Brainstorm

how we got here

E. D. MORIN & JANE CAWTHORNE

THE EDITORS OF THIS ANTHOLOGY have a shared history. We met more than twenty years ago when our children attended school together, and we have been friends ever since. For many years, we were also neighbours and occasionally dropped in on each other unannounced. The kettle would go on and tea would be poured and an hour or two could fly by.

Jane remembers one unusual occasion when she stopped by Elaine's house. She remembers Elaine's strange reaction when she opened the door, as though she was trying to hide behind it. Jane didn't know what to make of this, but her impression was that it was not a good time for a visit. As time went on, Elaine remained out of sight. Months later, Jane learned that Elaine had injured her head. Was it the brightness of the day that made Elaine wince as she opened the door? Was it the very idea of holding a conversation? Light and sound sensitivity often leave those with concussions shrinking from social contact.

Back then, Jane hardly knew what having a concussion meant. A few years later she moved to a different city and, soon after, Elaine and Jane began work on their first anthology. The book was almost finished when Jane's concussion happened. Elaine remembers a visit from Jane during that time. As they drank tea at Elaine's kitchen table and discussed details of an upcoming book launch, without warning Jane began to cry. She was overwhelmed with the demands of the trip and needing to escape to Elaine's quiet, dark basement to rest.

The seeds of this anthology might have taken root in Elaine's kitchen that day. We were looking for answers for ourselves, sharing our experiences. There was so little information available to us. Medicine had little to offer women with concussions even though, as we would learn, more women than men experience concussions and traumatic brain injuries (TBI) and, when we do, we also are more likely to suffer more serious consequences. Nevertheless, research on concussion still focuses on men, and particularly men in sport. The lack of research on women and concussion is just one example of medicine's patriarchy problem and of broader social inequities. When men's bodies and experiences are considered normative, women are invisible.

We still experience misunderstandings and dismissive attitudes when seeking care. A concussion leaves no visible trace on the body. With nothing to test and treat, it is hard to know what to do. And so we try to dismiss it, too. We tell ourselves that this feeling we have, this feeling of not being okay, is nothing. We want it to be gone, but there is no wishing it away.

When we began this work, we knew we did not want to offer medical expertise. We are not medical experts. Besides, even the experts disagree on concussion and TBI. What we wanted was to offer a forum for ourselves and other contributors to be authorities on our own experiences of concussion and TBI. We wanted to fill the significant gap we found in knowledge about our conditions. We wanted to take centre stage, as we must, since medicine continually leaves us in the wings.

We also wanted to find contributors who were professional writers. Seasoned writers understand how to get past the initial chaos of a disaster and turn a situation into a story. They are adept at finding the bigger truths among the facts. Stories of injury often get stuck in beginnings. They describe the initial drama of what happened and go no further. Sociologist Arthur Frank in his book *The Wounded Storyteller: Body, Illness, and Ethics*, calls this the chaos narrative. We wanted to encourage contributors not to emphasize the story of how their injuries happened even though these are often dramatic. Instead, we would ask them to focus on how the experience changed their lives. As Frank says, too often people are not asked what they would like to become in their illness. The assumption is always that they want to recover: that is, to go back to who and how they were before. But what if this is not possible?

As we began our search for contributors, we discovered that a shocking number of women writers have had concussions. Why this is true is not easy to answer. Julia Nunes quips in her essay: "Could there be a less injury-prone occupation than writer?" We think not, yet here we all are. The writers we contacted sent us to other writers they knew, and soon we had more contributors than we had ever imagined. The marginalization experienced by white women like us in the medical system is often worse for Black and Indigenous women and Women of Colour, all of whom face additional and unique barriers to appropriate care. The same is true for those who identify as LGBTIQ2+. For this reason, when we sought contributors, we made a special effort to ensure that Black and Indigenous women and Women of Colour—as well as those who identify as LGBTIQ2+—had strong voices in the anthology and to make our admittedly narrow group of "women writers with concussion and TBI" as diverse as possible. All of the contributors we found were as anxious as we were to write about this life-altering experience. Many said they had been searching for an opportunity to do so.

Another challenge we faced is that typical accounts of injury or illness are often only understood as palatable when they are motivational and even inspirational. Everyone wants a happy ending, which most often means recovery. Such accounts appeal to non-disabled people by making vulnerability and illness seem temporary. But medicine and time cannot always heal. In *Against*

Death: 35 Essays on Living, an anthology written by people facing life-threatening conditions, editor Elee Kraljii Gardiner notes that in many cases, it "*won't* be OK." Gardiner also writes, "This is not a book that pulls punches and offers platitudes." Neither is ours. It wouldn't be honest.

Yet, this too is inspirational. Adaptation is sometimes uncomfortable and yet many will find it absolutely necessary at some point in their lives. Our hope is that this collection offers perspective and guidance to women experiencing concussion and TBI but also to all people who are facing difficult and unwanted change. Change is both hard and inevitable. The writers who share their experiences with you in this volume have cleared some of the brush and have a few tips for fellow travellers.

Despite their brain injuries, the contributors reveal exceptional skill and nuanced approaches to language and metaphor. These writers make stylistic choices that convey their new states. Meaning and form coalesce. As editors, we did not dictate genre. We are delighted with the variety of works that came to us. What emerges reflects not only the pain and confusion of brain injury, but also embedded meta-discourses on what it means to be a writer attempting to regain mastery of craft while coming to terms with how our writing lives are forever altered.

Contributors to this volume mourn what is lost but the loss is often ambiguous. We explore what it is to have a disability, particularly an invisible disability, and how ableism compounds our problems. We negotiate terms like "normal" and "recovery." We describe what it is like to become strangers to ourselves and the people who love us. What we had cannot always be recovered, but sometimes we are surprised by what else we find. We recreate identity as we recover our creativity. Our understandings are embodied and visceral.

One of the people we encountered during the creation of this anthology was Dr. Shree Bhalerao, a psychiatrist at St. Michael's Hospital's Neuroscience Research Program and an associate professor at the University of Toronto. Our anthology was so novel that he and his team designed a research project around the works you are about to read. We are delighted that women asserting themselves as experts on their own experience will add to medical knowledge and potentially change medicine's approach to treatment. And we too learn from Dr. Bhalerao. For example, the terminology around concussion and TBI is ever-changing. Many contributors refer to post-concussion syndrome (PCS), a term that may be falling out of favour with specialists but remains in common use as of this writing.

We include three works that focus on caregiving and concussion because most caregivers are women and caregiving is another way that women experience concussion. In each case, the complexities of the issues explored are compounded because the caregivers have also had concussions. In one case, the caregiver experiences concussions in tandem with her son. Caregivers also face a lack of support, and struggle to find useful information and treatment.

During the editing process, we were delighted to find that Kyla Jamieson's poems could offer both a pause from the longer forms and also a thematic frame for each section. The section titles are phrases borrowed from Kyla's poems and, in one case, from Chiedza Pasipanodya's inventive work. WHERE TO BEGIN focuses on works that express the difficulties of coming to grips with one's injury. AM I GETTING BETTER includes works that detail the challenges of time passing and the injury remaining. NO LONGER THE PERSON I WAS is about the processes of rebecoming, even as the new destination remains unknowable. The works in I DREAM OF SWIMMING reference the recovery of creative practice, with connections to swimming and bodies of water. The final section, CARRIED THROUGH ALL THAT, includes several works about and by caregivers, as well as a meditation on limits by Julie Sedivy.

The injuries described in these pages cover a broad spectrum of severity. Some of the writers can no longer work in their fields or, at times, work at all. Some have limitations on their physicality. Some have lost their social connections and have become isolated. Some have grave difficulty reading and writing, which is shocking for writers whose ability to read and write defines them. The physical and mental effort it took for some to write for this project cannot be overstated.

The editing experience itself can be summed up by a line in Anna Swanson's essay. We "coped in the moment without collapsing because there were deadlines and the stakes were high." As editors, we made difficult choices. Many of the works were more fragmented in their original forms. While fragmentation matches the experience of concussion and TBI and we admire the effort to match form to content, fragmentation can be difficult to read. We had to find a balance between honestly representing the voices of writers and the choices they made against the demands of readability. Additionally, every work within these pages considers symptoms, and some works we would even describe as "symptom heavy." Listing symptoms is an essential part of each person's testimony, a wayfinding method that says, I am here, this is what is happening to me, this is who I am now. We are not our symptoms, of course. But naming symptoms helps us acknowledge this newly inhabited territory, this self that has become (or is becoming) increasingly foreign and unknown to us. In this regard, the editors have erred on the side of repetition, in part because it lends credibility to the accounts and speaks to shared experience. And readers should know that in almost every work, there were originally more symptoms mentioned than have made it to this final version.

On the other hand, naming is reductive. Lists of symptoms have to be accompanied by story. Within story, anything is possible and anything can belong. A childhood bicycle ride through Toronto. A recipe for beef and cucumbers. A harrowing security check in the Seattle airport. All of this adds dimension and complexity. In the works ahead, details are included meaningfully and with discernment and in a way that heightens the reader's understanding and fosters emotional connection.

Every brain injury is different, and every woman is, too. Our concussions were caused by sports injuries and car accidents and falling out of wheelchairs, by bumping heads with loved ones and other seemingly minor accidents, and by brutal intimate partner violence. There are difficult works ahead. Let this be your trigger warning. But there is also joy.

We have learned that a shattered narrative is still a narrative. We live in the moment, doing the best we can, sometimes unable or unwilling to get back to our pre-concussion selves. Brain injuries wreak havoc on our identities. We exit the world. We hide in dark rooms. We rage and cry and lose hope. Where once we pushed ourselves, we are withdrawn and careful. We are no longer ourselves. We miss our most cherished pleasures. We miss the aspects of ourselves that were unique to us. As Julie Sedivy writes, "We are defined, I think, not by the average bulk of what we do in a day, but precisely by what we do at our edges, at the very limits of what we're capable of." She concludes, "To have those boundaries blur and soften strikes at the heart of who we feel ourselves to be." Many of us do not know what lies ahead, yet we still look ahead.

If you are a woman with a concussion, we want you to know you are not alone. The editors are deeply grateful to the women who have laid bare their altered lives in this book. In doing so, they are advocates for all women with brain injuries. The book has become more than what took root way back at Elaine's kitchen table. There is art, humour, frankness, devastating truth, sisterhood, and hope. In sharing their most vulnerable selves through these works, these women create and add to a new body of knowledge about the lives of women after concussion. As editors, we have learned more from this group of writers than from any other source. They offer us the knowledge we needed when we were first injured and still need today.