down my throat to examine my digestive tract.

It was not the wolf. It was a much smaller predator. I was diagnosed with *Dientamoeba fragilis*, a parasite that lives in the human bowel, in trace amounts, and is commonly found congregating in raw sewage, possibly flowing into the motel on the banks of Hotel Lake. I do not remember taking a big gulp of lake water, but I must have on that happy day. It would be worse for someone with my immune system, already battle-weary. I was prescribed anti-parasitics and tapered off the corticosteroids, and the doctor ordered me to stay home for several more weeks. I obviously could not foresee this uncharacteristic time off would lead to my undoing.

By the time I returned to work in early 2009, struggling to do my assignments while my churning innards slowly recovered, the focus, culture, and economics of the paper were changing rapidly. The *Weekly* feature section, home to so many of my stories, had been axed, along with numerous other sections. The new editor-in-chief of the *Citizen*, Gerry Nott, had been interviewing editorial staff to seek their input on how to improve the functioning of the newsroom. As I sat nervously across from him, chest thick with congestion from some unknown new assault, he explained there would be changes to my schedule. A new era of fairness was coming to the *Citizen*. I was no longer a feature writer or columnist. Not just because my section no longer existed, but because several colleagues had complained that I got to write features, columns, and work from home when I wanted. Amid shrinking revenues and a decline in staff, Nott said I was needed on general assignment. In addition, he urged me to return to working five days a week.

I told him about the threats to my health — the wolf and the microscopic organism, one stalking me, ready to pounce, one eating my insides. I also explained I had

been working three days a week because my mother-in-law was dying of cancer, and I was also finishing a book project. None of that was of much consequence. I needed to transition back to full-time as soon as possible. No more special deals and nothing personal, he said.

For twenty years I had been a contributor, not a shirker, first fighting for my job, then lauded for it — except by some colleagues, who apparently resented me. I felt oddly resigned. *I get it. I had a good run.* I was prepared to adapt. But I was surrounded by new supervisors who did not know my health history, or my writing, and were not that interested. When I tried to fight for my column, which had mostly focused on issues of interest to women and parents, few of my new supervisors had read it, though it had been a staple for years at the paper. Side deals for people with invisible disabilities are impermanent by nature (Chapter 7) and put us in a state of constant negotiation. I was starting from scratch.

If I was hoping to demonstrate to new management that I was a productive employee, it would have to wait. A chest infection I had been battling was diagnosed as pneumonia. Blood tests revealed my white blood count, platelets, and hemoglobin were in the basement, and my sedimentation rate was very high, at 52 mm/hr. My immune system was devastated from fighting the parasite. My rheumatologist ordered me off work again, and prescribed intravenous immune globulin (IVIg), an off-label treatment for lupus. We hoped these highly purified antibodies (isolated from donated blood and administered in a large dose through the vein) might block my white blood cells from gobbling up and destroying the healthy parts of me. Each transfusion lasted four hours, and I was to have six of them at the hospital spaced a month apart.

I began the treatment with hope, but there was only modest improvement. And I was running out of my six-month allotment of short-term sick leave. How could these three Ps — a parasite, pneumonia, and prednisone — rob me of my health so decisively? I reached out to the HR manager to advise her of my return. While I waited for a response, she snail-mailed me an application for long-term disability (LTD) benefits. I could barely look at the brochure or the form, with a blank space awaiting my signature. Instead, I emailed again to say I was showing up for work the following week. In response, I was told I needed a return-to-work plan from my doctor, signed off on by my direct supervisor, in conjunction with the Editor-in-Chief. The HR manager also told me I would be wise to ask my doctor to recommend accommodations to show that I was not well, otherwise any future LTD claim might be jeopardized by a perceived period of good health. My family doctor obliged and wrote what we thought was a reasonable return-to-work plan. As I was prone to infection and triggered by stress, I needed naps, rest breaks, and possibly, to work from home on some days. This was only for the first month. As my hours gradually increased, I would be working full days.

However, my supervisor emailed to say I wanted too many accommodations. How could they assign me stories, on the daily, he asked, if I occasionally needed to nap? I was not a feature writer anymore and needed to get with the program. I could not tell whether senior managers and human resources staff thought I was too sick to work or faking an illness to hold onto my “cushy feature job.” Both theories had been suggested to me.

To get back in the door, I pleaded with my doctor to drop any requests for accommodations, which she did very reluctantly. I was finally allowed back in the

newsroom just days before my six-month short-term disability ran out. This meant I was working without any cushion of sick days, on a high wire without the net. I was also anxious about daily deadline reporting, which I had not done routinely since I worked at the *Toronto Star*. Nonetheless, I began weekend and night shifts, attending press conferences, raffle winners, and scrumming local politicians, while taking one day off each month to receive the remaining IVIg infusions. I was exhausted. Then, something even worse happened.

I developed a fever and sore throat, then a cough and mild chest congestion, suggestive of H1N1, a virus that was sweeping the globe.

After a few days of feverish daily reporting, I went to the Ottawa Hospital's emergency department. In addition to an alarmingly high pulse, tests revealed my blood oxygen levels were low and one heart enzyme so high that it suggested I had had a myocardial infarction (MI) — a heart attack. An MI was also an idiosyncrasy of H1N1 in younger patients without cardiovascular disease. Over the next several hours I had an emergency echocardiogram and was examined by two different cardiologists who determined I had not had a heart attack and my heart muscle was not damaged. Eight hours later I was sent home with confirmed H1N1 and another sick note for my employer.

During the two weeks I was off work recovering, my husband worked days on Parliament Hill, where he was a political reporter for the *Citizen*, then drove to the suburban newsroom to fill in for me, doing police checks and filing briefs to fill holes. He worked my shifts because I had no sick leave left.

I had made it through the three Ps, but another P, the H1N1 pandemic, got the

beleaguered best of me. Because I had no sick leave left, I headed back to work after two weeks, struggling from assignment to assignment, sometimes sneaking home between interviews to lie on the couch. My supervisor urged me back to the office. No working from home. I was drowning.

One weekend, I lost my sense of smell and parts of my memory, both indications of active lupus. I was driving with my youngest daughter, then seven, who was in the back seat. I pulled up in front of the drugstore and just sat there. I had no idea why I was in the car or where I was going. I looked back at her and could not remember her name. The confusion on my face made her burst into tears. "Call Daddy," she cried. "Call Daddy." It took me ten minutes to figure out how use my cell. "I don't know where I am," I sobbed.

On Monday, I headed back to the hospital to get more blood drawn. I was a regular donor by then. Returning to the *Citizen* afterwards, my legs were leaden, my thinking confused. My doctor's receptionist called to book an emergency appointment. I was too sick to drive, so I called my dying mother-in-law to pick me up from work. As I waited for her to arrive, I gave my green potted plant to a colleague and put old newspapers in the recycling bin. I was pretty sure I was not coming back.

Mother-in-law said she had never seen someone so sick and still walking; considering how often she had been hospitalized for treatment of her terminal ovarian cancer, that was saying something. An hour later, I was slumped in a chair across from my rheumatologist. My white blood cell count was as low as it had ever been at 1.1 kilounits per liter (normal is between 4.5 and 11 kilounits per liter), and I was severely anemic. If I were to get a flu or pneumonia or any other infection, I might not survive. A

chest exam showed I also had pleurisy, which is inflammation of the pleural cavity, consistent with a lupus flare. The parasites, the viruses, the pneumonia, and the unnecessary prednisone, and the months of uncertainty and stress, had devastated my health. “You aren’t going back to work,” my doctor said gently, writing me a new note to make it official.

Riddle of Madness

I have considered the many ways I could write this next section. There were so many union lawyers, doctors, human resources staff, insurance representatives, and supervisors involved in the end of days. I have kept all the correspondence, including couriered letters from my employer, rejected return-to-work plans, as well as all my medical files. It could read like a whodunnit; how, after twenty-five years of soldiering on, I was felled by a parasite, pneumonia, prednisone, and a pandemic, as well as a failed fight for job modifications — things my doctor felt would help me manage, but my employer felt made it impossible for them to run a newsroom. What was considered undue hardship for my employer certainly created undue hardship for me. I have made it as simple and straightforward as possible, bringing as much fairness and balance to the recounting of events as I can, keeping in mind the limits of my perspective and my attempt to make the invisible, visible. Why do I write about this? Because a successful journalist, one with numerous accolades who brought her best possible self to work, lost her career when she could no longer cut side-deals within a system that lacked the will or flexibility to find a solution.

I left work just before Christmas 2009, with pleurisy, declining kidney function,

low white blood cell count, and, not surprisingly, depression. With no paid sick leave, I had to apply for LTD, a benefit with a top-up that I paid into for more than twenty years. The HR manager had been right; I should have applied for LTD the previous summer, instead of dragging this all out through the transfusions and the swine flu. Because I had not applied earlier, I would have to wait six months without pay to make an application.

If it was called “long-term sick leave,” I would have had less opposition to making an application. But I think it was in part the negative connotations around the word *disability* that I could not accept. It seemed permanent, biased, defeating. I had spent years telling myself, and those who challenged me, that I was capable and able. It just was not possible to think of myself as needing “disability” insurance because the “overcoming” narrative was essential to my identity.

There were my emotional hurdles, and then there was the system. I applied for Employment Insurance (EI) sick leave and began the difficult process of applying for Canada Pension Plan (CPP) disability benefits, in case the LTD I was waiting to apply for was turned down, which seemed impossible to me.

In late May 2010, after my fifteen weeks of EI sick benefits had already run out, I was interviewed by the insurer’s case worker, who was following up on my application to determine if I should receive LTD. She told me that she would recommend I receive the benefit and assured me that if the insurer’s in-house physician had any questions regarding my claim, he would ask my doctor for more information before rejecting me. As if in passing, she mentioned one small concern with my application. In one letter, my doctor had written that I was “virtually asymptomatic despite worsening kidney function.” After I hung up the phone, I panicked, fearing that offhand and erroneous

comment from my rheumatologist foretold the outcome. I quickly followed up with a voice mail — she did not pick up — and an email explaining that my doctor had mistakenly typed “asymptomatic” when he had meant “symptomatic” in my application. At the time, I was on 25 milligrams of prednisone, with the worst kidney function and white blood cell scores in many months. I also had bronchitis and was on antibiotics. I had symptoms!

A few days later, I was turned down for LTD. As my lawyer had predicted months earlier, the insurer wrote that although I been quite ill for periods over the past year, I had also demonstrated by my work that I was not totally disabled. Also, there was my doctor’s comment about being stable. When I asked the insurance case worker what to do, she told me to go back to work for a day, make another health claim, and then go on sick leave again. That way I might qualify for drug benefits again, which had been cut off.

It was a riddle of madness. I could not get back in the door because my employer would only let me return if I could do daily deadline assignments, which my doctor did not recommend given my pleurisy, bronchitis, and failing kidneys. Meanwhile the insurer thought I was fine and did not award me LTD benefits, so they suggested I return to work, and so on.

My union-appointed lawyer advised me the quickest route to getting benefits was to sue the insurer, otherwise he feared I would be turned down again, especially if the insurer again relied on an in-house physician instead of a specialist to review my case. Filing a notice to sue against the insurer would lead to mediation, and it could also take six months to three years just to get a date. I did not have three years. LTD only lasts for

two years, less the six-month waiting period. Again, I was running out of time. I was supposed to be focusing on my health but was preparing to fight a lawsuit.

By early August, eight months after abandoning my office plant in the newsroom, I finally had the kidney biopsy ordered by a specialist, months earlier. It revealed I had Class III lupus nephritis and the recommended treatment was another immunosuppressant called CellCept, or mycophenolate, used as a transplant rejection drug. Its side effects included severe nausea, gastrointestinal problems, fatigue, and insomnia. I was again prescribed high-dose prednisone. In the weeks after I began the CellCept, my dear mother-in-law died of complications due to ovarian cancer. As a journalist, I have interviewed many ailing people, so I have seen how hard life can be, but sometimes its assaults are relentless. We had been there for each other throughout our many health struggles. I would have to continue without her love and encouragement.

My mediation date with the insurer for LTD was set for January 2011, a full year after I had gone on unpaid sick leave. To me, it defied all logic and humanity that I would be denied LTD. I had been granted CPP disability payments of \$1550 a month using the same supporting documents I had submitted in my LTD insurer application. CPP was supposedly harder to get.

Meanwhile, the CellCept was horrid. I vomited constantly and normal life was impossible. I would take a bike ride with a friend and end up in the bushes, heaving bile. At home, I was expelling my insides on the toilet. My life was made up of tiny pulse points around childcare. Picking children up from school. Sitting on the deck watching swimming lessons. Driving my eldest across town to her gymnastics practice. Often, I had to pull the car over to sleep halfway to the destination, even on short trips.

My stomach was always worse around 9:30 a.m., about ninety minutes after I took the CellCept, around the time of day my LTD mediation was set to begin. On that Thursday morning, as if on cue, I vomited all over the table as the mediator and various lawyers looked on. The details of the mediation are confidential and off-the-record. All I can say is that afterward I could focus on getting better, at least for a time. My LTD benefits that I had been awarded would expire in just under a year, in mid-December 2011. Either I would be back on the job by then, or apply for permanent LTD, meaning I was disabled from the essential duties of my own and any other occupation.

At long last, my health steadily improved, especially after I switched to a generic version of CellCept that was easier on my stomach. As I did tai chi, travelled, and volunteered, I spent at least six months preparing to get back to work, again working against the clock of a timed sick leave, this time before my LTD ran out.

Around this time, I read a piece in the *National Post* written by a former colleague, Aaron Sands, who had been a crime reporter “until the stress of the job and the daily tragedies wore me down and out” (Sands). He disappeared to suffer alone from depression and PTSD, wondering what we all thought of him, while we all just moved on. I understood. “Coming forward to seek help for my illness amounted to career and social suicide for me — it’s been an extremely painful experience, worse than any nightmare I’ve ever had,” he wrote. “I lost my very promising career, my professional reputation, and many of the people I mistakenly thought were my friends.”

He added that he had been labelled a “psycho” because he had mental illness, and his “insensitive” bosses made fun of him. Shortly after he went on sick leave, he heard rumours that he had been “carted off to the loony bin,” while a former colleague called to

ask him if he was going to “‘commit a Columbine’ ... because, you know, I was mentally ill.” He has lived with the “pain, anger, shame, self-hatred and humiliation,” as well as the loss of his career. “I became convinced that I should have killed myself instead of coming out about it and seeking help. I have attempted suicide a couple times,” he wrote.

I felt heartbroken for him. I also wondered how I would fare as I laid out the details of my invisible disability to my employer, a strategy recommended by my lawyers, and again asked for accommodations. I did not think empathy would be part of the equation. As it turned out, it did not matter how iron-clad my doctor’s note seemed. After months of a frustrating back-and-forth between my employer, insurer, and my specialist, I would not be allowed naps, any working from home, or relaxed deadlines. The insurance company’s doctor said I was fine to do daily deadline work, no matter what my rheumatologist, a specialist, argued based on his reputation and considerable experience. The only accommodation I was granted was a desk down a long dark hallway out of the glow of fluorescent lights.

The long-sought return-to-work plan? I would start by writing obits, slowly increasing the number of hours I worked each day, and then I would go into the regular daily reporting rotation, including weekends, nights, and varied assignments on deadline. I reminded my lawyers that, except for a couple of weeks over twenty years, I had never done daily general assignment at the *Citizen*. I had been a beat reporter, columnist, and feature writer. These duties bore no similarity to any job I had previously done; there was no proof that I could be successful as a general assignment reporter juggling many and varied assignments while managing my invisible disability.

My return-to-work plan was delivered on a Monday, and I was expected to show up on the Wednesday. Even if I did not agree with the plan, my lawyers told me my choices were slim: stay off work and grieve through my union about the lack of accommodations or go back and see if I could handle it all. If I did not go back, they felt I would likely be terminated.

I did not want to lose my job that way. On Wednesday, I went to work.

I did my best, writing one obit a week as my hours increased, and when the subject was famous or remarkable, I pitched feature-length obits to showcase my skills. When I realized how much the deceased families appreciated the work, I created a business plan where the struggling *Citizen* would charge for in-depth obits and photo galleries of dead loved ones, which resulted in a meeting with the paper's executives and finance department and a feasibility study.

By the four-month mark, when I was up to eight hours at four days a week, I was pitching my own stories. One about pregnant girls and women in the 1960s who lived in a downtown Salvation Army home while waiting to give birth, and later had their babies taken away. I wrote about hockey players' wives with image disorders; gay teens with depression fighting for acceptance; a CBC radio host with cancer; a Ghanaian man who scammed a Canadian woman into marriage for citizenship.

While I had to turn the pieces around quickly, most got front-page placement and a lot of attention. The editors were open to other ideas, and I was doing my job, to the best of my abilities. I was advised that the Editor-in-Chief asked regularly if I was taking and completing daily assignments. My supervisors responded that I was doing what they

asked me to do. So, the insistence that I do daily general assignment was bogus, at least within the newsroom.

Still, I was very tired. Through all the bureaucratic machinations and harsh medical treatments, I had not had a chance to recover. My own needlessly high standards were dogging me. Walking in the door, rising to the occasion each day, proving I was a good journalist, all were taxing. At one point, after hospital blood work, the nephrologist on call phoned while I was driving home to tell me that my white blood cell count was again dangerously low. It was flu season. He recommended that I stay away from sick people and work from home if possible. My GP called afterwards, urging me to go to emergency if I developed any signs of fever or other illness.

In the olden days, I would just work from home until things normalized, or colleagues stopped coughing and hacking. After stewing for an hour, I phoned my insurance caseworker, who thought it was reasonable I work from home for a couple of weeks until my blood levels normalized. Because my insurer caseworker could not violate my privacy, she suggested I email my HR manager and tell her what was going on and ask her to work with my insurer caseworker, as well as my workplace supervisor, on strategies to avoid sick people, including possibly working from home. Five days later, after hearing nothing from my HR manager, I urged my case worker to call her with the suggestion I work from home. I was very scared of catching something. No dice. The HR manager told her that working from home would violate my RTW plan. If I really needed to, I could go on unpaid leave again. My RTW plan allowed no sick days for six months.

I remembered sitting at my desk, crying. I wondered how I was going to survive future flu seasons and flares when I had no one in my corner. I truly felt no one cared if I

lived or died, even when I was trying so hard. In that moment, I knew that I had to leave the newspaper. I was done; done constantly advocating for myself, done always trying to prove myself, done feeling bad for having lupus. I resolved that if a buyout was offered, I would take one. I just had to hold on until then, without being forced back on to LTD. When I shared what had happened with my lawyers, they urged me to file a grievance. I was too fed-up with the bureaucracy to mount another battle.

While waiting for a buyout to be offered (they came around about once a year at the downsizing *Citizen* in those days), I tried negotiating as much flexibility as I could with my newsroom supervisors, a.k.a. workarounds and side deals. I had been on this path before.

The managing editor, Andrew Potter, told me not to take any assignments that I thought might tax my health or expose me to germs. “Just do what you need to do,” was the message I got, as long as it was from the office. I interviewed him later for this thesis. He told me he was not involved in my drawn out and ultimately unsuccessful negotiations with the *Citizen*’s HR to win accommodations, but he was aware of my chronic illness and immune system vulnerabilities. He also thought that I had been accommodated. “Apart from the people who needed standing desks, I think you are the only one who had an acknowledged issue that we accommodated,” said Potter. “You were made to sit down the hall. And didn’t they put you on obits or something?”

I found Potter’s memory of my situation intriguing, considering I had spent much of three years going back and forth with my then employer, trying to get relaxed deadlines, the right to rest, the option to work from home when immunocompromised. Granted, he had left for another media outlet for a significant part of that time. It does

suggest HR did not consult the managing editor about my role and whether I was needed on general assignment.

If I had stayed at the paper, Potter likely would have provided me with workarounds and side deals to succeed at my job. As mentioned, those deals only last if the manager you made them with remains. Potter left for McGill University in 2016.

When we spoke for this project, he also called the requirement to make all reporters be daily news reporters an “artificial requirement” that does not reflect how the newsroom was organized. There were *Citizen* journalists who fought against daily assignments and were impossible to assign, he recalled, even though they had no accommodations for medical conditions. Newsrooms are filled with people with special deals, long-term assignments, beats, excuses, and bad days.

“It’s one of the quirks of journalism, this idea that journalists are all platoon soldiers, like everyone’s a rifleman, and we all need to be able to pick up a rifle and shoot, or anyone should be able to pick up a pen and go report cops, or if you’re a rock reporter you need to be ready to be assigned to Parliament Hill. Newsrooms don’t really work that way,” he said.

In July 2012, when a buyout was offered in the hopes of cutting excess editors, I took a serious look.

Figuring out an escape plan was one thing, deciding to leave was another. Being a writer and a journalist is central to my identity. It is who I am, how I express myself. I see the world around me in anecdotes that need to be told; I love probing people’s lives for hidden truths and insights about how we live. I had fought so hard to hold onto this career for so many years, was I really willing to walk away? I had proved I could be successful

and valuable under the right conditions. But those conditions seemed beyond my reach. I thought of all the unknowns. A flare that was always looming. The ongoing stress, which would get worse as the newsroom continued to cut staff. I longed for a stretch of good health, free of the need to negotiate for every bit of freedom, flexibility, and fairness.

That July, more than twenty people asked for the buyout. I was one of them.

My HR manager asked for a meeting to find out why I was leaving, and if things had “gone awry” again. Gone awry? That is a good way to describe life with a chronic illness, I thought bitterly. If I said I was unwell, I feared she would refuse me the buyout. I told her that in the current economic climate, my husband and I did not want to draw both salaries from the same paper. My husband would stay, while I would go.

The news travelled fast. Back at my desk, Potter approached. He said he was heartbroken to learn I wanted to leave and asked if there was anything he could do. I know I could have said that the job was too hard for me, and I needed more flexibility, and I likely would have gotten it, unofficially. But it would always be a negotiation and I was too tired to continually advocate for myself. I did not know what the future held for me, but told him no.

I was just done.

Chapter 10: (Not So) Accommodating: Can Newsrooms Make Room for Disability?

My former Carleton classmate Sheyfali Saujani called it a “coming out struggle” — a year-long sick leave from CBC Radio to come to terms with her disability, and other issues. “People who don’t think there is a stigma around disability should talk to someone who doesn’t want to accept their disability identity,” the activist and academic told me. “If it was okay to be disabled, everyone would come out.” Although legally blind, for twelve years she had never asked for accommodations to help her perform her Toronto-based chase producer job. Nor had any been offered. She contorted her body — and mind — to read scripts and research materials, held to her nose for hours at a time. But it was the emotional stress of attempting to excel at a role designed for someone with perfect vision that eventually overwhelmed her, compounded by incidents of racism, budget cuts, and layoffs at Canada’s national broadcaster.

A year later, after receiving psychotherapy to accept her disability, she tried to return to her job. Armed with medical proof that she is legally blind, Saujani sought doctor-recommended accommodations she hoped would make her work life more bearable and reading less painful. Reasonable requests, she and her union representative thought, such as modified deadlines and adaptive software that enabled screen magnification and text-to-speech reading. The technical support was relatively easy to get, but her previous current affairs chase producer job was suddenly considered beyond her abilities.

Her doctor had recommended that she work on assignments with three-day deadlines, and so her employer wanted to send her to work in the archives. They could

not find her a position in current affairs radio, even though “there are lots of weekly radio programs,” Saujani recalled.

“After a lot of back-and-forth, including a fairly aggressive stand from the union about disability rights accommodation,” she said she was assigned to work halftime in the archives and halftime for *Cross Country Check Up*, the weekly Canada-wide open-line radio show. Neither role took full advantage of her journalism experience. After years spent overcompensating in silence, Saujani was “suddenly seen as incompetent,” she said. “They just assumed because I was blind, I couldn’t do the work. But I was the same person, just asking for support.”

She remained in those non-journalistic roles for another twelve years, occasionally being asked to fill in as a chase producer, while channelling her energy and frustration into academic work, earning a master’s degree related to feminist historical theory. In 2017 she was finally rescued from her archivist role by a senior manager, who told Saujani: “We should treat people with disabilities better than this.” She returned to full-time chase producing in current affairs radio, as well as producing several specialty programs. In 2019, she took early retirement and is now a disability rights activist and academic, pursuing her PhD at the University of Toronto.

I revisit Saujani’s case here because, like me, she understands what it is like to seek help for an invisible disability and come out the loser. “It bears out our suspicions, right?” she told me. “We knew that we would be punished if we officially disclosed our disability, and we were.” Though our punishments took different forms, we both know how devastating and infuriating it is to face an intransigent bureaucracy that diminishes your abilities because you have a disability.

Since leaving my reporter job because I could not get my doctor-recommended accommodations, I have long wondered if other journalists with invisible disabilities have experienced similar challenges. As Saujani said, “Was it something we did or said, or is it the playbook they all use to bring us to our knees?”

Researching this thesis, I tracked down several journalists who worked in daily news with disabilities, until they could not find the support they needed. Some were fired for missing too much work, others forced onto long-term disability because their workplaces would not make changes suggested by medical professionals. A few gave up trying to work full time without accommodations and turned to freelancing.

I spoke at length with Aaron Sands, a former *Ottawa Citizen* colleague and crime reporter who suffers from intractable depression (and whose situation I described in Chapter 9). In the fall of 2021, he had been on long-term disability (LTD) for eighteen years. Like the others I interviewed, he still replays the circumstances of his career loss, as well as the twisted machinations of a system he thought was meant to help him. He wrote poignantly in 2011 in the *National Post* that instead of revealing he lives with depression and seeking help, he wondered if he should have killed himself. He added the stigma is so great his union representative had discouraged him from filing a grievance against the *Citizen*, saying “because of your illness, you have no credibility.” When we spoke, he told me that an investigation into how “the corporate world — and especially the vicious, macho news business — treats people with disabilities is so badly needed.”

“We need to start trying to understand the difficulties disabled people face, and the accommodations we need, so we can continue to contribute despite our disabilities,” he told me, adding, “There is a serious lack of empathy in this world.”

One former daily news journalist I interviewed, who has lupus and identifies as mixed race, recently showed me the termination letter she received from the news organization she worked at for fourteen years. Her employer said she missed too much work due to her autoimmune disease, a post-pregnancy surgery, and depression. Her health difficulties started two years after she was hired as a reporter at the newspaper, when she developed symptoms of lupus, including extreme photosensitivity, chronic unbearable pain, fatigue, anorexia, and mental confusion. “I looked like a skeleton, I could wrap my hands around my thighs,” she told me. “My face was on fire constantly. I was in so much pain I thought I might have a cardiac arrest. I’d almost go into a trance, where I was floating above like I was dissociating from my body.”

She took a series of short leaves, reduced work weeks, and then was off for an entire year. With the support of her doctor, she tried for a series of accommodations in the hopes she could return to work, but they were refused by her employer. At one point, she sued her insurer for her disability benefits, and then fought to get back into her workplace. A doctor hired by her employer to examine her suggested she take morphine for the pain and get back to work. “I really wanted to be vaporized. I was so angry because I was sick, and I wanted every trace of my existence on this planet burned,” she told me.

After a change in medication, her condition eventually improved. Her doctor agreed she was fit to return without the accommodations. It took more than four months of delays before her employer allowed her back in the newsroom. “They really didn’t want me,” she recalled.

Motherhood followed and she had two high-risk pregnancies, which required more time off, as did caring for them when they were sick. She also required surgery due to complications of one pregnancy. There were also episodes of depression, she attributed to having lupus, as well as her ongoing struggles with her employer. A psychiatrist told her she had “permanent psychological damage” from the stress of battling her employer and insurer, she said. At one point, her employer warned her that she had missed too much work, so she said she worked diligently to regain her professional standing and even won a respected journalism award for her efforts. She had been doing well but slipped into depression again and her doctor recommended more time off.

While on leave for depression, she received a termination letter from her employer, advising she had missed too much work, including absences related to lupus ten years earlier, pregnancy-related complications, and the depression. Times were tough, her employer said, and they needed a reporter they could count on. She was devastated, but in a depressive state, could not fight for her job. “The shame of it, the whole pregnancy and childcare stuff was behind me, and I should not have taken time off for depression, I should have just struggled through,” she said. “It didn’t occur to me they would ever use every single absence against me, or I’d be penalized for being depressed.”

She blames herself for her fate, not the fact that she wasn’t properly accommodated for lupus or depression. “Maybe I wrecked my life by telling everyone I was sick,” she wondered. “I’m a fairly healthy woman now, but I screwed up my life because it’s on the record now that I’m the sick one.”

With any termination, it is difficult to know all the factors that may have been at play in terms of performance, but there is no denying that having a complex disability

and being a racialized women were unwelcome complications. “It’s a bad combination,” she told me, with regret and anger.

We live in a world where journalists with invisible disabilities — rare autoimmune diseases, depression, and PTSD, among so many other conditions — are considered damaged goods. It is an unforgiving terrain to inhabit. We are treated as outliers, but we are not. We represent the millions of Canadians who make up the 20% of the working-age population with disabilities (Morris et al. 7). The machine that chews us up and spits us out works to isolate us. Many of us are enticed to sign non-disclosure agreements in exchange for severance packages. Sometimes, it only takes one person to cast light on a dark system.

I was already contemplating my exit from the *Ottawa Citizen* in May 2012 after poor health and a protracted fight for doctor-recommended accommodations left me depleted. Then I read Jan Wong’s self-published *Out of the Blue: A Memoir of Workplace Depression, Recovery, Redemption and, Yes, Happiness*. I devoured it all — the public and personal attacks she endured for a controversial story she had written, and how the former *Globe and Mail* foreign correspondent descended into a clinical depression and, unable to work, went on sick leave. A long battle ensued that she described in the book, with many grievances filed, arbitration, medical reports not accepted or not forwarded to the right contacts. She was eventually fired.

I could have mapped out the plot elements of her story without reading it. An employer thought she was faking, or at least malingering. An insurer did not believe her medical experts. She was turned down for disability benefits that she had paid into for years. Non-disclosure agreements were couriered to her door, which she would not sign.

The isolation and deception — her employer told her to disguise her absence as a book leave. She thought she would be inoculated from such treatment because she has been a decorated soldier, with tenacity and awards.

I asked Wong what her advice is to journalists seeking accommodations for an invisible disability. Although she does not recommend disclosing invisible disabilities until you have been hired and passed probation (see Chapter 4), she has a very different take on things once accommodation requests become official, and survival tactics are called for. “Go public, tell your colleagues,” she said. “If you’re caught in the system, get as much support as you can. They count on you remaining silent but speak up and neutralize the stigma.” She added: “For people in the media, it is soul destroying to keep secrets because our whole reason for being is to inform people. We tell stories, we fight secrets. Tell your story.”

I suspect there are dozens of us out there who went quietly with a package, disappeared onto long-term disability, or changed careers. The numbers are unknown, but this behind-the-scenes erasure adds to the picture of an unforgiving and ableist daily news culture. I interviewed current and former journalists, newsroom managers, union officials linked to all major Canadian news organizations, as well as representatives from some of those news organizations. While several tentatively agreed to interviews, only CP and CBC management followed through. My intent is not to prosecute any one organization but to understand what happens generally when journalists with invisible disabilities disclose their disability and seek accommodations. Is there really a playbook?

At the very least, there are general findings. From my many interviews, it seems

journalists who seek accommodations for disability, illness, or injury that has a quick-fix with new technology or short-term leave — such as a bad back, broken leg or a heart attack — will be supported. In addition, journalists who suffer what is perceived to be a workplace injury, like repetitive strain, will be accommodated to avoid claims to the Worker Safety Insurance Board that may increase an employer's premiums. Journalists who develop PTSD related to their jobs are generally not accommodated for a whole host of reasons, including controversy surrounding its definition and diagnosis, and doctor-recommended accommodations that often include significant changes to return to work (although that may be changing). Journalists with chronic health conditions, especially mental health issues and autoimmune diseases like multiple sclerosis, lupus, or rheumatoid arthritis, reported difficulty getting official accommodations.

Much of the above is similar to what happens in other workplaces according to the union representatives I interviewed, but what makes daily news organizations unique is the prevailing macho, competitive culture that disapproves of weakness and does not court workers with disabilities; and what makes this significant is that these organizations are therefore not representative of the audiences they so aggressively court.

Why Accommodations Are Difficult to Get

My research for this thesis was slow; those on long-term disability (private or government benefits), and those who were fired or quit or took a package, do not exactly advertise their situations. It took detective work to find former journalists to interview about their experiences. Securing an interview with Terri Monture, of the Canadian Media Guild, one of the largest media unions in North America, confirmed some of my

early research and my own experiences. She represents CBC staff on human rights and equity issues and has over thirty years' experience representing journalists at *The Toronto Star*, *The Globe and Mail*, *NOW* magazine in Toronto, and the CBC.

“Around the accommodation piece, employers are terrible, especially for invisible disabilities like mental health and episodic disabilities like lupus or MS or fibromyalgia,” she told me. “There’s this idea that you look perfectly fine, so you must be a malingerer, and this is the automatic judgment, despite medical certificates, even though the person may be on a merry-go-round of seeking a diagnosis. It’s the hypothesis of your thesis and it’s bang on.”

The CBC is different from most other Canadian news organizations because it’s federally regulated and must adhere to the Employment Equity Act, requiring employers to engage in proactive practices to increase the representation of four designated groups: women, people with disabilities, Indigenous peoples, and people of colour (in the act referred to as visible minorities).

Monture described in detail some of the challenges faced by media workers with disabilities seeking accommodations, adding that it’s not easy to get back into the workplace after receiving short- or long-term disability benefits paid by the company insurer.

In the spring of 2021, a CBC journalist with severe depression went back to work because her two years on LTD had ended, even though she was not ready. According to Monture, the woman’s doctor recommended a new role, one that did not include on-air reporting, but the corporation put her back in her old job. “She lasted two and a half

weeks on the job,” according to Monture. “Now she’s without benefits. It’s a mess.” She said forcing someone back to work before they are ready is counterproductive.

Rachel Desjourdy, senior specialist (accessibility lead) at CBC, joined the People and Culture team in 2021. She is driving the national accessibility strategy at the Canadian broadcaster. She has met with approximately sixty CBC employees with visible and invisible disabilities. They had similar comments to employees she has spoken to in other workplaces: “When I ask them to describe the accommodation process, they use the words ‘trauma,’ ‘policing,’ ‘not being taken seriously,’ ‘I feel like I have to defend myself,’ and ‘hostile.’ So inherent in our system is the burden of proof on the person with a disability,” Desjourdy said, who too often get the message “We don’t believe you.”

The analogy Desjourdy often uses is pregnancy. If a pregnant employee needs to adjust their work schedule because of regular doctor’s appointments, “I really hope that the next part of the conversation is not ‘I need to see your medical documentation to prove that you’re actually pregnant before we can go forward with making these arrangements,’” Desjourdy said.

In the case of invisible disabilities, “here’s a physical situation that requires flexibility that’s relatively simple to accommodate, yet we’re making it a big deal. And I think in most cases, invisible disabilities have the added challenge because it’s not visible,” she said, adding this applies to employers generally, not the CBC specifically. “It’s not top of mind, so even when they do have accommodation arrangements, they get forgotten or they get dismissed.”

Recent internal research showed of 603 people with disabilities surveyed, 64% said concerns about losing their current “accommodations” prevented them from

applying to other positions. “Whether that is self-accommodated side deals or formal accommodation it doesn’t matter, it’s impacting people’s mobility in terms of their career advancement,” Desjourdy said.

Jovane Drouin, CBC’s director of Equity, Diversity, Inclusion (EDI) and Engagement, said with respect to disclosure and accommodations, “We are not doing a very good job providing all the proper tools to help employees to self-report, and making sure managers know the process.”

In addition to the pregnancy analogy Desjourdy used above, Drouin mentioned other workplace “adjustments” granted to parents, including the ability to leave early for daycare pickup or work from home when children are sick. “Those adjustments happen frequently,” he said. But if someone with a disability asked for a similar adjustment, “It’s stigmatized,” he said, adding, “No one would call picking kids up from daycare an accommodation. It’s an adjustment or workplace adaptation. It’s a better way and it makes it not a big deal. We want to make receiving adjustments for a disability as normal and common as possible.”

He said managers need to be aware that most accommodations are very cheap and easy to make. “Very generally, the vast majority of accommodations cost less than \$500 and are not at all destructive on operations,” he said. (A 2020 report prepared for the U.S. Department of Labor’s Office of Disability Employment Policy showed that 56% of workplace accommodations for employees cost nothing to provide, while the remaining ones typically cost just \$500. Canadian employers, as with their U.S. counterparts, enjoy tax incentives for making their business more accessible (“Benefits and Costs”).

Drouin and his team have been discussing a “central accommodation fund,” a

possible solution to support employees seeking accommodations and help managers bring consistency to the process, “so we don’t have a request being denied because of funding issues.”

What Is Undue Hardship?

Daily news organizations, just like employers of all kinds, do not accommodate staff with disabilities for several common reasons, according to Monture. Generally, they have branded the employee a “malingerer” or a “liar” and challenge their medical certificate; they “won’t change their paradigm” for work assignments or employee classifications; or they don’t want to be flexible. Often, said Monture, there are claims the requested accommodations will cause “undue hardship” to the employer, who has a legal responsibility to make changes — up to a point.

Under the Ontario Human Rights Code (and other provincial codes), employers have a legal duty to accommodate the needs of people with disabilities who are “adversely affected by a requirement, rule or standard” (OHRC 28). The Supreme Court of Canada has ruled “the goal of accommodation is to ensure that an employee who is able to work can do so. In practice, this means that the employer must accommodate the employee in a way that, while not causing the employer undue hardship, will ensure that the employee can work” (28).

According to the Code, some degree of hardship may be expected — “it is only if the hardship is ‘undue’ that the accommodation will not need to be provided” (OHRC 49). Relatively simple accommodations may include making policies, rules, and requirements more flexible. This might be inconvenient, it states, but “inconvenience by

itself is not a factor for assessing undue hardship.” The Code prescribes only three considerations to assess undue hardship: cost, outside sources of funding, if any, and health and safety requirements, if any. This assessment belongs to the employer. “It is not up to the person with a disability to prove that an accommodation can be accomplished without undue hardship. The nature of the evidence required to prove undue hardship must be objective, real, direct and, in the case of cost, quantifiable.” If an employer claims cost as a reason for not accommodating a disability, the undue hardship standard is high, altering the “essential nature of the enterprise, or so significant that they would substantially affect its viability” (49). As with any law, it must be interpreted by people with various interests. What is reasonable? What is undue? What is breaking and what is bending?

Michael Lynk, associate professor of Law at Western University, has written extensively about disability discrimination and the law. He described the high standard for undue hardship. “It means [employers] have to take substantive measures to try to adapt the workplace to that individual.” He said the employee still had to be productive, but the employer must take measures — minor or significant — to reorganize the workplace, whether it is the physical architecture, exclusionary policies, and even discriminatory attitudes.

From a legal point of view, Lynk said, “we have what I think are a cutting-edge range of legal decisions [in Canada] that make it very clear what employers are supposed to do.” Though there is law, and there is application. “But I’m the first to say it’s probably an enormous gap between what the law requires and what employers actually deliver, because employers will only do this if they’re pushed,” he said.

He said the law on accommodation applies equally, whether you are missing a limb or have bipolar disorder. Employers must accommodate visible and invisible disabilities to the point of undue hardship. “And you can’t apply blanket rules,” Lynk said. If a daily news organization expects all journalists to be able to meet same-day deadlines, for instance, that could be interpreted as a blanket policy when “in order to treat people equally, you sometimes have to treat them differently.”

When I suggested that some of the journalists I interviewed took a termination package or buyout rather than make a grievance or human rights complaint, Lynk said, “It’s a bit surprising to me, and maybe to you, that journalists who would have at least one if not more university degrees, and advocate for other people, are poor advocates for themselves.”

Before making a complaint to a human rights commission, unionized media employees would typically file a grievance alleging a violation of their rights on the job — under the collective agreement or under legislation — which would be investigated and possibly arbitrated. Monture said journalists with disabilities, often exhausted or unwell from the fraught process, opt for an exit package instead of filing a grievance. In this way, journalists with disabilities seem disposable, Monture said. In October 2021, four months after I first spoke with Monture, she had just filed seven active “failure to accommodate” grievances against the CBC.

“I always say to the employer, ‘If you thought their skills were good enough to hire, then they’re good enough to retain, with whatever issues they have,’” Monture added. “Instead, they’re treating their once ‘best available candidate’ as a felon.”

She said journalists who have developed PTSD are particularly vulnerable to

mistreatment. A doctor might recommend that a journalist with PTSD avoid breaking news or deadline work, but many employers will not permit these changes, claiming “undue hardship” to the corporation. Never mind the hardship on the journalist, who got PTSD on the job covering natural disasters or gruesome murder trials. Monture specifically mentioned several cases that had caused PTSD in CBC employees, including the 2018 Humboldt bus crash in Saskatchewan; the 2010 trial of Colonel Russell Williams, former base commander at CFB Trenton, convicted of first-degree murder in the deaths of Jessica Lloyd, twenty-seven, and Corporal Marie-France Comeau, thirty-eight; and the 1995 trial of Paul Bernardo, who was convicted of murdering Kristen French, fifteen, and Leslie Mahaffy, fourteen.

“We’ve had reporters really damaged due to their work and the CBC claims it’s undue hardship to accommodate them,” Monture said. “It’s not undue hardship. It’s very easy to assign people to a specific story or a specific beat or role where they don’t have daily deadlines.”

I wonder about the “undue hardship” that employees with disabilities experience as they go through this onerous and unforgiving process. Why are so many of us made to suffer?

When *do* employers accommodate? “Unless it’s extremely easy to do with a shift change, reassigning somebody to a different manager, or maybe allowing more break time, they are really reluctant,” Monture explained. “If something more is required, they won’t trust the employee’s medical certificate, even when they’re supported by a company doctor. It’s ridiculous,” Monture said. “The immediate default is that they must be lying.”

Kathy Viner, formerly of the Canadian Media Guild, was the lead union staff representative for CP and Thomson Reuters (1996–2011). “Anything the employer couldn’t see was a fake,” she recalled. “It broke my heart that the starting point was to suggest that everyone with a problem was a malinger out for an easy cruise.”

When a doctor recommended that an employee with a disability or temporary injury should work from home, “the employer would come up with all these arguments, from the sublime to the ridiculous.” Among them: “What if the employee got hurt at home, or someone coming into the home for an interview got hurt, did they have the correct liability insurance?” Viner called this “absurd,” especially given the millions of people around the planet working from home during the COVID-19 pandemic. Did every remote worker update their homeowners’ insurance? she asked. Another objection related to preferential treatment. “The employer said, ‘If we accommodate you, there is going to be all this resentment and anger, and it’s seen as favouritism,’ which is, again, absurd in the extreme.”

Jan Ravensbergen, former president of the Montreal Newspaper Guild, described his experience trying to win accommodations for journalists with disabilities as “deny, deny, deny.”

“Off the top, they pre-screen before the hiring process, so the *Montreal Gazette* wouldn’t hire anybody with any kind of disability,” said Ravensbergen, who was active in the guild for twenty-seven years, and president from 2003 to 2006. If a union member develops a disability or injury and makes a claim for accommodation — rest breaks or occasionally working from home — he said the company will fight it as hard as they can. “They can’t see that journalists with disabilities have other abilities,” he said, offering an

example: “Say, you have multiple sclerosis or a visual disability. Other parts of your brain develop, and you have other skills. But the employer is indifferent to that. They want white-bread squares.”

Ravensbergen said the “easiest position to take is the most profitable one,” and the Postmedia-owned *Montreal Gazette* would claim “undue hardship” if they had to make any schedule or deadline changes to accommodate a journalist. He said he pities the journalist trying to get doctor-ordered accommodations because “it’s literally a fight to the death. The employee gets spit out. They can’t fucking take it anymore, so they opt to leave. Or at some point, a buyout will be negotiated.”

The opening position of the company is, “they’re just trying to get a free ride,” and that “transfers the burden of proof to the employee,” Ravensbergen said. The company or insurer-hired physicians offer “so-called independent assessment” for a price. “The companies that offer these experts know who pays the bills — the employer. They’re hired guns. He who pays the piper calls the tune.” Ravensbergen stressed he is speaking from his experience, and it is possible that workplace accommodations have improved at Postmedia papers. (Postmedia did not respond to a request for an interview).

Allegations that doctors-for-hire make it very difficult for journalist to get accommodations for invisible disabilities reminded me of what happened to Paul Taylor, former *Globe and Mail* medical reporter and editor, who developed repetitive strain injury (RSI) in the mid-1990s. After Taylor developed RSI in his hands, wrists, and arms, he made a claim to the Workplace Safety Insurance Board (WSIB), which was allowed. Later, using a voice-activated computers, Taylor developed vocal strain that jeopardized his career. He required seven months to rehabilitate his voice. He made a second WSIB

claim and was sent to be examined by an expert medical witness, who decided that the voice-activated computer was not causing the problem. "It was a new type of injury and there wasn't a lot of information on it," said Taylor. This expert shared his opinion with another doctor, who then provided an opinion to the WSIB. "This other expert never actually examined me but argued to disallow my claim," Taylor said.

He took both doctors to the College of Physicians and Surgeons of Ontario and "challenged the whole process," including "doctors being paid to provide opinions about patients." He explained to me, "I had covered the College [as a medical journalist] and knew it's a nightmare for doctors to go through. I wanted them to experience what I was experiencing."

His case worker eventually overruled the opposing medical opinions and allowed his claim, "I think because I worked at *The Globe and Mail*, and she found me credible." The College dismissed Taylor's complaint because "in their eyes" the issue had been resolved when the WSIB accepted his claim, which Taylor saw as "an easy way out for the college." But he learned that hired medical experts can foil the cases of ailing workers.

Not all union representatives share the negative perspective of Monture and Ravensbergen pertaining to the representation and accommodation of journalists with disabilities.

Paul Morse is president of Unifor Local 87-M, which represents 1,400 workers in Southern Ontario across many sectors, including journalism, broadcasting, audio-visual, education and not-for-profit. Its members work at *The Globe and Mail*, *The Toronto Star*, *The Toronto Sun*, *Maclean's*, and CTV, among others. He said the union is advocating

for inclusion of more Indigenous, Black, and other racialized workers, especially in news organizations, but “disability has not been identified as an issue,” adding the union representing journalists at media outlets had not surveyed members to gauge its importance. As for what is being addressed, he has a positive outlook for progress. “Discussions are around the very pressing issues around equity in the news media and about BIPOC issues.” He said the union is in talks with various media organizations’ management to “make more than the incremental progress around these issues with a number of policies.”

On the issue of supporting journalists with disabilities, he said “there isn’t a lot of data,” but he believes the “union is actually at the forefront of advocating for representing disability accommodation in the workplace. There should be no barriers to them working in news.” He said union involvement in employee requests to accommodate disabilities is “rare,” usually connected to a mental health or substance abuse issues.

In those cases, “We have a very strong track record of being able to advocate for those folks, we know what the laws are and employers, for the most part, know what the laws are. And we reach resolution fairly quickly.” Morse has not heard of the “undue hardship” position being used by news organizations as an excuse to avoid accommodations to members.

As an example, he said the *Toronto Star* has been “very accommodating” and certainly provided the ability to work from home when required, as well as equipment necessary “to do the work of a full-fledged journalist.” He used examples of visually impaired journalists. For other types of disabilities, “we have provided paths for those folks to get modified and return-to-works that are necessary.”

Asked about winning accommodations for journalists with invisible or episodic disabilities, he said “I don’t have any direct experience with problems around that,” but added, “hypothetically, where it is an issue identified, there is a process that will allow an employer to accommodate that issue.”

Working Together on Solutions

Paul Woods is a former journalist and HR executive who worked at CP and briefly at *The Toronto Star*. I spoke with him about the recruiting, inclusion, and accommodation of journalists with disabilities and what claiming undue hardship can mean for a daily news organization. He used the example of a journalist with a disability who is also the only person in a bureau, such as city hall or a rural location. “If that person were to need to be accommodated so they can manage the bureau, what are you going to do? Hire a new person? That would mean an extra cost for the news organization, so maybe instead that person might not be accommodated.”

I asked him specifically about accommodating people with episodic or invisible disabilities like mine. His outlook was lukewarm. “It’s a very sad thought that the answer to that question might be that journalism just never can accommodate it. I hate to think that’s true, and I guess maybe in my naive, optimistic way, I don’t believe that’s true.” To include journalists with disabilities, accommodations must be “driven from the top, and leadership has to embrace it and has to drive it down to the resisters,” he said. “And there’s going to be resisters in management.” When a journalist gives up and leaves because they are not granted accommodations, he said, “upstairs in the executive suite there’s some who are high-fiving each other because we got rid of two problems.”

Woods talked about CP's hiring blind journalism student Michelle McQuigge directly out of university in 2006. He got a call from an instructor at Ryerson University's School of Journalism who described McQuigge as an outstanding student who was not getting any offers, despite sending out many applications. "I sat in on the interview, conducted by two newsroom managers, and they both came away like, 'Wow, we've got to hire her.'" Woods said "it took some juggling," including changing the office's keypunch entry system and accommodating her service dog.

"In that newsroom, Michelle raised the consciousness of everybody, managers and staff, that there is value in diversity, there is value in having people that don't fit the so-called norm," he said.

Fifteen years later, McQuigge is a leader and a role model, both for visually impaired journalists and for others with disabilities. In November 2020 she was promoted from writer/editor to CP's assistant weekend news editor, and then, a year later, into management as weekend and special projects editor. Before her promotion she chose to write about disability issues in her spare time, in stories that ran on news platforms across Canada. And within CP, she led an initiative to make progressive changes to the *CP Style Guide* on how disability, accessibility, and ableism are written about.

Andrea Baillie, editor-in-chief of CP, said now that McQuigge is on the management team, she is "excited" to see how she will influence decision making and coverage.

When CP put in a new content management system (Superdesk, by Sourcefabric), McQuigge worked with the developers to make it accessible to the visually impaired. "They hadn't had that opportunity to do that before, even though it's used by half a dozen

wire services [around the world], so that shows how few visually impaired people are working at news services. Maybe none,” Baillie said.

McQuigge challenges assumptions throughout CP. Said Baillie: “Every once in a while, I think, *how does she do it?* It kind of blows my mind.” McQuigge’s presence and her success in her role challenges Baillie to hire more people with disabilities, which she admits is difficult with so few open roles and current priorities to hire racialized journalists. “We’re working right now on our hiring practices to make them more intentional,” Baillie said. Like many media outlets, “we want to recruit more diverse candidates so our newsrooms can be more diverse and more accurately reflect the communities that we cover.”

Baillie suspects there are already journalists with invisible disabilities working at CP, they just do not disclose. She said staff surveys — “even with the best of intentions” — have not been effective in getting a true picture of CP staff. “What would it take for them to feel comfortable to share that information?” she asked, adding: “I don’t think they would disclose unless they absolutely had to.”

Woods blames the unwillingness to accommodate journalists on the adversarial climate in unionized news organizations. “I think these things are done so badly because of the history of management fighting with unions and unions fighting with management. Rather than focusing on issues that need to be solved and working together, like accommodations, both parties dig into their trenches,” he said. “The more adversarial power-based approach, where you choose to fight over finding a solution, is part of some news organizations’ cultures.”

“We have to think creatively,” the CBC’s Desjourdy said. “There could be

accommodation processes that allow workers to job share, optimizing your skills within your unit or team by “bartering elements of your job description.” As one example, “Job description A requires these skills and job description B requires these skills. We’re going to get A and B done, but it requires two people to do elements of both, based on their skills,” she said. “That requires corporate and union structures to support job sharing within the organizations.”

She said management must trust workers with disabilities more. “Really early in my time at CBC, someone told me, ‘I have had a disability my entire life, I would say that I’m an expert in my lived experience, but I am not an expert in my accommodations, which means that I would still benefit from resources, suggestions, and advice in the workplace.’”

Desjourdy added: “My hope is that we can move forward as an industry and be a bit more innovative with our ways of doing things, so we can harness the talent that is all around us.” She said, “I see a lot of barriers to entry; people have a hard time accessing a career in journalism.” As an example, she cited not being able to drive as a barrier to becoming a journalist. “Unless you can work in an urban environment that has good public transportation, that will make or break your experience.” She said media organizations should be open to other modes of transportation.

The CBC Ability Crew Placements for Excellence (CAPE) Program was launched in 2019 to kickstart the careers of people with disabilities by eliminating barriers to employment and showcasing their talents. There are ten positions, mostly as researchers, across the broadcaster during the annual twelve-week program.

Nick Davis, CBC’s executive director, Equity and Inclusion, said the CAPE

program “sends a strong signal that we see the value of having persons with disabilities as part of our team.” Once journalists with disabilities are “embedded within the CBC, everyone realizes they’re no different or maybe even better than anyone on their team.”

In the 2021 cohort, seven of the ten who were hired had invisible disabilities, ranging from visual and hearing impairments to multiple sclerosis and mental health issues, Davis said, adding the majority who participate in this program are retained. “Our goal is that in the future, we don’t need a CAPE, and instead we’re just hiring people with disabilities as part of the regular process,” he said.

The interviews I did suggest that ableism at news organizations does not just dictate hiring processes, it also infests management and HR policies and procedures. This leaves journalists with disabilities hiding in plain view, or outside looking in. More research is certainly needed on the make-up of news organizations and the number of journalists with disabilities, their accommodation needs, and related issues. In addition to revisiting the qualities and characteristics needed to diversify news organizations, the sector needs to find and support those with disabilities who are already there. This isn’t an indictment of any one news organization but a call to action: meant to raise questions about how ableism dominates news organizations and keeps journalists with disabilities on the sidelines.

The litmus test for all this is when an employee, in this case a journalist, feels they can safely disclose their disability — from bipolar disorder, to MS, to lupus, to rheumatoid arthritis, to irritable bowel syndrome — and they will not only be accommodated, but treated with empathy.

Chapter 11: Lost and Found Voices Write about Disability

Journalist Steven Ladurantaye launched his personal newsletter, *Broken Brain Journal*, with a haunting scene near train tracks outside of Glasgow:

I'm thinking the express to Edinburgh is the way to go, and this time I won't need a ticket. Whoosh [...] I called an ambulance two hours ago, telling them I couldn't control the racing thoughts in my head and was pretty confident I was going to kill myself. The first dispatcher stays on the line for a half-hour and then says she has to take more urgent calls. The second lasts 20 minutes, then calmly explains she has to go too. Call back if things worsen, she says, as if they aren't bleak enough.

Ladurantaye, then Head of News for the Scottish broadcaster STV, confessed in this post to a prolonged two-year meltdown, his brain "cycling out of control. All I can think about is dying, and with each passing minute, it becomes less abstract and more matter-of-fact." What he was experiencing, he wrote, was like mental whiplash. While there were no voices in his head, he dipped "in and out of rational thoughts (there's a store on the corner, we need milk ... the train will be here in six minutes"

An evocative, edgy writer, he described the wet-stick-snapping sound of his mental collapse. He had been medicated on-and-off for depression since his mid-twenties and had bouts of prolonged, unexplained hypomania. His hyper-productivity probably helped him drive up important metrics at STV, where he had been lured from the CBC in 2018. But he became agitated, illogical, confused, and overmedicated, which only increased his mania. By the time he ended up beside the train tracks, he could see no way

out of his suicidal fugue. It took the British transport police to rescue him; he ended up in a psychiatric hospital, where he received a bipolar diagnosis and better meds.

After he resigned, in October 2020, his employer issued a press release: “Steven Ladurantaye has resigned as STV’s head of news and current affairs for medical reasons around mental health, for which he is receiving treatment.” The spokesperson added his “alleged inappropriate conduct” was also being investigated, after *The Times of London* reported he had offended some female staffers (Horne).

I met Ladurantaye in 2006 when we were both up for an investigative award from the Canadian Association of Journalists. We sat beside each other. He was quick-witted, fast talking, fun. He was at *The Kingston Whig Standard*; his impressive rise within Canadian journalism was about to begin. Soon, he would be at *The Globe and Mail* to report on media, and then become head of news for Twitter Canada. Later, at CBC, he rose to managing editor, in charge of rebooting the flagship news program, *The National*. After Ladurantaye joined a Twitter discussion that was seen by many to make light of voice appropriation as an issue in Canadian fiction, Ladurantaye was very publicly reassigned in 2017 to the CBC’s Content Experience area (Raynor). In 2018, he left for STV.

The *Broken Brain Journal* launched in February 2021 on the paid newsletter platform Substack, to offer “insight, updates and hope” so others find help for mental illness. His is also an attempt to explain his erratic behaviour. “This [journal] attempts to explain a lot of my behaviour and be a voice for those who have these problems in various forms but can’t write or figure out how to work a website. And I can do all these things and be outspoken.”

Legacy news media such as the CBC, *The Toronto Star*, and CP, among others, have publicly committed to bringing more racialized journalists into their newsrooms to diversify their overwhelmingly white staff. CBC also committed to hiring more staff with disabilities, stating a goal for 2022: half of all new hires for executive and senior management positions will be Indigenous people, visible minorities, or people with disabilities; with plans to double retention and promotion rates for people from those three groups. As a Crown corporation, the CBC/Radio-Canada is mandated to reflect Canada's diversity in its workforce.

Outside the public broadcaster, hiring journalists with disabilities, arguably the most marginalized and disadvantaged working population in daily news, is not a publicly stated priority. Without a place to practice their craft in traditional news media, many find other means to create and be heard. The efforts of journalists with visible disabilities — such as those who use wheelchairs or guide dogs — to utilize alternative media has been documented by Jones in 2019 and Jones and Saujani in 2021.

In this chapter, I focus on journalists with invisible disabilities, including myself, who are attempting to counteract our erasure, tokenism, and insecure employment by writing our own professional identities. To find a place for our missing voices — and expertise — we are seizing the opportunities available on new platforms to write or broadcast confessional posts, memoirs, and 'coming out' pieces; some appear as one-offs on legacy media platforms, while others, like me, use personal blogs, podcasts, or newsletters. As mentioned previously (Chapter 3), for three years I wrote a personal blog titled *The Sick Days*, to document my experiences working as a young journalist with lupus. The blog, which garnered positive feedback and a decent thirty-thousand views,

inspired this thesis, and I have revisited past posts throughout this document.

There are others like me. I will provide several examples, including a more in-depth exploration of writers Diane Sims, Jaclyn Law, James Davidson, and Ladurantaye, who have used various platforms to share difficult health journeys, while building community and educating niche audiences. Traditional media do not include their voices or typically report on issues they champion in the mainstream.

Countering Erasure Through Lived Experiences

Callison and Young noted in “‘Speculative’ Memoir Fragments and Existential Dilemmas,” a chapter from their 2019 book, *Reckoning: Journalism’s Limits and Possibilities*, that racialized journalists are using alternative platforms to “make sense of the limits of journalism — and its possibilities in near real time” (99). These journalists are struggling with an existential crisis, issues of “truth, subjectivity and power,” as well as how to narrate oneself in a global journalism landscape with multiple colonial histories. Callison and Young focused on the confessional efforts of Indigenous, Black, and other racialized journalists, drawing on a range of memoir fragments, including a Vice Media series of behind-the-scenes first-person animated graphic videos titled *Correspondent Confidential*, as well as pieces of “quit lit” in which journalists explain their reasons for leaving journalism or for doing it differently. Among their examples is Sunny Dhillon, who quit the *Globe* in 2018 and wrote a much-quoted piece on Medium, “Journalism While Brown and When to Walk Away” (100).

Callison and Young argue marginalized journalists are creating an “emerging meta genre” as they “publicly try and make sense of themselves and of what journalism is

trying to do — and when it does not work — in a moment when journalism’s dominant aspirations are being challenged and commercial models are failing with no road map in real time” (81). This new genre is a reaction to legacy media’s idealized “view from nowhere” that reinforces the false god of objectivity, while upholding “white masculinity” and maintaining “social orders,” at the same time ensuring the “structural subordination” of racialized, gendered, and Indigenous groups (5). The universal human condition, in their view, has historically been funneled through one very specific lens.

The authors contend that “these life story fragments become a means to access and assess a journalist’s navigation of subjectivity, distinct from previous forms of journalistic autobiography and memoir” (87). Given the “shifting political economy of North American journalists and the market failure of commercial media in a media system defined by commercial media,” the authors consider this emerging genre worthy of further study (102). Journalists with disabilities are also be affected by the economic conditions that gave rise to this meta genre for Indigenous and racialized journalists, and I argue, are also writing to make sense of where we have found ourselves, mostly on the outside of mainstream media.

Journalists with disabilities — not part of Callison and Young’s analysis — may not be grappling with the long arm of colonialism, but we are dealing with the pervasive blanket of ableism that smothers daily news media. I have found that journalists with disabilities also use memoir fragments, tapping into this “emergent ethical meta genre” (81, 106) to educate, enlighten, and situate our experiences working within daily news organizations, or around its edges. We expose ableism, give voice to our own experiences of marginalization, highlight disability issues not covered by legacy media, and attempt

to build community.

Chelsea Temple Jones is one of few academics to study the intersection of media and disability in Canada. She points out that the *Star* discontinued its disability beat after Helen Henderson, who had multiple sclerosis and spearheaded the initiative, retired, leaving a gaping hole in mainstream coverage. Jones points to new and important means to explore the issues that might be just as valuable, if not more so. In her 2019 “Dropping the Disability Beat: Why Specialized Reporting Doesn’t Solve Disability (Mis)representation,” Jones argues advocating for a mainstream disability beat overlooks “alternative” or “dissident” media that are free to deal with disability differently (331). She provides examples of alternative disability media, including the Canadian lifestyle magazine for people with disabilities, *Abilities* (1986 to the present), and a late-1990s radio/television show from CBC, *Moving On*. These productions tied audiences to local, accessible community events, going beyond the “traditional journalistic news values of objectivity and non-bias,” writes Jones (333). Content not only reflects the disability community but supports it. She also cites the use of social media as an effective tool for advocacy and community building, listing the trending hashtags #CanadiansWithDisabilitiesAct and #wheelchairsarentluggage. Jones also suggests a new framing mechanism is emerging: autobiographical writing, citing the late Barbara Turnbull’s memoir (“Literature Review” 91).

As Jones points out, a lack of disability coverage in legacy media means disabled journalists who pick up the mantle don’t just write about it, they act as default advocates, activists, and community builders (“Dropping the Disability Beat” 332). Advocacy and community building are the hallmarks of alternative media, according to Kozolanka and

co-authors in the 2012 essay collection *Alternative Media in Canada*, which explores the evolution of Indigenous, ethnic, and feminist media against the backdrop of political, historical, economic, and cultural developments in Canada. Kozolanka and colleagues, like Callison and Young, did not include in their research publications focused on the disability community or disability issues. In their introduction, “Considering Alternative Media in Canada: Structure, participation, activism,” they stressed how necessary alternative media is for giving voice to marginalized communities and individuals (16). Disability, despite being left out, applies here, too.

Before diving deeper into the memoir fragments of journalists with invisible disability, I will explore the powerful impact one journalist can have working in the mainstream.

Michelle McQuigge, who is blind and uses a guide dog, drove disability-related coverage in media outlets across Canada over the past few years, since everything she wrote for CP when she was an editor/reporter was distributed widely (“Hello Lucy”). “The issue of disability in journalism is not one that I feel gets as much scrutiny, especially at a time when there is much more focus on diversity initiatives,” she told me. She acknowledges “some people don’t want to be the disabled reporter who only writes about disability issues — that can be a poor look.” (McQuigge herself tackles many issues beyond disability.)

“I believe I have something to contribute to the conversation in a meaningful way.” As examples, in 2017, McQuigge wrote about a discriminatory VIA Rail policy that forced a married couple, both of whom used mobility scooters, to travel in separate cars on the same train; in 2019 she tackled the federal accessibility bill, and in 2020 the

inequitable treatment of Canadians with disabilities during the COVID-19 response, among other disability-related topics.

When she was promoted to CP's assistant weekend news editor in October 2020 the news agency's coverage on disability issues seemed to disappear, based on my unscientific search of the issue on Google News. Editor-in-Chief Andrea Baillie expressed surprise in an interview when I pointed out a possible unintended consequence of McQuigge's promotion to full-time editor. Baillie explained that COVID-19 overtook the agenda, but she hopes CP will resume covering disability issues, as well as make the hiring of journalists with disabilities a priority within her tight budget.

Meanwhile, in her supervisory role, McQuigge continues to question norms. As CP discusses ways to diversify its staff amid limited available hires, "Michelle is at every meeting, asking, 'What about disability?'" said Baillie.

Journalists with Invisible Disability Defy Marginalization

My experience with invisible disability is deeply personal, episodically painful, consistently fatiguing, and impacted every part of my career. I would eventually share parts of my experience in columns and feature stories in the *Ottawa Citizen*, and then, after my journalism career ended, in a personal blog where I wrote about old-school sexism, with a twist: girl reporter also has a disabling chronic illness. I wrote about discrimination, harassment, and invisible disability amid the addictive thrill of chasing front-page news at the *Vancouver Province*, *Toronto Star*, and *Ottawa Citizen*. Through these "memoir fragments," to borrow from Callison and Young, I was trying to make sense of my situation, and declare my experience with a chronic condition as an

expertise. My response to this situation is not uncommon. Journalists working in mainstream media are disclosing their mostly invisible disabilities in “coming out” columns, on Twitter threads, and in blogs.

In 2020, political journalist Kristy Kirkup discussed her Crohn’s disease and the COVID-19 pandemic in a *Globe and Mail* column titled “COVID-19 Is Teaching Us All How to Live with Uncertainty,” and then on Twitter revealed her attempts to accelerate her vaccination because she is taking immunosuppressants (“I’m 34”; “People in Toronto”). *Star* health reporter Theresa Boyle shared in a Twitter thread that she had suffered a stress-induced heart attack, diagnosed as a spontaneous coronary artery dissection that she linked to ongoing harassment by an editor (“Next month”). She was sidelined by management, she said, unable to report on the COVID-19 pandemic (“You may have noticed”). On social media, she found community support for her heart attack and harassment claim against the editor, as well as her fight for an investigation into the *Star*’s practices.

In other “coming out” columns, sportswriters Steve Simmons and Bruce Garrioch disclosed mental health challenges in the *Toronto Sun* and *Ottawa Citizen*, respectively. Simmons revealed his debilitating panic attacks, expressing vulnerability despite the macho veneer of professional sports. Garrioch shared the day-to-day mental health costs of covering the Ottawa Senators hockey team. “It was about a year ago that I made the difficult decision to get help with my anxiety. In many ways, it had taken over my life,” he wrote. “It was mainly centered around travel, which those closest to me will tell you was tough, to put it mildly.” Hockey teams play lots of away games.

Margo Kelly, a former CBC arts reporter, wrote in the *Globe* about her career-ending chronic pain, caused by a car accident. Her freelance feature advocated for better access to pain management. Former CTV Ottawa journalist Anna-Karina Tabuñar developed Guillain-Barré syndrome, and once she found herself in the land of the unwell, where so many people are out of work and living in poverty, she raised funds to produce *Talent Untapped*, a 2016 documentary about the issue. I supported Anna-Karina on her video as a sounding board and writer while we were both recovering from our health setbacks.

As journalists with invisible disability rail against erasure, their diverse memoir fragments pile up.

Steven Ladurantaye Makes a Bet: “Transparency Is Better than Cloudiness.”

“Do You Punish Someone for a (Potentially) Violent Suicide Attempt?”

“Nobody Believes in Your Depression, (Probably) Not Even You”

“When Alcoholism Meets Mental Illness”

“The Enticing Minefields of Insanity Porn”

Ladurantaye knows how to write a sizzling headline, as the above, from his journal on Substack, demonstrate. He is also doing community service, declaring his lived experience as expertise, one of the most prominent Canadian journalists writing in 2021 about the experience of invisible disability.

With public knowledge of his mental health challenges in Scotland preceding him, Ladurantaye decided to educate his colleagues. “I’ve made a bit of a bet that transparency is better than cloudiness. I’m also making a bet that not only will greater

good come from it, but it does clear the road for me to do something else. I'm trying to make a fresh break," he told me.

Since his first post in February 2021, "literally hundreds" of people have reached out with similar stories of misdiagnosis and other challenges. "A lot of journalists, but not only," he said, adding people are craving a forum. "One of the things that's lacking around probably every kind of disability, but I can only speak to mental health, is an open, frank discussion about how much this fucking sucks, right? It just sucks," he said. "And you get these warm hug campaigns, but mental illness is ugly and it's sloppy. And it is not fair to the people who have mental illness to just be ostracized."

In retrospect, he said he must have suffered from bipolar disorder long before his diagnosis. "I'd get amped up about nothing but a minor story. I was very enthusiastic but charged up on brain chemicals." By the time he got to the *Globe*, he and his editors recognized a pattern and learned to work around it. At Twitter he enjoyed a period of stability but said constant travel triggered mania. "I had a really good period going up, up, up, up. But I got to the point where I had this sense of invincibility, that I'm a genius and nothing can go wrong and I'm completely bulletproof," he said. Then he hit a wall and switched jobs.

At the CBC, he again rose quickly onto the executive floor, only to be reassigned for participating in a controversial Twitter conversation that many felt made light of Indigenous writers' concerns about cultural appropriation (Raynor). "All of a sudden people wouldn't even look at me in the hallway. And I had two hundred people in a room yelling at me for being horrible, with my boss sitting beside me."

Under the scrutiny, his mood plummeted, he sought help and was prescribed antidepressants. Less than a year later, he was headhunted to a position at Glasgow-based STV, and within weeks had laid off 15% of the staff in a restructuring. “I was doomed from the start,” he said. “I don’t remember most of my time there because I was hypomanic.” His brain was moving at a frantic pace; so was his work. “I’d be creating shows and putting them out next week, new formats, whatever it may be. And it all worked well. But people can’t sustain that, and I started to lose the thread.”

After his stay in a Scottish psychiatric hospital, he and his family made their way to Ottawa, where he eventually found a “proper psychiatrist.” He told me he has tried out different medications, just as he tried to figure out the tone — and pace — for his newsletter. “It’s never going to be a multimedia empire, but I do feel like I should be doing good stuff, using my skills to be an advocate.” He paused his newsletter in July 2021 to pursue new career opportunities.

Diane Sims Donates Royalties to Disabilities and Diseases That Consume Her

The last time I spoke with author and journalist Diane Sims she had just pinned a note on the front door of her home: “Due to Diane’s fragile health condition please do not come in unless you’re vaccinated.”

In late 2021, at age sixty-three, she was dying from an inoperable bowel obstruction, but wanted to do so on her own terms, and not because she caught COVID-19 from one of at least four — by her count — unvaccinated homecare workers coming in and out of her Stratford, Ontario, home. The note was a small gesture of defiance as she waged an Ontario-wide campaign — radio, print, web interviews — to demand the

province require homecare workers to be vaccinated. The *Globe's* health columnist Andre Picard wrote: "As Ms. Sims so eloquently stated, workers who refuse to be vaccinated during a pandemic are violating and betraying the most fundamental ethical principle that must guide their work: First, do no harm."

Sims has lived with MS for decades, since before she arrived as a journalism student at Carleton, determined to make an impact despite those who said her MS ruled out a journalism career.

Sims has an important and irrepressible voice as an activist and author, though she did not fit the stereotype of a successful reporter. During her first newspaper job at *The London Free Press*, when she confessed to her boss that she had MS, he told her to keep her disability to herself or she would never work again. Sims has a Bachelor of Journalism (1986) from Carleton and, despite worsening MS, worked as a successful journalist throughout northern Ontario — as a contract reporter for CBC Radio North, a stringer for *The Toronto Star*, and editor of *The Manitoulin Expositor*. She left that last job to return to Carleton. But as her disability worsened and she was hospitalized for exacerbations, applications for journalism jobs did not result in interviews. After taking a job as Corporate Editor for the Ontario Lottery Corporation (now the Ontario Lottery and Gaming Corporation), she developed ovarian cancer and ended up on long-term disability. None of this dampened her determination to tell stories or crushed her identity as a journalist. She is most proud of her books.

She may have been deemed too flawed to work as a journalist at a daily news organization, but her books show what the mainstream has lost. Writing about MS, disability, ovarian and breast cancer, spirituality, and resilience, among many topics, she

offers her unique and wise voice while building community. In *Gardens of Our Souls*, a work of creative non-fiction published in 1998 in Canada, Japan, and China, she wrote about the courage needed to live with the uncertainty of illness. “Sometimes it takes immense courage to close your eyes and go to sleep, for fear of waking in the morning, knowing this is all real, your life is changed forever. God knows what other tales our morning tests will tell. But you don’t think about it,” she wrote, adding that instead you think about “everything from your husband weeping to the mess in your closets to feeling betrayed by your body. Nothing seems logical because nothing is, right then (*Gardens*, 45–46).

Another of her books, *An Ovarian Cancer Companion*, was purchased in bulk by a large pharmaceutical company and then distributed to obstetricians and gynecologists across Canada. *A Life Consumed: Lilly Samson’s Dispatches from the TB Front* is Sims’s last book, about her aunt, a teacher in a one-room school north of Sault Ste. Marie who contracted tuberculosis at age twenty-two and died three years later in a sanatorium. Sims used her aunt’s letters as a centerpiece, wrapped in evocative prose, forensic fact-finding, and historical commentary, to examine the impact of TB in Canada in the 1920s. Only someone who has experienced illness and disability, as Sims has, could combine so many complex elements, from the personal and romantic, to the origins of health-care policy (the provision of TB care for Saskatchewan residents was the province’s precursor to medicare).

Through many of her books, Sims weaves her experiences of MS. “I want to convey that I would not accept what the doctors gave me, which was a drop-dead deadline,” she told me. “And I fought and fought, and I was able to stay on top.” That is

another lesson: prognosis is not gospel.

When she told the two doctors “fuck you” after they predicted she would be dead from MS by thirty-five, “those two words framed my attitude forever,” she told me. Along her journey, she has leaned on other word pairings. Gratitude and joy. Hold on. Hold fast. Hold hands. An essay called “Two Words” was published in 2021 as part of a collection released in Australia and New Zealand. In it, she also wrote about how determination and stubbornness have “stood me in good stead for MS and cancer and cancer again, and now this,” referring to the bowel obstruction that will end her life. “My doctor told me this morning, ‘You keep winning this, day by day,’ but ... [she whispered] I’m a goner.”

From Ignorance to Selena Gomez, Jaclyn Law Writes Against Stigma

The two of us began our interview by comparing symptoms and treatments, as those who share the same chronic condition often do.

“Pleurisy?” I asked.

“Yup,” she said.

“Nephritis?”

“Yes, nine years after diagnosis.”

“I was diagnosed with nephritis seven years after.”

“CellCept?”

“Yeah. It made me vomit. You?”

On it went. Writer and editor Jaclyn Law has long written publicly about having lupus, ever since her diagnosis at age seventeen, in 1995. While finishing high school,

she started a zine called *Lupus Girl* and then wrote about her publishing efforts in *The Toronto Star* shortly afterward (“Lupus Girl”). Law’s goal is to raise awareness. “I think it’s important to write and talk about lupus because few people know what it is, lupus research needs more funding, and the disease disproportionately affects women, especially women of colour,” said Law, who is Chinese Canadian. “I also think it’s important for people to understand the episodic nature of lupus, and that just because someone looks fine on the outside does not mean they aren’t struggling with their illness.”

That said, it was a difficult story for Law to tell at first, embarrassed that she had the “whole puffy face thing” from taking high-dose prednisone. “I had to buy all new clothes [because of weight gain], but it wasn’t as fun as it sounds.” Sharing her story was also a way of coping. *Lupus Girl* was for young people with lupus, covering body image, the history of the disease, its medications, and “lupus moments” — lists of lupus sightings in popular media.

Law studied English at the University of Toronto, and then earned a Magazine Journalism Certificate from Ryerson University. Even though she steered away from daily news reporting, I include her here in part because we share many of the same symptoms, but also because she chose a slower-paced magazine career, which in retrospect seems like a wise decision.

After working as copy chief at *Chatelaine*, Law became managing editor at *Abilities* magazine. For one of the few examples of independent disability media in Canada, Law said having lupus wasn’t seen as an impediment at the publication. “My boss said it would give me insight into what readers go through,” she said. “And it’s true;

having this illness has given me more empathy.”

At *Abilities*, she said, they were very open to hiring people with invisible disabilities. “They were activists around disability issues. So they were very supportive and understanding, especially my boss,” Law recalled. “I had this issue with my lungs. I was doing acupuncture. He would go to the appointments with me. He was very supportive.”

After *Abilities*, Law decided to freelance so she could choose assignments that suited the ebb and flow of her health, focusing on personal finance, lifestyle, and seniors’ issues. But when we spoke in November 2021, she had just been appointed managing editor of *MoneySense*, a digital personal finance magazine, where she had been freelancing. She said she had to “think long and hard” about taking a full-time job but was a fan of the publication and decided to jump back in. She plans to hire more writers with disabilities, as well as cover more disability issues — as she always has, filling the gaps in mainstream media.

Law is a community builder for me; I have read her mainstream pieces and others she has written for the Lupus Ontario website and, more recently, for the *Globe*, about pop star Selena Gomez. Law and I, like Gomez, suffer from lupus nephritis and have received strong immunosuppressants and new biologic therapies; Gomez, however, required a kidney transplant. Few understood the potentially fatal illness until Gomez spoke publicly about her disability and transplant in a 2015 *Billboard Magazine* interview. With one of the world’s largest social media followings (275 million on Instagram as of November 2021), she has brought attention to the little-known disease.

When Gomez revealed her kidney transplant on Instagram, she was doing what all

the independent journalists I feature here are doing, but in a far more public way: inviting people to follow her health journey on her own terms. After Gomez disclosed she had lupus, Law wrote about the perils and pain of invisibility in the *Globe*: “People with lupus often look perfectly healthy. I appreciate being able to choose when and where I disclose my illness, but I’m also aware that, too often, the disease isn’t taken seriously,” Law explained in “Thanks, Selena Gomez, for Shining a Light on Lupus,” adding, “Online lupus communities and blogs are filled with cringe-inducing stories of people with lupus being told, often by well-meaning friends and even physicians, that their symptoms are all in their head. (Ninety percent of lupus patients are female. Coincidence? I think not.)”

Jim Davidson Writes to Make Sense of Lost Days

Former *Globe and Mail* sports journalist James (Jim) Davidson, fifty-nine, spent fifteen years living at home with his parents in rural Quebec, devastated by undiagnosed Lyme disease. He lived in a small bedroom upstairs, with a TV and a meal tray. On some days, he had to crawl to the washroom because he was too weak to walk. “I felt like I was living under water,” he recalled.

When he was finally diagnosed with four strains of Lyme disease in 2011 (when the blood test became more readily available), he began painstakingly rebuilding his health while plotting a comeback as a journalist — an integral part of his identity.

Like several of the journalists with invisible disabilities I have interviewed for this thesis, I have known Davidson since journalism school. In the early eighties, when I was a second-year volunteer at *The Charlatan*, Carleton’s campus newspaper, Davidson was

its editor-in-chief. We also played together on the journalism school's intramural basketball team. While I limped around the campus gym with undiagnosed lupus, he sometimes wondered why he was so winded, but brushed it off. At the end of the semester, after he completed his television reporting course, he recalled being "so bagged" it required a full week recover. "It was the first real inkling something was not quite right."

He wanted to become one of the country's top sports writers; he sent clippings to then-legends in the business, seeking advice — *Montreal Gazette* sports columnist Mike Farber, the *Globe*'s Trent Frayne, and Earl McRae, who had just joined the *Ottawa Citizen*. That is hustle. After graduation he landed his dream job, working in the *Globe* sports department. As he got progressively better assignments, travelling to FIFA World Cup events and to cover the Olympic Games in Calgary, he was hobbled by fatigue, crushed by deadlines and too many late nights.

He started making "subconscious" career choices based on his flagging energy, not his unlimited talent. "You don't admit to yourself that you don't have the same stamina as the other reporters," he told me. He angled for feature-writing assignments and imagined a less punishing career. He pursued a master's in history at the University of Toronto while continuing to work part-time at the *Globe*.

When he and his wife moved to Ottawa in 1994, he took on contract work for a CBC TV show while freelancing for the *Globe*, including a regular university sports column. He also co-wrote the memoir *Killer: The Brian Kilrea Story*, along with the Ottawa 67's hockey coach.

Davidson marks his declining health by disappointing sporting performances. Not

keeping pace with a buddy playing pickup basketball. Being stunned by the weight of a softball bat. After throwing a ball around with a friend for thirty minutes, he was “beyond done.”

The following winter, he got increasingly ill, until some days he was crawling from his bed to the bathroom, while trying to continue his contract work. He and his wife had a newborn. She was struggling to care for Davidson and the baby, in a home they had just learned was infested with mold. As his health worsened, he estimated he went to a dozen doctors looking for a diagnosis; the default became chronic fatigue syndrome, with no known treatment.

In the spring of 1998, Davidson’s wife left him. He moved in with a friend, and then into a rooming house. “I was desperately trying to hang on in Ottawa to be near my son.” Finally his dad drove him back to Quebec’s Eastern Townships, where he had grown up. He was thirty-six.

He remained in an upstairs bedroom for much of seven years. His weight dropped to 120 pounds from 170. “I am five foot eleven, so I was really thin,” he said. He phoned his son in Ottawa every two weeks but did not see him for seven years.

“You were an invalid,” I observed while we were talking.

“I hate that word,” he cut in. “One time I heard my mother talking on the phone to one of her friends, and she mentioned her ‘invalid son.’ I told her, ‘Mom, I love you, but don’t ever call me that again.’”

His dad was a minister, and many people in the small community were praying for him to get better; in 2005 he started to feel well again. “I guess it could have been a miracle, but something changed,” he said. He put on weight. He had enough energy to

travel to Ottawa to see his son and his doctor, who tried various experimental treatments on him. Six years later, when he tested positive for Lyme, it was a relief. He was forty-eight.

In 2013, he returned to Ottawa to be close to his son, by then in his first year of university, and to receive treatment. Among Davidson's first acts once he was well enough, in 2016, was to re-establish himself as a writer, including launching the blog *Lymetips* to share what he has learned through his struggles. "I got the full meal deal with this disease — several strains of Lyme, several co-infections, several viruses, severe candida. So, whatever you've faced, I've probably faced it too," he explained in one post ("Intro"). In his blog he has covered everything from suffering "wobbly legs" in the supermarket to experimental Lyme disease therapies, anti-inflammatory diets, Lyme flares, spirituality, and Christianity.

So far, he has close to twenty-thousand views. He had hoped for a thousand, though it is hard to know what metric to use. His sports stories in the *Globe* would have earned thousands more eyeballs.

After all these years, so many spent in bed, he identifies as a patient, educator, and advocate, but especially as a journalist. He cannot put aside his compulsion to write; it is part of his recovery plan. One day he might write a book. Until then, you can find his writing online, his long-lost voice a solace to other sufferers. He also writes to define his experience: "Lyme has stolen an unbelievable number of things from me, mostly the important things," ("The Best Thing").

The case studies I cite are both heartening and disheartening. These journalists have so much to say, but they are pushed to the edges of the mainstream, tentatively

using memoir fragments to reveal important perspectives. Any one of these fine writers deserves a huge audience, instead of casting out into the internet in search of readers. Some, like Jones, have argued that dissident or alternative media or social media are the best places for these journalists to situate themselves. It is hard to argue with that perspective when the mainstream media are not interested in either hiring journalists with disabilities or writing about disability issues. There seems to be no other option. But I would suggest the continued marginalization of disability issues seems foolhardy when 22% of the population identify as having a disability.

Reading the works of these journalists, I was struck by their tenacity, drive, and empathy, as well as their story sense. They each know a good story when they stumble across one, and in these cases, it is their own. I was especially moved by their courage to say “This is who I am, this is what I have experienced, and this is what needs to change.” If only more people were paying attention.

Chapter 12: Conclusion

I did get better.

Almost immediately after leaving the *Ottawa Citizen*, I was offered a full-time role with a non-profit that allowed me to work from home as I regained my equilibrium. Eventually I travelled frequently, mostly to Toronto but also across North America and internationally, to visit development projects. I oversaw tight deadlines for books, videos, social media plans, and content-marketing campaigns for some of the world's largest brands. I eventually founded a large department of twenty-two people. To manage my invisible disability, which few of my new colleagues knew about (although my employer did), I sometimes worked odd shifts and spread my hours over seven days instead of five. Three years after leaving daily journalism, I was prescribed an inexpensive drug that dramatically improved my energy. I am as well as I have ever been, lingering chronic pain and immunosuppression aside.

Throughout all this, I have mourned the loss of my journalistic identity and the work I was best at. I have also tried to make sense of the “undue hardship” I was forced to experience, simply for daring to be a journalist while managing a difficult chronic condition. After I moved on, concern lingered. I sensed something terribly wrong about the way people with disabilities are treated in daily news organizations. Observations I had made over decades seemed too important to ignore, too revealing of a trend beyond my own experience. I started this project with two overarching questions: Is there something unique about the culture and attitudes of daily news organizations that made

my experience particularly difficult? What can be learned to make the journey easier for other journalists with invisible disabilities?

I have no doubt, after my extensive research, that the macho, competitive, survival-of-the-fittest culture of daily journalism, as well as a scarcity of jobs, plays a seemingly insurmountable role in how people with disabilities are viewed and treated within news organizations. We are seen as fragile, pitiable, and expendable.

Many of the thirty-seven current and former journalists with disabilities I interviewed also spoke of a strong attachment to their work; some described it as a calling. It is a feeling we cannot just turn off when it is at the core of our identity. I think of the words of Aaron Sands, who had been an award-winning crime reporter at the *Ottawa Citizen*. He told me: “I have been living in exile for eighteen years and I don’t understand why I haven’t come to terms with all of it.”

A 2020 study of nearly 350 journalists who had been forced out of print media found a “surprising” 36% of respondents still identified as journalists, while 39% experienced emotional difficulty such as feeling devastated or depressed (Reinhardy and Zion). “When you’re committed to the idea that you are a journalist, that’s who you are and when you’re told you’re not going to do that anymore, it takes a real part of you,” Reinhardy said (Krings). Many journalists with disabilities cling to that professional identity, no matter how unaccommodating the workplaces, no matter how much undue hardship we must endure.

Through my interviews, I found a level of human suffering that I had not expected, as journalists with invisible disabilities came up against a system that keeps them in hiding, discouraging disclosure; or requires side deals and workarounds because

official accommodations are unlikely. Their unduly hard treatment inspired the title of this thesis, “Undue Hardship,” which is typically what an employer claims as the reason they cannot accommodate an employee.

Ableist attitudes infest job descriptions, policies, and accommodation agendas at daily news organizations. Rachel Desjourdy, senior specialist (accessibility lead) at CBC, recalled the words of those she interviewed about the accommodation process: “trauma,” “policing,” “not being taken seriously,” “I feel like I have to defend myself,” and “hostile.” As Desjourdy explained, the burden of proof is on the person with a disability, and too often they get the message “We don’t believe you.”

No wonder so many of us do not want to disclose disabilities unless we absolutely must. But we hide at our own peril. By remaining silent we are complicit in our own erasure, obligingly keeping the issues related to representation and accommodation off everyone’s agenda.

Amid conversations about representation and reckoning, we need to redefine what it means to be a journalist. As former *Globe and Mail* journalist Jan Wong asked me in Chapter 4, “Do all journalists really need to be decapitating gladiators to be effective?” Lynn McAuley, former associate editor of *The Toronto Star*, had a similar observation in Chapter 7: “I don’t know why we pretend that we have these fully well-rounded people who can do anything. That’s just not true. I think that’s a fake construct.”

The invincible gimmick no longer applies, if it ever did.

Combatting ableism in daily news organizations is as equally important as tackling pervasive racism and sexism, though far less recognized or prioritized.

Accommodating journalists with disabilities is a choice; or rather, an abdication, as many

of my interviews showed. “If you ask me where disability is as issue, it’s nowhere, it’s disgracefully nowhere in the conversation. And when you bring it up, people kind of go, ‘oh, yeah, that’s a good point, we really should think more about the disabled,’” said McGill University associate professor and author Andrew Potter (formerly editor-in-chief of the *Ottawa Citizen*).

So, what should be done? It is difficult to imagine a movement around opening the doors to more journalists with disabilities, though one is desperately needed; whether it is nixing requirements for driver’s licences, granting flexible deadlines, installing screen readers for those who have visual impairments, or just showing empathy for (and interest in) someone who does not fit the old-school mold of gumshoe reporter but offers a new perspective. If these things seem out of reach, there is precedent for at least one crucial element. The fight to be allowed to work from home might have seemed futile, until now, when so many of the world’s workers, including journalists, have been doing just that since the COVID-19 pandemic was declared in March 2020.

Some of the change should start in journalism schools, with educators changing expectations to show that there is more than one way to approach any assignment and perceived weaknesses can be turned into strengths. Journalism educators, like news organization leaders, need to see our unique qualities, including problem-solving, empathy, lived experiences, and tenacity. Journalism schools also need to teach about how to cover disability, as well as to diversify their sources in news coverage to include those with disabilities. Journalism educators can also coach their students on how to adapt assignments to complement their abilities. Conversations between journalism

educators and the news organizations that hire students are crucial if that hiring is to expand to include young journalists with disabilities.

More Research

I see the original stories collected here as a foundation for future research, especially as demands for better representation in media, including daily news, grow louder. My own story aside, each of the main topics I have covered — journalistic identity versus disability identity; fear of disclosure; workarounds and side deals that erase disability; difficulties getting accommodations; and writing about disability from the margins — could have been separate thesis subjects. There is no question more research and more data are needed in each of these five areas if we are to relieve the silent suffering — the undue hardship of the employees, as opposed to the employers.

It is impossible to know how many of us are in newsrooms. Nor do we know how many remain on the outside looking in because their disability has kept them out. No one is counting. This is an oversight (or failure) that seems to legitimize ignorance and ongoing inaction. The CBC is making some progress, as they must adhere to the federal Employment Equity Act, but other organizations have yet to seriously include disability in their plans for inclusivity. Undoubtedly their workforces include people with invisible disabilities who choose not to disclose for fear of discrimination.

Build Community

Without numbers, it is difficult to find each other. There is no group or organization representing Canadian journalists who have disabilities. Few attempts have

been made to bring our perspectives to larger audiences, although in late 2021 I organized three panels for journalism students in post-secondary programs across Canada, including participants I have met through my research. Meanwhile, there are few journalists with disabilities publicly taking daily news organizations to task for systemic ableism, as racialized journalists in Canada have increasingly done (Balkissoon; Paradkar; Mattar). Unfortunately, until we start advocating for ourselves, we will not be heard.

Activist Aimee Louw writes frequently on disability issues. She and I were both on the advisory panel for the Public Policy Forum's Access Ability project. "In this environment of relative silence, the voices that get picked up the most are those of outrage, scandal, exasperation, or inspiration," she wrote on *Canadaland*. As a result of limited coverage, the Canadian population does not see Canadians with disabilities reflected in the media landscape, which leads to inaction on related issues. There must be "out" journalists with disabilities proactively setting the agenda, not just reacting, Louw observed.

But how? Who would "come out" in these harsh conditions, only to be met with disbelief and refusals of flexibility? My wish list includes newsroom managers hiring more journalists with disabilities to tell complex, challenging stories about our lives, while also creating safe and welcoming workplaces so those in hiding can disclose without fear. At the very least, offer prominent columns to some of the journalists I have profiled here to write about disability issues. We also need to assess job descriptions and therefore the journalist's role itself for exclusionary language and policies that keep those with disabilities down.

It is important to note that several of the racialized female journalists with disabilities I interviewed seemed to have been treated especially poorly and expressed concerns that they are triply disadvantaged, reinforcing Professor Kimberlé Crenshaw's 1989 theory of "intersectionality." She has said certain aspects of who we are, including race, class, gender, disability, and economic status, "will increase your access to the good things or your exposure to the bad things in life" (Steinmetz). Women face a well-documented "double bind" in the workplace of higher expectations and lower rewards, while women with disabilities face a "triple bind" or "triple jeopardy" (Moloney et al. 243; Smith Randolph 372). As news organizations hire more racialized journalists their fears of disclosing disabilities and legitimate fears of being treated unfairly should be acknowledged, at the very least.

Disability can happen to anyone. Accessibility makes life easier for everyone. As mentioned earlier, there may be lessons from the flexibility afforded journalists allowed to work from home during the COVID-19 pandemic. According to Terri Monture, who works for the Canadian Media Guild and represents CBC workers, employees with disabilities who have been working from home have experienced improved health, as well as increased efficiency and participation in the workplace, because they do not have the difficult commute. She hopes their experiences might open the door to news organizations acknowledging that with accommodations, employees with disabilities are not disposable but can provide meaningful contributions.

Michelle McQuigge, weekend and special projects editor for CP, thinks journalists should "organize and make our presence known." So, too, do many others I interviewed. Perhaps an association of journalists that bridges the gap between those who

have visible and invisible disabilities would create momentum and offer validation. Maybe our coming together would be a sign to media insiders that we're wise to the obstacles they stack in our way, and act as an impetus to improve how we're welcomed into the industry. Meanwhile, we are no one's preferred diversity hire.

For me, this exploration has been emotionally difficult and not just because it was conducted entirely online during the COVID-19 pandemic. Revisiting my moments of poor health and career disappointment, as well as tracking down journalists exiled from the work they love, was not for the faint of heart. At times I found it too much. In the final stages of editing this work, exhausted, I knew that I was avoiding checking in with some of the former and current journalists who had the most difficult experiences. So I spent the final weekend before this thesis was due reconnecting with many of them to ensure I had fully captured their stories and they felt represented in this work. Some conversations were hard, but they urged me on, expressing hope that this project would matter in some way.

Robert J. Nash has long advocated for using "SPN as a way to bridge the gap between scholars, students, and the general public," arguing that "public-intellectual writing based in storytelling and self-disclosure" can reflect complex daily life and personal identity to the general public ("Chapter 4" 39). To fulfill his belief in the power of Scholarly Personal Narrative, this thesis will hopefully reach beyond an audience of journalism educators and disability experts and find new audiences within news organizations, which ultimately serve a broader public audience. One new audience for this work might be frontline workers in news organizations – especially those without disabilities, who need to understand what may be going on with their colleague at the

next desk (or video call) so that they can be slower to judge and perhaps even able to recognize how they can act with empathy and professionalism. Reaching this audience, as well as others within news organizations and journalism schools, is my long-term goal.

For the readers of this thesis, I ask you to consider the wisdom, empathy, and tenacity that those of us with disabilities bring to our work. If disability were embraced, accommodated, and considered a normal part of the workplace, daily news organizations would better represent their audiences. If we are not there, and if no one covers these issues, it reinforces to the millions of Canadians with disabilities the idea that they do not matter. How can this be allowed to continue?

Appendices

Appendix A: Methodology: Scholarly Personal Narrative Informed by Journalistic Practice

Almost forty years after graduating from Carleton with a Bachelor of Journalism, I applied to do my master's in the same school, with plans to explore my own experience living with invisible disability and working in daily news. After considering other formats, including memoir, autoethnography, and personal journalism, I stumbled across these books: Robert J. Nash's *Liberating Scholarly Writing* (2004) and *Me-Search and Re-Search: A Guide for Writing Scholarly Personal Narrative Manuscripts*, by Nash and D. L. Bradley (2011). Nash is a professor at the University of Vermont specializing in philosophy of education and applied ethics. In these works he makes a case for the SPN, an approach to academic writing and research he developed and popularized. It focuses on the journey of the author while combining "scholarship, personal stories, and universalizable themes in a seamless manner" (Nash and Bradley 24). The approach encourages researchers to tell a personal story in a scholarly way, with the objective of effecting widespread change related to an area of personal expertise.

This spoke to me. I felt I could use my story as a narrative engine to explore some of the common challenges that arise during different career stages for those working with invisible disability in daily news organizations, while also exploring existing academic research and popular commentary.

Finding an Audience

A journalist returning to school already knows the satisfaction of having their work read and discussed widely, even effecting change. I was certainly wary of spending a year or more on a project that few will read. Nash cites journalist Naomi Schaefer Riley, who reported that books written by academics in the social sciences or humanities, published by university presses, sell about three hundred copies, mostly to university libraries (qtd. in Nash, “Chapter 4” 43). Meanwhile, a research-based article in a refereed academic journal fares worse, averaging about a dozen readers (Vedder, qtd. in “Chapter 4” 43). Richard Vedder, a distinguished professor emeritus of economics at Ohio University, wrote in *Forbes* how “incomprehensible the typical academic paper sounds today to more than 99% of the population.”

I wondered if another format could draw in more readers, a diverse audience that might include academic researchers, journalists, and people within the disability community, and lend itself well to narrative storytelling.

Nash argued that using SPN to report findings in accessible, engaging prose, and “even tell a few personal stories along the way,” might get more engagement from readers (“Chapter 4” 43). Even scholars do not want to write like scholars, he argued, citing those who, mostly later in their careers, popularize their ideas through more accessible writing, punditry, memoirs, and journalism. He mentioned “star public intellectuals,” including Richard Dawkins, Marian Wright Edelman, Anne Lamott, Annie Dillard, Henry Louis Gates, and Cornel West, among many others. In these popular formats, Nash said “their work actually gets read. It doesn’t languish for years as a reference in a standardized curriculum vitae or get lost as a title in the depths of a

departmental website” (“Chapter 4” 48). One cannot rally change without widespread appeal.

SPN as Methodology

For scholars looking to tell a personal story, SPN might be considered the sophisticated offspring of memoirs, autobiography, and autoethnography, growing out of a tradition in qualitative research to combine scholarly literature with personal narrative. “Narrative research is best for capturing the detailed stories or life experiences of a single life,” suggests Creswell (55), “reporting individual experiences, and chronologically ordering the meaning of those experiences” (70).

In SPN, Nash urges the scholar to move from “me-research” to “we-search.” According to Nash and Bradley, “While it is personal, it is also social. While it is practical, it is also theoretical” (19).

My story needed a format that would accommodate my internal journey of invisible disability, while weaving together theory and criticism. First, let’s look at the three words in SPN’s name, which represent the essential components of the methodology. Through a scholar’s prism, the author must identify the most relevant and informative themes with academic rigor. From a personal perspective, “the self of the scholar [is] front and center” (Nash, *Liberating* 18). SPN writers narrate in the first person, incorporating deep self-reflection, differing from other methodologies in presenting the researcher’s own experiences as a valid object of study, something that “signifies” (24). SPN addresses not only personal background and biases that might have shaped the scholar’s choice of research methods and interpretations, but also the

significance of the scholar's own actions, choices, and values both for the scholar's field and the larger community. And as the name implies, SPN creates a literary and scholarly product that tells the reader, "This is what happened to me, this is how I reacted and dealt with it. Does it resonate? Does it make a difference?"

Nash has said this approach lacks a "well-established research template," as autobiography is "always profoundly personal and unique to some degree, never replicated in exactly the same forms by anyone else" (*Liberating* 55). However, he identified ten "tentative guidelines" for SPN, which Heidelberger and Uecker (7) skillfully summarized as follows:

1. Establish clear constructs, hooks, and questions.
2. Move from the particular to the general and back again ... often.
3. Try to draw larger implications from your personal stories.
4. Draw from your vast store of formal background knowledge.
5. Always try to tell a good story.
6. Show some passion.
7. Tell your story in an open-ended way.
8. Remember that writing is both a craft and an art.
9. Use citations whenever appropriate.
10. Love and respect eloquent (i.e., clear) language.

Heidelberger and Uecker make clear that SPN is "not carte blanche for unstructured, self-centered yarn-spinning," but instead, SPN writers must frame their stories around meaningful constructs and seek connections among "their experiences, the experiences of

others, and the broader knowledge of their discipline,” always striving for universalizability (7).

Before I explain why and how I also incorporated a journalistic approach, especially with primary interviews, I will explain the four basic parts of SPN: pre-search, me-search, re-search, and we-search.

My SPN Process

Pre-search

Nash and Bradley defined pre-search as “the internal and external actions of an SPN writer before even one word is put on the page” (36). My pre-search had been ongoing since my diagnosis with lupus between my third and fourth year of undergraduate studies at Carleton University’s School of Journalism. I read self-help books about coping, resilience, meditation, and nutrition, and advice from philosophers and physicians with insight into coping with invisible disabilities and chronic illnesses, long before I ever considered researching and writing a master’s thesis about the challenges of working with invisible disability within the competitive, masculinized environment of daily journalism. As I read more deeply, I learned about the social and medical model of disability and disability identity, as well as critical disability studies.

As I began my thesis work and set my mind to official pre-search, I kept turning over in my mind the burning questions that would drive me forward: Was being a journalist with an invisible disability incompatible with the competitive, masculinized environment of daily journalism? If not, why was the journey so isolating, difficult, and lacking in support and role models? To that question I would add: Was I alone in these

experiences within daily news organizations? This last question would lead me to do many journalistic interviews.

Me-search

The core of my me-search was chronicling twenty-seven years of working in daily journalism with an invisible disability (from my diagnosis in 1985 to taking a buyout from the *Ottawa Citizen* in 2012). I surveyed this vast period in detail, looking for telling moments and lessons as I strived for success in that unique environment despite ongoing chronic illness. The examples I sought would be about more than overcoming obstacles during a career, more than “inspiration porn” (Young). I looked to see if there are any systems, structures, or injustices that inhibit advancement of journalists with disabilities, especially those that are invisible.

As a writer who had maintained a blog about some of my experiences, I believed my stories were interesting. According to SPN’s loose methodology, “how I make sense of a phenomenon is a product of my own construction” (Anderson 17). My blog, called *The Sick Days*, was reference material for several early chapters in this thesis.

I did struggle with how much of my personal story to include. I had blogs, medical records, detailed datebooks, and copious notes. However, as I amassed interviews with other journalists, the number of stories I included from my own experience steadily declined. I made the hard decision to write Chapters 5 and 6 about my coping and career advancements, to ensure my own story was still a significant part of the narrative, and that decision increased the length of this document.

Re-search

From these perspectives and stories, I developed themes and then questions around identity, disclosure, workarounds and side deals, and official accommodations, as well as the unique content created by journalists with invisible disabilities, mostly outside the mainstream. This was in preparation for the external exploration that marks the research phase. SPN writers do not follow the format of a traditional literature review, but use what Nash and Bradley called “lit embeds,” where the literature “emerges organically within the flow of the text” (85). However, my early study of the literature showed that no one in Canada had conducted an academic study or general survey of journalists working with invisible disability. My SPN is therefore enhanced by the writings of members of other marginalized groups working in and around daily news organizations; studies of disclosure experiences in other workplaces; and a study of “speculative memoir fragments” (Callison and Young 99) from journalists with invisible disability.

We-search

Although my story is personal, I long believed it might be universal, and I take care in the last section to discuss the implications for others in my profession, by way of learnings and recommendations. But admittedly, in the re-search and we-search phases the SPN method fell short for me, and I had to expand my knowledge and my quest by turning to my journalistic expertise to do primary research. So my SPN is enhanced by journalism practice in the form of multiple interviews.

Including Interviews and Journalistic Research

While Nash writes that self-interrogation is crucial to an SPN, he does not specify that journalistic rigour or original interviews are required. He does, however, in a blog addressed to his class, describe advice given to one student to interview her relatives about their experience during the Holocaust for her SPN (Nash and Viray). I have found some other SPNs where the researcher conducted interviews, especially to bring forward marginalized voices. As an example, Sandra Unger conducted several interviews for her 2014 dissertation that explores the issue of reciprocity in cross-race and cross-class relationships. She took this approach for two main reasons: first, as a “way to triangulate” her own recollection of stories and events, because her interviewees may have remembered things differently and arrived at different insights, thereby creating a “stronger, if less black and white, narrative” (28). Second, she said it was “an opportunity for people who are often overlooked by society to voice their thoughts, ideas, and life experiences to a wider audience” (28).

Without extensive scholarship on my topic to explore, I made the early decision, in consultation with Professor Dave Tait, my thesis adviser, to interview current and former journalists, editorial managers, union officials, media executives, and subject-matter experts to see how my experiences compared to what they had experienced or overseen. This decision forms part of my approved thesis protocol.

I feel it was important to lead with my strength, which is interviewing, a skill I developed throughout my career. I was lucky enough to attend John Sawatsky’s investigative reporting class in 1986 at Carleton University, when he began to formulate the principles and techniques of good interviewing that he later brought to the Poynter

Institute, CBC, ESPN, and newsrooms around the world. Also, as I began to do scholarly research and realized that voices of journalists with invisible disability were largely missing from published texts, whether popular or academic, I decided to lean into primary research to see what I could find that would illuminate or expand on my personal experience.

I used the “snowball method” to find journalists with invisible disability. I reached out to senior journalists I know in Ottawa, Montreal, Toronto, and Vancouver and asked if they knew any current or former journalists who had worked with invisible disability. If so, I asked for an introduction. Most people I spoke with knew of one or two others to whom they could introduce me. I also reached out to interview current and former union officials and editorial managers in key markets. In addition, I found a handful of journalists who had disclosed their disabilities in first-person articles in either mainstream or alternative media, and in many cases I approached them for interviews. Working journalists who had never disclosed their disabilities and recent journalism school graduates were interviewed anonymously to mitigate any social or economic harm that might come from speaking about their condition, which was part of my protocol approved by the Carleton University Research Ethics Board.

I believe my methodology is unique in that it follows the SPN approach but is strengthened by journalistic practice and mastery of journalism skills, including the tool of the interview.

In this thesis I tend to use people-first language, such as “journalist with a disability” or “editor with bipolar disorder” or “feature writer with lupus.” This puts the person first and the disability second.

SPN's Limitations, Ethics, and Generalizability

Scope

I could not interview every journalist I found. I spent six solid months conducting interviews, and even when I had started writing, more potential interview subjects came forward. In some cases I did these additional interviews if they seemed to represent a new issue or perspective, to ensure that my research was as extensive as possible. In others, I did preliminary background interviews with journalists with disabilities to broaden my understanding of the issues, but they are not quoted in my thesis.

Some journalists I interviewed complained about their treatment by employers or managers. The scope of this thesis, as well as privacy issues regarding human resources matters, made it impossible to verify many of these stories. Where applicable, I asked to see documentation, and those requests were met. In addition, as I became confident that the ill-treatment of journalists with disabilities is a systemic issue, I decided to look at the issue across news organizations as opposed to examining any one outlet. I also removed the names of anyone who might have been personally attacked by a participant, and in many cases did not use the name of a news organization. My intent was not to indict any one news organization but explore the issue industry-wide.

Interviewees raised many complex issues — especially pertaining to employment law, human rights law, collective bargaining agreements, the grievance process, as well as the influence of private medical insurers — and it was not possible within this thesis to

examine each in detail. In Chapter 10, which deals with the accommodation process and undue hardship, I believe I have provided an important but somewhat superficial exploration of the challenges of accommodating journalists at daily news organizations. If the concerns of employees and union officials around the application of “blanket” job descriptions or overuse of “undue hardship” are found to be an industry-wide issue, more research is certainly warranted. More research is also needed to explore concerns of a few journalism students who said they did not disclose their invisible disabilities for fear of jeopardizing their future advancement.

Subjectivity

The subjective nature of an SPN is a strength as well as a weakness. Should the reader believe my stories, my account of circumstances? Do I have to externally validate everything and investigate every conclusion or claim that I make? As Nash and Bradley state, “The writer accepts full responsibility for the personal self-disclosures, universal themes, and illustrative stories” (84). Instead of *validity*, SPN researchers favour the terms *plausibility*, *honesty*, and *coherence*, as well as preferring the term *universalizability* to *replicability* (84–85). Readers will decide if my stories, and the stories of my interview subjects, ring true or align with their experiences.

Constantly linking the me-search to the research of scholarly literature and/or the experiences of others acts as an interrogation of my experiences and hopefully increases trustworthiness. In the many interviews I conducted with other journalists with disabilities, I hunted for similarities, differences, patterns, and insights. Identifying and expanding on those patterns brings more context and credibility to my experiences. In

those interviews I focused on the main themes of my exploration and did enough interviews to convince me that the marginalization and discrimination faced by journalists with disability is systemic. My story is the story of so many others.

Ethical issues

In SPN research, ethical issues are tied to the personal nature of the research — namely confidentiality and anonymity — sometimes granted to those close to me. Although this is my story, it cannot be told without involving others, ranging from family and friends to loved ones and colleagues. Readers may find themselves in my work, most likely unnamed.

As mentioned, working journalists and recent university graduates were all granted anonymity, as per the CUREB-A, so disclosures about their health and disability status do not cause social or economic harm. This is especially important in the case of young journalists who may be bold enough to speak on the record but do not yet know the impact that disclosure could have on their careers.

Nash and Bradley advise, “A simple ethical rule of thumb to always keep in mind is this: SPN writing is non-fiction, not fiction” (189). The researcher’s responsibility to tell their truth may conflict with the feelings of others and cause harm. In those instances, I questioned whether a particular story or episode was critical to the research, or whether there might be another approach to make the same point, and then made a judgment call. In my case, some of my stories focus on fighting to win accommodations and on job loss. There are important points to be made, but not at the expense of someone else’s reputation. I have excluded certain former colleagues’ names, so I can explore the issue

without taking any one person to task. I took the same approach with other journalists I interviewed. If they made claims against a supervisor, I do not include the supervisor's name and make clear this is my participant's recollection and has not been fully investigated. Essentially, I pull my punches, wanting to make important points but not taking anyone down in the process.

I also keep in mind there is an intentional activism embedded in SPNs. Good SPN writing "aims to fix the brokenness whenever possible" (Nash and Bradley 59). SPN writing is an approach that enables researchers to more fully incorporate aspects of human experiences into scholarship, building and exposing instead of tearing down; that was my guiding light.

Finally, I made the decision to lean heavily on the personal stories of those I interviewed because so many of them had never been shared before, neither with professors, managers, colleagues, and media executives, nor their news organizations' audiences. If these experiences remain in the dark, inaction will be perpetuated. By giving so much time and space to tracking down their stories, and listening to their experiences, I put an emphasis on storytelling over analysis. This is because these stories first need to be told, felt, and understood before being dissected as an issue to be fixed through policies and rules. That work is needed and will be important but must wait its turn. I hope my personal story, as well as this primary research, will be meaningful and helpful to any subsequent investigation. My efforts here show just how much more work there is to be tackled.

Appendix B: Participant List

Current and Former Journalists with Disabilities

The list below refers to current and former journalists with whom I conducted full interviews or extensive preliminary interviews. As is journalistic practice, I sought on-the-record interviews with former journalists with invisible disabilities, and anonymous interviews with current journalists with invisible disabilities. Some of them appear in the Works Cited list, with many quoted by name. However, I present this list separately to capture the full range of people I interviewed, including their age range, self-identified race/ethnicity, and disability. This list includes thirty-seven current and former journalists ranging in age from their early twenties to late sixties; twenty-three are female, including eight who are racialized; fourteen are men, including one racialized male. I note below and in the thesis participants who identify as racialized, because they all said this intersected with their disability status and impacted their experience as journalists.

1. Former newspaper reporter and TV producer; Lyme disease (white male, 60s);
January 2021
2. Former radio journalist; chronic pain (white female, 60s); January 2021
3. TV journalist' inflammatory arthritis (white female, 40s, employed); January 2021 –
preliminary interview
4. Former newspaper editor and reporter; repetitive strain injury (white female, 60s,
retired); January 2021
5. Business editor; lupus (racialized female, 40s); January 2021

6. Former TV journalist; Guillain-Barre syndrome (racialized female, 40s); January 2021
7. Former newspaper journalist; chronic migraine (white female, 40s); January 2021 – preliminary interview
8. Former newspaper reporter; depression and complex PTSD (white male, 30s, freelance); January 2021
9. Digital news platform editor; chronic leukemia (white male, 40s); February 2021 – preliminary interview
10. Former journalist; multiple sclerosis (white female, 50s); February 2021 – preliminary interview
11. Newspaper editor; rheumatoid arthritis (white male, 50s); February 2021
12. Radio broadcaster; visually impaired (white male, 30s); February 2021
13. Former newspaper journalist; addiction (white female, 60s); February 2021 – preliminary interview
14. News service editor and writer; visually impaired (white female, 30s); February 2021
15. Former newspaper reporter and editor; repetitive strain injury (white male, 60s); March 2021
16. Former newspaper journalist; lupus (racialized female, 40s); March 2021
17. Freelance journalist; mobility disorder (white male, 40s); March 2021
18. Former newspaper editor; chronic pain and paralysis (white male, 60s); March 2021
19. Former newspaper reporter; heart disease and anxiety (white male, 50s); March 2021
20. Former newspaper reporter; clinical depression and PTSD (white male, 40s); April 2021

21. Former newspaper reporter; chronic vertigo (racialized female, 40s); April 2021 – preliminary interview
22. Radio and digital journalist; endometriosis and PTSD (white female, 30s); April 2021
23. Broadcast journalist; multiple sclerosis (racialized female, 30s); April 2021
24. Former newspaper reporter; multiple sclerosis (white female, 60s); April 2021
25. Senior Manager; sarcoidosis (white female, 60s); April 2021
26. Recent journalism graduate; obsessive compulsive disorder and anxiety (white female, 20s); April 2021 – preliminary interview
27. Recent journalism graduate; clinical depression (racialized male, 20s); April 2021 – preliminary interview
28. Former newspaper reporter; depression (racialized female, 60s); May 2021
29. Editor and writer; visually impaired (racialized female, 50s); May 2021
30. Newspaper and broadcast journalist; bipolar disorder (white male, 40s); May 2021
31. Editor; chronic pain (white female, 40s); May 2021
32. Recent journalism graduate; lupus (racialized female, 20s); May 2021
33. Recent journalism graduate; irritable bowel syndrome and anxiety disorder (white female, 30s); May 2021
34. Freelance writer and journalism graduate; severe asthma (white female, 40s); May 2021
35. Newspaper editor and reporter; clinical depression (white male, 50s); September 2021
36. TV journalist; chronic migraine (white female, 40s); September 2021 – preliminary interview

37. TV and radio broadcaster; hearing impaired (white male, 60s); November 2021 – preliminary interview

Managers, Executives, Union Officials, and Experts

Some of participants below also appear in the list above, fulfilling the dual roles of having been a journalist living with disability as well as acting as a manager/media executive.

- 6 current and former media executives
- 5 current or former union representatives from three different unions
- 7 current or former newsroom managers
- 3 subject-matter experts: labour law; human rights, academic, and women's issues; disability and rehabilitation.

Appendix C: Interview Questions

As is journalistic practice, I sought on-the-record interviews with former journalists with invisible disabilities and anonymous interviews with current journalists with invisible disabilities. I used journalistic interviewing techniques for this research as a tool to draw out a subject's experience with invisible disability and opinions on themes drawn from my own lived experience related to education, ableism, disclosure, workarounds and side deals, accommodations, and creation of content related to disability issues. I also used these journalistic interviews to draw out anecdotes and important details to provide colour for storytelling within the thesis, while keeping journalistic principles of fairness, balance, and accuracy at the forefront. The question list was a guide and it changed depending on the interview subject and their responses. I would add additional questions to seek details for anecdotes or personal experiences.

How many years have you been (or were you) professionally employed as a journalist in a daily news organization?

Prior to finding work, where were you trained as a journalist?

Describe how you landed your first daily journalism job.

What news organizations have you worked at?

What different roles have you had as a journalist over the course of your career?

How has having invisible disability/chronic illness impacted your career?

Did you have invisible disability/chronic illness prior to landing your first job?

How did it impact your training/schools as a journalist?

Did you disclose to your educators, managers, and/or colleagues that you had an invisible disability/chronic illness? Why or why not?

How did you disclose this information?

If working, what were your job responsibilities at the time of disclosure?

How did disclosure impact your standing as a journalist? Were you treated any differently?

Describe if or how disclosure changed the way you perceived yourself.

Describe how having an invisible disability/chronic illness impacted your behaviour at work. That is, did you overcompensate? show false bravado? talk frequently about your situation?

In the workplace do you/did you think of yourself as having a disability/disease?

What does the term *ableism* mean to you?

Do you feel ableism interfered with your advancement? If so, in what way? If not, why not?

Describe any unofficial accommodations/workarounds or side deals you had in order to perform your duties. Did you ask for these workarounds or side deals or were they offered? Explain.

Describe any unofficial accommodations/workarounds or side deals you wish you had to perform your duties.

Did your manager support your need for unofficial accommodations/workarounds or side deals?

Describe any situations where there was resistance to unofficially accommodating you.

Did you seek doctor-recommended official accommodations? What happened? Why or why not were you accommodated?

Did you ever consider taking a package or buyout due to your disability or failure to get accommodations? Explain what happened.

As a journalist, how did having invisible disability/chronic illness impact your choice of stories you told or people you interviewed?

What, if any, benefit is there to having people with disability working in daily news?

Describe any occasions where you acted as a mentor or role model to others with disability.

Did having an invisible disability/chronic illness make you a better journalist, poorer journalist, or about the same?

Why did you leave daily journalism?

Describe what role invisible disability/chronic illness played in that decision.

What would you tell would-be journalists with disability who want to break into the field?

What do you want to say to media industry leaders or media managers about employing people with disability?

What steps could be taken to improve your experience or the experience of others?

What haven't I asked that you think is important to share?

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