Returning: a memoir of home, place, and identity

Claire Christine Crisp

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Caveat lector: some names and places have been changed to preserve the anonymity of certain persons and events.

Note To The Reader

Writing involves taking calculated risks. That is especially true when writing creatively. World-building is hard to do. This is my second significant piece of creative writing, having previously composed a memoir about the circumstances surrounding the diagnosis and treatment of my third child. The book, *Waking Mathilda: A Memoir of Childhood Narcolepsy* (2017), was the culmination of three years of blood, sweat, and tears, as well as many, many revisions. This is a very different project, and it has a very different tone. It is much more about the author, and about matters pertaining to large, amorphous concepts like *home, identity, belonging*—things that it is difficult to pin down, conceptually speaking, though they are ideas that shape us in fundamental ways even if we don't think about them every single day. The work is also much more episodic. *Waking Mathilda* was a more conventional story, and followed a basic narrative arc: beginning, middle, end. This work is, in many respects, non-linear. The focus is not on a chronologically sequential narrative structure (first this, then that, then the third thing, and so on, each event following the previous one in a single timeline). Rather, the emphasis is on episodic content: a moment when a particular event occurred, or a memory of a something important, or an experience, a thought. It is not the stream-of-consciousness of, say, *Mrs Dalloway*, and the different episodes take place over a longer period of about two years—roughly, from the summer of 2019 to the summer of 2021. But it is nevertheless about moments, and about memories, of transition. Given that this was written in a time of great change and upheaval for many people, that seems appropriate. In fact, the COVID-19 pandemic forms a kind of invisible thread throughout the different episodes of this work. If there is not a narrative arc holding the different pieces together there are elements and themes that recur like leitmotifs in a great piece of orchestral music. The pandemic, and its deleterious effects on all of us, is one such motif—refracted through my own experience. In a way, these occasions and my reflections upon them are a means of recounting aspects of the human condition (i.e., universal themes) through the lived experience of a particular individual. Thus, there is still a narrative of a sort standing behind the different episodes. But it is a story with a non-linear structure.

For these reasons, the authorial voice in this work is also much more fragmented than in my previous work, or in a more conventional piece of creative writing (‘conventional’ in the sense of following the traditional practice of a story with a beginning, a middle, and an end). There are chops and changes, moments of lucidity, times where the author seems confused or lost, grasping for meaning in the midst of the confusion that has attended the last year or more of living through this enormous global upheaval. To begin with, that was not intentional but simply a byproduct of setting out to write as I have. However, as I came to edit the work, and put the different pieces together, that sense of fragmentation seemed to ring true to what it meant to live through this strange time. It was a way of showing rather than telling the reader how life in the pandemic, and reflections that occurred during that time, pick up on the uncertainty and difficulty of *living through* the dissolution of much of the fixtures of daily life, and the reorientation and recalibration of the quotidian that ensued. This should be borne in mind in reading the pieces collected here. In one sense, they form a whole composed of various parts written in this specific time. In other respects, they are disparate parts, pasted together. But that is also a reflection on life in the pandemic: it has so often felt as if life was reduced to discrete moments that we have had to cobble together for ourselves because the narratives that shape our lives have given way in the face of the corrosive effects COVID-19 has had on the way we live. We evolve as a species, and maybe the pandemic is a practical example of that; this work has evolved as well. It is a record of one writer's life living with its deleterious and discombobulating effects.

ONE

Court cases

The scene inside a London courtroom in September 1973:

> —a young girl stands on a stool in the dock. She is enclosed in what she thinks is a small wooden house with a dusty floor. It smells of old things and is not a place to stay or play; there is nothing to do in there although it could be a good place to make a pretend home, with a friend, like the corner of her classroom at preschool. It lacks what is needed to make it fun--dressing up clothes, play food, a toy oven. There is no make-believing here in the court. No creating. No distractions. No way of escaping. All she can do is listen to the voices, men's voices that are speaking loudly from the other side of the room. She can also hear what sounds like a typewriter clicking in the corner. Today is an important day. She knows this because it is a day out of school, and earlier, her mother dressed her in a new yellow plaid wool suit, that was itchy on the legs and tightly fitted in the shoulders, making

cartwheels on the walk from their flat impossible. As her thick hair was being straightened in preparation for the important morning, there were firm instructions to stay looking neat. To be polite; to answer *all* the questions.

—it is a test. If the girl passes, she gets a bag of sweets and a small piece of paper that says the name of her new Dad. She cannot know that she will also get a new birth certificate; one that changes her age and last name for years to come. It will be presented to her on her 7th birthday with a brief explanation on adoption then locked away again, this time for a decade in a black box inside the home filing cabinet.

—one of the men wearing suits leans over the wooden house and, in a severe voice, asks:

What is your name?

What is the name of your baby sister?

What do you like to play?

Do you obey your parents?

How do you like your new home?

She must have answered correctly between thoughts of getting out of there and trying not to fail the test because before they leave, a man in a suit leans into the wooden box and gives her a brown paper bag. Inside are sweets. The same man says, ‘*Congratulations! Is it not every day a girl gets a new father!*

—when my new Dad carries me home to our flat in West London, less than a mile away from the courthouse, I remember clutching the bag of sweets ever so tightly, wanting to savour them alone. I might have forgotten the ride up to the seventh floor of Highfields tower block in Feltham, but for a young man who entered the elevator at level three. Held over my Dad's shoulder by what felt like pride or perhaps protection, I thought about what might be inside the bag that was now wet from the rain and soft on the bottom. The man turned to the corner of the lift, undid his flies and peed like he was alone in a bathroom.

—I write this now, remembering how my mother had walked on ahead, without us. There is an acrid smell of ammonia in the lift and the wet bag has dropped, the milk bottles bleeding in colours by the man's feet. I see the sherbet fountain soaking in umber-coloured urine and the rainbow chocolate buttons dissolving along with my desire to belong to that place high up in the sky or to him.

* * * *

When the World Health Organisation issued a statement declaring the 2009 swine ’flu a global pandemic, thousands of young children across Europe received a vaccine to prevent them from contracting the H1N1 virus with its potentially severe systemic complications. The vaccine, developed by Med-Tech One, a pharmaceutical giant based in Chelmsford, U.K., was rushed into production, testing, and distribution because governments across Europe needed the vaccine quickly and cheaply. And on an unprecedented scale. Panic over the 2009 swine ’flu prompted authorities to act urgently, issuing immunisation protocols to protect the most vulnerable. This group included the elderly (those over eighty years old), and the very young (the under-fives). General practitioners in England, financially incentivised to vaccinate as many people as possible, sent out letters to parents of children under five between October and Christmas 2009.

A letter arrived. Addressed to the parents of Mathilda Crisp, it contained a warning: ‘the failure of your child to receive the H1N1 vaccine could result in serious complications and high rates of admission to critical care units.’ A second letter from the ENT (Ear, Nose, and Throat) department at the Bristol Children's Hospital reminded us that Mathilda, then three years old, was still listed as a ‘failure to thrive’ on account of a minor respiratory condition from birth. It was true. Mathilda was born with what the medical professionals called a floppy larynx, was delayed in various developmental milestones as a consequence, and was still on the small side when compared to her siblings at the same age. The letter urged us to consider the new H1N1 vaccine.

Two things in particular stick out in my mind from this time. First, as a family none of us had ever had a ’flu vaccine. Second, we had no idea that the vaccine Mathilda received on January 16th, 2010, was adjuvanted with AS03, an oil-in-water solvent approved by the European Medicines Agency. Later, when urgent questions were being asked (by scientists in the USA and their colleagues in Finland) over the safety of the H1N1 vaccine, we learned—along with hundreds of other families—that AS03 had been effective in diluted doses, but only in H1N5, a cousin to H1N1.

> *Adjuvant:* chemical(s) added to a vaccine to boost efficacy by stimulating the body's immune response. For example, Squalene from whale liver, which was an adjuvant in chemical anthrax, an agent implicated in Gulf War Syndrome.

We would come to understand why Mathilda collapsed, in January 2010, a week after receiving the H1N1 vaccine. We would also slowly comprehend why she began hallucinating at night instead of sleeping, and why, to this day, she loses control of her body and collapses whenever she is happy. However, the journey to a correct diagnosis took months, delayed by clinical incompetence, and further complicated by misdiagnoses: a cerebellar tumour, epilepsy, muscular dystrophy, end-stage Lymes disease, and psychosis. Somewhere in the mess of those months spent in and out of the Bristol Children's Hospital, I also secured a provisional diagnosis—that of Munchausen syndrome by proxy (MSBP). This was never relayed to me verbally by the staff, though I had questioned why it was necessary to draw Mathilda's blood every eight hours throughout each admission—their response always being that her results had been lost in the lab. It was only years later when reading through a copy of Mathilda's medical notes when researching *Waking Mathilda* that I saw it documented--'*possible drug abusive by mother. MSBP? Referral to psych? Need to question father. Observe behavior of siblings.'*

> *Narcolepsy:* an incurable sleep disorder affecting 1 in 2,000 people; 3 million worldwide. Characterised by rapid-eye-movement (REM) intrusion, hypnogogic and hypnopompic hallucinations, sleep paralysis, cataplexy, and excessive daytime sleepiness. Auto-immune in origin. It is always caused by the destruction of approximately 70,000 hypocretin cells within the hypothalamus.

The change in Mathilda began in late January 2010, when at night around 9 pm, her sleep became elusive, unrecognisable. Mathilda would moan, grunt, shriek with fear, thrash around the bed, wake up, cry until we held her for as long as it took to calm her down. Sometimes this meant carrying her downstairs, putting on the lights in the kitchen and sitting her on the countertop while one of us made tea. After waking her fully for as long as an hour, we would try again and put her to bed. There may have been slices of silence when I thought she had achieved sleep, but they were not long enough for me to relax to a point where I could find any of my own. The long hours at night became weeks, months of sleep deprivation that became exhaustion on a level I had never before experienced. Looking back on those nights, what was worse than the wakings were the times Mathilda who was three years old at the time, told me that she was breaking to pieces. Incredibly, she may have been articulating a process of cellular demolition that was happening in her hypothalamus. I have wondered since if the 70,000 neurons needed to regulate sleep and wake cycles were lost in one go, on one night. Or were they slowly destroyed during the weeks and months during which her health dramatically declined? Either way, we saw the symptoms of something profound that coincided with a distinct change in her personality. We were losing her. And, other than the complex, bizarre presentation of symptoms emerging, that was all we knew.

In February, there was an abrupt decline. The nighttime hallucinations became sinister and began with the bullfrog night. I had rushed into Mathilda's room after hearing her cry out, ‘Get it off me! Mummy! It's on my tummy. Get it off!’ By the time I was in her room, she had already hit her head on the wall and was lying semi-paralysed in a dreamlike state on her back. She had seen (and smelled) a giant bullfrog filling the room, and felt it bounce on her stomach. Its front legs around her neck. Its face in her face. Despite efforts to console her, Mathilda remained unreachable—a state which we came to understand as sleep paralysis. Though Mathilda could hear me trying to comfort her, she was unable to move or respond for ten minutes or so. I switched on the light and lifted her into my lap, talking gently of her being safe and reassuring her that there was in fact, no bullfrog nearby—that she was in her room, with me, safe. I felt she needed to wake up fully and took her down to the kitchen where Oliver had made tea. He and I exchanged alarmed glances but talked of mundane things, while she sat on the counter, her body still shaking, her face red with tears. We had no explanation for what had just happened, no idea that the hallucination Mathilda had, was one of the hallmarks of narcolepsy and that they would return each night until eighteen months later, once she was medicated.

> *Hypnogogic and hypnopompic hallucinations:* vivid, multi-sensory episodes that punctuate sleep—usually terrifying, realistic and recalled in exquisite detail. Hypnogogic hallucinations occur during the process of moving from wakefulness to sleep. Hypnopompic hallucinations happen during the process from sleep to waking. Such hallucinations are specific to a diagnosis of narcolepsy and are not to be confused with the more generic phenomena of night terrors in children.

After the bullfrog night, I took Mathilda to our GP, one of several visits before we noticed something else. Mathilda began falling asleep at random times during the day in very inconvenient and often dangerous places-- a supermarket trolley, during a swimming lesson, on the beach with her head in the sand, and even in the bath. I found her passed out on top of board games, folded over the top stair on the landing, and once when I asked the kids to get in the car, on the driveway. Mathilda lay on the tarmac by the passenger front wheel while the older two children had strapped themselves into the back seat. It was not safe to take my eyes off her for fear of some serious injury. Oliver and I drew up a twenty-four-hour supervision schedule switching out nightshifts and daytime care around his work commitments in the week. Liberty and Elliot, our older two children who were ten and eight years old respectively, took on much of the housework, answering the phone and helping each other with schoolwork. I cut corners on things like food shopping, opting for weekly deliveries of ready-made meals, something I had not done before.

> *Excessive Daytime Sleeping (EDS):* an overwhelming and unavoidable urge to sleep during the day. Naps might last minutes or hours and frequently occur throughout the day—characteristic of narcolepsy type 1 and 2, sleep apnea, idiopathic hypersomnia and parasomnia disorders.

Of all the symptoms Mathilda developed in the spring of 2010, cataplexy was the most disturbing and dangerous. It was impossible to ignore what by now looked like drunk walking, known in clinical terms as Ataxia. More than that, whenever she was excited about something, like jumping on the trampoline, or when someone made a joke that she found amusing, her tongue would thrust out, her head would bob, and her knees would buckle, finally giving way to complete collapse. We didn't make the connection then between her feeling happy and at the same time experiencing muscle paralysis or understand what she meant by having ‘the floppies.’ Still, the sudden episodes where she remained conscious but paralysed, took us into the A&E at the Bristol Children's Hospital more than a half dozen times between February and April of that year. By that point, she had also gained over twenty pounds, become incontinent, and we, as a family, were housebound.

With all the symptoms adding up on the final visit, Mathilda was admitted to the neurology unit with a cerebellar brain tumour as a provisional diagnosis. Once that was ruled out, other suggested diagnoses (epilepsy, muscular dystrophy, leukemia, and Lyme's disease) led to further exclusion tests--MRI's and CT scans, blood work, x-rays, and EEGs.

> *Cataplexy:* muscle atonia triggered by sudden, strong emotions such as laughter, fear, anger, stress, or excitement. A highly specific and disabling symptom of narcolepsy where the patient is fully conscious but unable to move. It can lead to injury, avoidance behaviours, social withdrawal, poor psychosocial health, and co-morbidity issues.

Given that the various tests returned either negative or inconclusive, the team led by a consultant paediatric neurologist settled on a psychogenic diagnosis and a referral to CAMHs, which was the Child and Adolescent Mental Health unit. The consultant, a balding forty-something man had grown increasingly frustrated with the lack of answers and by May of that year believed the answer to Mathilda's illness, whatever that might be, lay with me. I was by this time already a suspect in her case: a putative abuser drugging my child, hoping to receive their attention though her blood work was tested every eight hours. But their calculations of Munchausen syndrome by proxy never held up. Those months spent driving back and forth between home and the BCH were fraught with anxiety, not knowing what new symptoms might emerge next or if she would ever sleep at night, ever wake for more than twenty minutes in the day without losing consciousness. Oliver was trying to hold down his job as an academic at the University of Bristol and relieve me when he could by cycling home early so that I could take a nap before the evening bought forth another nightshift. I struggled to educate Liberty and Elliot, manage our lives in the house, and keep it together. Never had we experienced such extremes of exhaustion and heartbreak, and at times, I wondered if we as a family would survive. In the afternoons, when Liberty and Elliot were playing upstairs and Mathilda was asleep in the lounge, I would take out a notebook and journal. Often, in those quiet moments, I would watch Mathilda and feel shame for the frequent thoughts I had about leaving—walking away, alone, toward the sun with a bottle of water. Images of dusty roads that led nowhere in particular were strangely comforting in that all I had to do during these visions was put one foot in front of another. More than that, I never had to see her suffer. For those few moments when the sun beat down on my back it seemed that abandoning them would somehow stop all our pain. It felt as though someone had cut open my chest, put their hand inside and ripped out my heart.

As far as miracles go, only a day or so after the two of us were deemed psychiatric cases, we were rescued by a man called Siddarth Shah, a doctor from Ahmedabad. The resident consultant paediatrician went on leave and had Mathilda transferred off his ward. The rest of the team, primarily junior doctors on rotation, headed for the new admissions, more important cases or ones they might solve.

On a wet Friday in May, Mathilda was still lying in a bed as an outlier in a renal unit when Dr Shah, a locum paediatric consultant, asked to see us. Mathilda, characteristically gripped by sleep, looked small, lost in the hospital bed with safety rails. Oliver had just stepped off a plane, having been delayed returning from a conference by the Eyjafjallajökull volcanic eruption in Iceland, and was angry with me for bringing her back in while he was away, and distressed over our joint referral to psychiatry. I was exhausted, emptied, unable to explain the team's incompetence or why Mathilda had been transferred to a ward dedicated to patients with kidney disease. My parents had just taken Liberty and Elliot home, my Dad visibly frustrated with Oliver for having been out of the country on a work trip when Dr Shah arrived. Somehow, the two of us summoned our recollections of. the last six months and told it all to Dr Shah, who stood calmly by Mathilda's bed without taking notes. He listened, asking the odd question here and there, like can you describe her floppies? How often does she fall asleep in the day? How much sleep have either of you had in the last two months? Have you taken her out of the country? Apart from our recent year in Princeton, our lives until the January of 2010 had been unremarkable. Mathilda had been healthy, beginning to reach developmental milestones, trying to keep up with her older siblings, learning to read even. After an hour or so, he told us we needed a break and to get home for the weekend but to return with a record of symptoms, all the times she fell asleep, collapsed, slurred her words—photographs and film that might show what the team had previously missed.

Three days later, I took Mathilda back to see him with the video footage he requested, this time to the clinical investigations unit. It was easy: filming Mathilda asleep, wobbling her way between the rooms of our house two miles from the hospital, tongue thrusting, knees buckling every time she felt happy. I managed to capture on video several hallucinations in the dark of her bedroom, screaming for her legs to be sawn off because of a new pain that had developed in her ankles. Dr Siddarth Shah looked up from the images he had downloaded onto a screen in a small room, somewhere in the windowless corridors of the clinical investigations unit, deep within the children's hospital. It came to him, then. I sensed a shift in the air as he watched them twice again before announcing, with absolute confidence, that he knew what it was.

Narcolepsy.

Though he had never seen the condition in a child under seventeen, this, Dr Shah said, was a clear case. Cataplexy, the hallmark of Narcolepsy, was the giveaway symptom. All that was needed to confirm the diagnosis was another blood test—this time to run Human Leukocyte Antigen (HLA) typing and identify the genetic marker for narcolepsy type 1. By this point, Mathilda had become afraid of male doctors and was already refusing this round of blood work, crying in the stroller, pulling her arm away. She could see the needles being prepared, sense what it meant when the doctor moved toward her. On this occasion, it fell on me at that time to pin her down and subject her to another tourniquet, another needle and risk losing her three-year-old trust in me as a caregiver and protector. Somehow, I believed his assessment enough to put her through it again for what I naively thought might be the last time.

But then, his assessment made sense. The diagnosis, albeit provisional, rang true. It was there all along, hidden in plain sight. And, as the tourniquet released, while Dr Shah went about labelling the six vials of blood, I played the word narcolepsy over and over and allowed myself to cry.

> *HLA DQB1*0602:* the genotype identified in the clinical expression of narcolepsy. Associated with hypocretin deficiency in CSF. The HLA-DQB1*06:02 allele is strongly present in over 98% of individuals with narcolepsy type 1.

I walked Mathilda home in the pushchair she had years outgrown, relieved that although narcolepsy was not curable, it was not a death sentence. Dr Shah had not explained much about the condition, but on some fundamental level, I understood that our next step would be to find a treatment that would help her sleep at night and stay awake in the day—medications that might improve her quality of life and in turn, ours. I had no idea that would require leaving the country, our three-bedroom semi-detached in Bristol, our friends and family.

I found Oliver at home in the kitchen. He looked up at me expectantly as I walked in, having left Mathilda asleep in the car. He was seated on an old rocking chair we'd picked up years ago in an antique shop after our honeymoon at just the right height to hold me around the waist. I said the word narcolepsy. I told him that the blood results at the end of the week would confirm the HLA-typing. And that Dr Shah had made the provisional diagnosis based on the videos, particularly the ones showing cataplexy. The more we Googled the word narcolepsy, the more the last six months made sense, though not once did we ever come across an online case of a child with the condition. We absorbed the basic facts: a life-long brain disorder, destruction of the sleep centre in the Hypothalamus characterised by terrifying hallucinations, excessive daytime sleepiness, and sleep paralysis—where people with narcolepsy wake up but are physically unable to move, their muscles locked. This was new. Mathilda would often wake from a nap but lay frozen still for several minutes, looking deathly. As I read out the various sources, wanting to know more, Oliver left the room, needing time alone. And, other than calling our parents that day, neither of us bought it up again. No amount of information would change what we were facing in the next few weeks, months, years.

Oliver's fears centered around Mathilda needing care as an adult, and not being able to live independently. The reality that we might be caregivers for the rest of our lives was beginning to dawn on us. We were both desperate for sleep: hers and ours. Desperate to spend time with the older children, desperate for answers which might lead to hope. From nowhere, Dr Shah had swept in, out of the blue it seemed and solved a clinical mystery that had eluded a team of leading doctors trained at Great Ormond Street Hospital, specialists in paediatric neurology. I had foolishly expected Dr Shah to come up with a treatment plan at our following outpatient's appointment, which was several weeks later. Even locate and provide treatment through the NHS. It never occurred to me that he would not show up--that he was only covering a two week leave of absence.

His abrupt return to Ahmedabad put Mathilda as an outpatient back in the hands of the original team, who, despite the confirmation of a diagnosis of Narcolepsy, still thought the two of us psychologically disturbed, our relationship untenable. Melatonin and modafinil, a wake-promoting agent, were prescribed, but they did little for her. To my mind, what Mathilda needed was to be able to sleep at night, a medication that would help her achieve deep, non-REM sleep.

That summer, we spent time hunting down sodium oxybate (Xyrem), the only medication approved to address both nighttime and daytime symptoms in narcolepsy. Unavailable in Bristol and unable to find a doctor, even a sleep specialist who would prescribe it to a three-year-old anywhere in the UK, left Mathilda untreated and me without hope. For the first time, Oliver and I began to think about getting an opinion abroad, knowing by now there were several experts located in Europe: Paris; Bologna; and Milan. We still did not know then why Mathilda had developed Narcolepsy or that her diagnosis at three, already collected in digital patient data portals, classified her as the youngest narcoleptic in the world.

The connection between the onset of Mathilda's narcolepsy and the H1N1 vaccine came soon after. In September of that year, a few months following the diagnosis, I received a call from the Center for Sleep Disorders in Stanford University, California. A team led by Professor Emmanuel Mignot followed new research emerging in Finland that had identified an unprecedented rise in especially young cases of narcolepsy—typically seen in young adults after contracting mononucleosis, strep-throat or seasonal 'flu. Hundreds of children were being diagnosed with narcolepsy; their data collected in Finland, Sweden. Norway, Denmark. Research confirming the link between the H1N1 vaccine, its As03 adjuvant, and the rise in childhood cases of narcolepsy were months out from being published in scientific journals. But already the link was made, implicating a specific pharmaceutical company responsible for the vaccine and the European governments that had sanctioned and distributed an untested immunisation program during the swine ’flu pandemic.

> *Swineflufix:* An H1N1 vaccine approved for use by the European Commission in September 2009, following a World Health Organisation (WHO) declaration stating swine flu a global pandemic. Found to be associated with an increase in cases of narcolepsy.

Britain, however, was the last to admit the connection. It was even slower to settle court cases with the pharmaceutical industry for the hundreds of paediatric cases of narcolepsy. Sweden had already awarded damages to vaccine damaged families. Norway and Finland followed suit within the next year, compensating young children for the brain damage inflicted by the rushed vaccine. By then, we had already moved our family to California to secure treatment and expert care for Mathilda at Stanford University, with Professor Mignot as her specialist. In 2011, it was another move for our family, but this time, not for tenure.

Years later, I located Dr Shah via email and had begun authoring a book about our journey as a family. It was intensely important to me to thank Dr Shah for sweeping into our lives for those few brilliant hours in the May of 2010. I let him know how Mathilda was doing on Xyrem, the frontline treatment at the time, and how we, as a family were making a new life in Los Angeles.

His response reached me one hot morning in July. I was sitting in the front yard at Shadow Grove in Pasadena, laptop open, when I saw his name slide across the top right-hand corner of my screen.

> Dear Claire, Mathilda and family,
>
> I am delighted for you all. I do remember seeing you on the renal ward at the Children's Hospital, and then us meeting up at the CIU. I am extremely happy that Mathilda received appropriate treatment and has grown into a smart young lady! I am humbled by your kind words. I cannot describe how much it means for you to take the effort to find my email and write to me.
>
> I have left Bristol and relocated to India (my hometown Ahmedabad). The fewer resources and less training opportunities out here means I have a greater chance to diagnose and manage sick kids with neurological disorders who need it.
>
> Please keep me updated on the progress.
>
> Best Wishes,
>
> Siddarth.

Several years earlier, just after arriving in Los Angeles, Oliver had seen an article in *The Guardian* that caught his attention. To stay up to date with British news and culture, he had ordered a weekly delivery of several UK newspapers early in the transition to the US because we felt adrift, disconnected from home and family. It was a way of staying in touch with the U.K., reading the papers on the weekends—something we had done for years.

The headline read: ‘Swine flu vaccine can trigger narcolepsy, UK government concedes—Review of fresh evidence finds jab given to million people in Britain can occasionally cause sleep disorder.’ The article quoted research on four to eighteen-year-olds by the Health Protection Agency, which found a high correlation between the Swineflufix vaccine and a rise in the abrupt onset of sleep disorders in children. Following a paragraph explaining the nature of narcolepsy, the welfare minister at the time, Iain Duncan Smith, was quoted saying, ‘It has been accepted that, on the balance of probability, vaccination has contributed to disablement.’

The article also defended the Government's decision to recommend that children be vaccinated based on advice received from the European Medicines Agency. A Department of Health spokesperson was quoted saying: ‘Swineflufix was developed specifically for use in a flu pandemic when the number of lives lost, and serious cases could have been enormous.’ Other statements from the manufacturing pharmaceutical company defended their commitment to patient safety, how the research was a priority and how narcolepsy was a complex disorder to understand and navigate:

> Patient safety is our number one priority, and we are actively researching how Narcolepsy is triggered and how this vaccine might have interacted with other risk factors in affected individuals. We hope these ongoing research efforts will enable us to provide more answers. Narcolepsy is a complex disease, and its causes are not yet fully understood, but it is generally considered to be associated with genetic and environmental factors, including infections. We remain committed to pursuing additional research to understand the association between Swineflufix and Narcolepsy and continue to support the research of others who are investigating reported cases.

It was not the first time we had seen the possible connection between Swineflufix and narcolepsy hit the headline news, but this article listed a legal firm in London representing families in the UK through a group action claim, stating that young claimants adversely affected by Swineflufix qualified for compensation. There was more. Martin Latimer, representing multiple claimants, highlighted that the drug company had instigated an indemnity clause—a contract with the British Government releasing them from any financial fallout should the vaccine be proven to cause long-term physical damage. In other words, if families with narcolepsy won their cases against the pharmaceutical company, it would be the government, at the end of the day, that would foot the bill.

The article concluded, ‘The government is to reverse its stance on the safety of a swine flu vaccine given to 6 million people in Britain and accept that on rare occasions, the jab can trigger the devastating sleep disorder narcolepsy.’

Oliver called me over to the table in the kitchenette where he had spread out the newspaper. We were still in rented accommodation at the time, a year out from finding our house on Shadow Grove. The older two children were at their new school, Mathilda home, struggling with the side effects of Xyrem—which included nausea, headaches, anorexia and struggling to attend kindergarten at a local school. I read the piece, pausing on how many families in the UK had come forward, how the link between the Swineflufix vaccine and narcolepsy was no longer a debate but a multiparty legal action against a giant pharmaceutical company. We already knew Swineflufix had caused the destruction of Mathilda's sleep centre located deep within her hypothalamus. We knew she would not recover those brain cells or ever function without medication, but that it was public knowledge I felt was validating. The idea that justice might be done for her was also unexpected. At the very bottom of the article, in small print, was an email address. And, within a week, Mathilda had become Martin Latimer's 81st case.

* * * *

London, EC1 February 20th, 2019.

I walked across London at 7 am on a sunlit morning in February, pulling a small suitcase, dressed in what I thought was suitable attire for a day where I would give evidence. A trouser suit, flats, and a wool wrap when outdoors, bracing myself for a week in winter weather. As it turned out, it was unseasonably warm that week with temperatures in the low ’70s, so I sweated my way between the room where I stayed near Chiswell Street and the offices of Addleshaw Goddard on Milton Gate.

For the past nine years, Oliver and I had worked with a team of lawyers to build a case demonstrating that, without doubt, Mathilda had been vaccine-damaged by Swineflufix. The science was there. Multiple individual cases of young children with narcolepsy were already successfully compensated, and all within the group action claim led by the lawyer Martin Latimer.

By then, almost a decade of research published in sleep journals had established a link between a sudden rise in paediatric narcolepsy and the 2010 H1N1 vaccine endorsed and distributed by the British Government. In preparation for our meeting, Oliver and I had given countless interviews and testimonies. We met with Martin regularly as well as other legal team members he had instructed to pull documents, medical notes, occupational therapy assessments, and school reports. During those years, the most challenging times were when we were asked to provide witness statements, pages of written content that told the story of our family and our marriage, encroaching on deeply personal details.

As a rule, Oliver and I wrote the statements out individually and interviewed separately, but because our retelling of events had to align, there were times when we also had to present a joint report for the team to scrutinise before the final prosecuting submission. We told the journey over and over again. The same onset of symptoms, the same visits to the BRI, the same moment of diagnosis, the same struggle to get treatment in the UK, the same decision to leave. But we could only ever manage an hour of reliving it all at a time. Sitting down on weekends and focusing on what Mathilda had lost amounted to recalling her suffering and facing up to her future—the realities that lay ahead. Often, he would say that it was *too much*. Which it was. When the hour allocated to the 'reliving' was up, he would take himself off, usually to the bedroom and close the door. I wanted to seem brave and would wait a while before going into him. More than that, I wanted to be supportive, though often, after our 'reliving,' I could not find a way to draw him out. All those meetings with each other and the team left us both emotionally drained, the weekend ruined.

'I need to think about something else, do something else,' he said lying on our bed after one particularly upsetting session. Knowing better than suggesting we head out somewhere when what he needed was time out, I sat beside him and reached for the body lotion on the nightstand.

'I know it's hard. Lots of people give up or settle early because they can't hang in there emotionally. But this will be worth it,' I said rubbing cream into his hand—something he found soothing.

'Will it? Really? What makes you so sure we will win this?'

'Because Martin is so thorough, and Mathilda is such a severe case. And don't forget, all the published data from Finland and the US. How can they deny it?'

'They have the best lawyers, Claire. Martin is a good chap, and I am sure he is very good at his job but you're talking about going up against a multi-billion-dollar pharma company who are more worried about reputational damage than the people they injured,' he said giving me his other hand.

'Exactly! Reputational damage limitation is precisely why they will pay up.' I said, wanting to encourage him, to convince him that it was worth the time, all the pain of reliving every detail.

Oliver was distrustful of a process that was, from his point of view, weighted against a three-year-old represented by a small no-fee-no-win firm located next to a Mexican restaurant near Euston Station. And although the government was picking up the tab on these cases, we were bringing charges against one of the largest pharmaceutical companies in the world who were paying top attorneys top prices. It felt at times like a legal version of David and Goliath, with only one shot at the sling. Working remotely with the legal team in London, we were living on Shadow Grove in Pasadena during those years, fitting the meetings around our jobs, often working in the small hours of the night, given the eight-hour time difference between the West Coast of the U.S., and the U.K.

Mathilda, for the most part, was responding well to treatment, and it helped that we had by then connected to various communities and were preoccupied with other things. There was our work and writing, and school events, and we were supported by a handful of friends who tried hard to accommodate our family schedule, which was always dictated by Mathilda's needs for naps and medications.

A final date was set for February 2019—the months leading up to the case's conclusion, were intense in that Martin had us both rewrite our personal statements considering the medical assessments that had been submitted by the defence team. At the last moment, we were asked to present the most recent medical notes, prescription receipts, and teacher’s reports, which threatened to undermine Mathilda's case. Despite napping in class every day, missing assignments, and being late on homework, Mathilda was a straight-A student. One reason for such good grades was that she had nothing else in her life outside of school, none of the extra-curricular activities in which many of her peers participated. Martin knew this but it was a considerable risk, he said, to submit the teacher reports, which also predicted a successful academic career with few accommodations required.

Another thing we did not anticipate was the coaching. We had already decided that I would be the one to go to London and that Oliver would stay back in Los Angeles. After all, one of us had to look after Mathilda since she still needed supervision through the night when taking Xyrem. Around a week before leaving, Vanessa, one of the paralegals, explained what I could expect from the day in court on a zoom call: that it would take all day, and that there would be food and beverages provided, and time out if I needed a break. That much didn't surprise me. But what I really wanted her to say was something more reassuring. Though I knew none of the team could make any promises, it was not clear that Mathilda would ‘win’ or what ‘winning’ meant, even though Martin had completed other Swineflufix cases. What the last nine years preparing her case amounted to in the end, was a settlement. A figure. A number. But what price point might compensate for brain damage and a young life ruined? No one could tell me.

I should have done a dummy run of the one-mile route between the trendy Travelodge and the Addleshaw Goodard building on Chiswell Street. The journey from Los Angeles had been straightforward enough, but it had been years since I had been to London, decades since I had commuted across the city as a student. The swell of people hurrying to work on foot carried me along back streets behind the Barbican before I began to doubt if the Concierge's instructions back at the Travelodge were correct. More likely, I had taken a wrong turn feeling overconfident after a long shower and meditation that morning, when I should have left on the early side given how important it was to be on time. Either way, without cellular data and the Maps app on my phone to fall back on, it was a homeless man outside a pub that got me in the right direction. Falling short of the simple task of getting from A to B quickly put me in a bad headspace. I was stupid, someone who couldn't find her way to Milton Gate from Clerkenwell Road on one of the most important days of her daughter's life.

An hour earlier, I had visualised the scene. I saw myself answer questions from the defending QC and legal team calmly, eloquently. I was sitting upright, looking serene. Not settling for less than a certain amount, a lump sum large enough that she could afford a paid caregiver if anything happened to Oliver or me. Failing, not an option.

Applying mascara in the mirror that morning, I reminded myself that if I had done this sort of thing before, as a four-year-old in a courtroom with little idea of what was going on, I could do it again. This time, as a much better informed mother. I would not cry. I could speak my mind—I was, after all, an expert on Mathilda and probably knew more about the nuances of narcolepsy than anyone on the case. But, looking in the mirror that morning I swung between the frightened and confused child of forty years ago, and the mother now advocating for her own daughter. Keeping it together throughout the long hours ahead was intensely important at the time as I put on a mask: an uncharacteristic amount of foundation, eye shadow, and lipstick. And although Martin had recently reminded me that nothing was certain, I packed up the hotel room thinking that the day would work in her favour. I could get on a plane back to California, knowing Mathilda would be able to afford the medications she would need for the rest of her life.

Not crying in front of either legal team may have been an unnecessary requirement, but it had something to do with wanting my family back in LA to be proud of me. Not just in securing Mathilda's compensation but also in a way that maintained our integrity, not giving over more personal information than they already had. Oliver and I determined that certain topics were off-limits—extreme behaviours that Mathilda had adopted as coping mechanisms and details around how her illness had impacted our relationships. She would, after all, one day be an adult who would only need to Google her name and find details of her childhood and our family all over the internet. Ahead of time, we had been contacted by the British press for interviews which, as a rule, I declined, not wanting her story to be sensationalised. But already, Mathilda was cited in scientific journals and radio shows in the US, and photos of her were being used by anti-vaxers on social media.

On reflection, my sense of resolve for that day probably had a lot to do with *returning*. I didn't realise it then, but this time, facing this legal hurdle, I wanted a voice. I wanted to be heard. Not as a four-year-old girl whose identity had been permanently altered in the courtroom years before.

Milton Gate was not what I expected. An imposing modern space, fronted by enormous sheets of emerald green glass, it looked out of place as if it belonged in the city of Oz. It stood out, taller than adjacent buildings between a mini-Sainsbury’s and the dining rooms on Chiswell street.

The road was narrow, crammed with cars and cyclists and a line of taxis dropping a flow of people outside the rotating doors, presumably for meetings like mine.

I entered the central core of the building twenty minutes late, hot and flustered. My Dad's words about always being on time, sitting up straight and walking 25% faster than everyone else, taking me right the way back to his lengthy ‘I am your father,’ lectures: how I should do better, be better, be like him. The only way to beat others at their own game, he would say after tellings off that had nothing to do with poor teenage posture or punctuality, was to do what he had done to ensure success. Look smart, stand up straight, shoulders back, and *never*—no matter what you are up against—*never* give up. And, as if he was speaking to me then and there, like I was 6, 10, or 13 years old, I felt the same sense of hopelessness. After all these years, I still didn't have what it took to win at life.

The atrium, like the rest of the building, was all immaculate clean lines and cool glass. After presenting identification at Guest Services, I was escorted by a security guard upstairs on a long escalator that stretched diagonally across the whole atrium, bisecting it. The team had already assembled inside the room designated for the proceedings, and on entering I had none of the confidence or calm I had felt earlier. Martin was there. For the first time, I met Andrew Sawyer, the QC on our case, who shook my hand, sat down again and promptly pushed a box of tissues across the table.

‘These are for you. Every claimant gets their own box,’ he said in a matter-of-fact tone of voice, pausing to pour himself a coffee. ‘Most people need them by the end of the day.’ I thanked him, resolved to myself not to need them and, straightening in my seat, asked nervously for the WIFI password.

Oliver dialed in from LA, appearing on an iPad like a bobblehead figure in the dark of our kitchen since it was 1 am Pacific Standard Time, and he had just given Mathilda her first dose of Xyrem. I brightened. It was good to see him if only on an 8-inch device, and with that connection came relief—not just that he would be digitally present all day, but that I could perform a task as simple as hooking up the tech to the internet. He seemed upbeat, optimistic despite being exhausted. During the introductions, we moved him around the room, sliding the iPad across the large desk as he met individual team members. He did a good job hiding what he had felt over the years, namely, that this was a legal game of sorts, one that our daughter may or may not win.

The team briefed us both before filing out of the room to meet the defence team next door. In the several minutes we had alone Oliver reminded me that whatever the outcome of the day, we had already done our best by Mathilda as her parents. And that we would find a way forward, together, regardless of the outcome.

I took him with me, holding the iPad carefully, worried that I might drop *it*, and drop *him* when taking the twenty or so steps between the two legal teams. They had an empty chair set aside for me, right in the middle of a large conference-style table: eight defence attorneys on one side of the table to our four on the other. I placed Oliver on the desk, directly facing their QC. The room went quiet. The atmosphere tense. No polite introductions. No niceties. Another box of Kleenex nudged carefully in my direction.

Over the next 10 hours, what transpired amounted to arguments back and forth over every detail of Mathilda's health, every assessment scrutinised, the damage to each part of her body as a result of the vaccine priced up. Arriving at an agreeable figure, what it would cost to provide Mathilda with ongoing care, and support at home if she ever wanted a family and medication for the rest of her life ultimately fell to us and a stable Skype connection. Andrew would go back to the room next door, carrying Mathilda's files (three oversized ring binders), and return, frustrated by what he felt were insultingly low offers. I was then handed a newly printed spreadsheet documenting the aspect of her life they had just discussed—line after line, of how narcolepsy had affected her and an acceptable price range for compensation as they saw it.

There were never any questions around culpability, given all the data collected in peer-reviewed science journals and subsequently reported in the media. There wasn't any doubt either about the havoc narcolepsy had wreaked on Mathilda's childhood or that she would suffer lifelong disabilities as a consequence of the vaccine. But the government official present at the proceedings was set on keeping damages to an absolute minimum, the defence keen to avoid reputational damage in the press—something they felt was within our power should the outcome not be in her favor. I had a platform on digital media, a book about our journey on Amazon and several articles on Mathilda’s diagnosis had already been published in the British press. It would not be difficult to link the pharma company responsible for causing Mathilda's narcolepsy with negligence given my following on social media, but it was not something I wanted to do. Unless I had to.

Lunch came. Halfway through the afternoon, a waiter wheeled in a trolley of cuts of salmon topped with capers, white square plates with quiche tartlets, matching mini bowls of tangy sauce for the sushi. Another followed with a wide selection of hot and cold beverages. Martin offered to make me tea, which I accepted. Earl Grey. I didn't want to seem like the ‘I never eat lunch type,’ but I wasn't hungry and what I really wanted was alcohol. On any other day, in another life, I might have tucked in, joining the office banter that had begun to surface. Instead, I switched Oliver off and went outside for some air.

Finally, just before five, the seven defence lawyers offered a final settlement and a statement of regret. I sat looking at them, and when they asked if I had anything to say in closing, I paused to give Mathilda a voice, find the words that might make meaning of all the arguments, the spreadsheets where her symptoms were listed as line items, our last nine years. I remember saying that no amount of compensation would restore her to us. Neither would it enable her to sleep at night and maintain wakefulness in the day, which they did without thinking. By now, the defence knew about cataplexy and how children like Mathilda avoid being happy and would go on avoiding joy so they might not collapse or injure themselves. And I asked them how they thought it was possible to carry on like that—if life was worth living without feeling or being happy. It was a question for the universe. There were no answers. I knew that, but I said it anyway. The room went silent. Martin leaned toward me and quietly asked if I was ready to leave as the claimant, having the final word.

At this point, Martin stood up first, gesturing that I should do the same. Only once Andrew, Vanessa, and the others began to file from the room did our opponents stand, heads slightly bowed like a bunch of cowed schoolboys, lined up with their hands behind their backs, in the headmaster's office, shamed at being caught out. It was the most formal proceeding of the day, and now that it was over, all that remained for me to do was sign the papers accepting damages and an additional contract stating we would not, under any circumstances, speak to the press.

In our room next door Oliver, still with us on the iPad, thanked the team for bringing Mathilda's case to resolution. He asked to be passed around to each person individually and speak virtually face to face. In turn, I did the same, thanking the team with a handshake, but when it came to Martin, my legs went to rubber. It wasn't a wave of relief that brought the tears then, but pain—a profound pain that spanned the last nine years, reliving it all these last nine hours. He held me momentarily, long enough to say in the absence of a cure, the money would go some way to support Mathilda when she reached adulthood and that as her mother, I had done my best by her. I cried then, not the animal sobs of years ago but quiet tears. It was the grief of losing one daughter and gaining another. It was knowing that the full cost of getting Mathilda treated had meant leaving our home in the U.K., and making a new one in the U.S. And it was acknowledging what that meant not just to Mathilda but our whole family, and how it had already redirected the trajectory of all of our lives.

Out on the street beside Milton Gate, I watched commuters disappear down side streets for some time until I realised I had no idea how to get to Waterloo Station. Do I go West? Which way is West? Left, right? Should I retrace my steps back to the Travelodge and figure out the route that way? Or get back to the Barbican and go from there? London, where I was born and raised and went to college and worked in my twenties, suddenly felt foreign, a place that belonged in my past. My parents and sister still lived here, along with more distant relatives and old friends, but beyond that, my connection to the place was as broken as the systems that had failed Mathilda. What I saw was streets crammed with healthy people hurrying home on foot and on bikes—people who belonged, people who knew where they were going. I stood long enough to see both legal teams leave the giant green glass Oz-building and head across the road together to the court dining rooms. Unexpectedly, I had the sudden urge to flee. I couldn't fully process, still can't say, what had taken place that day—whether it would, as Martin suggested, give closure, but the pull home to Oliver and Los Angeles gave me the sense of direction I needed at that moment. I stepped into the next cab that approached the rotating doors of Milton Gate and asked the driver to take the fastest route to Waterloo station.

TWO

Shadow Grove

> There are dead stars that still shine because their light is trapped in time.
>
> Where do I stand in this light, which does not strictly exist?
>
> —Don Delillo, *Cosmopolis*

August 2019:

I am standing on the steps of our home in California, waiting for an Uber driver to take me to Los Angeles International Airport. The destination is Scotland. It's a return move that has been planned for months, and I am about to do something I have done more than a dozen times over in the last twenty years—leave.

Looking up through the branches of oak trees overhanging the front yard, the sky screams with unfiltered light, the kind so piercing that without sunglasses it might cause migraines or even retinal damage. Before the 1950's, Shadow Grove was home to densely planted oaks and sprawling orange trees and was a place where cattle would find relief from the midday heat. According to local folklore, the site on which our home was built had been a place of refuge for cows and farmers, who at lunchtime would dwell under the oak trees and nap. This image of resting farm hands and sleeping cattle was easy to conjure as Brits who struggled with the soaring summer temperatures of Los Angeles and were living with our own version of sleepiness--we needed all the shade and rest we could get. More than that, it offered something else. A sense of belonging.

But now, on the precipice of another move, I draw a deep and difficult breath, trying to soak in the last eight years, wondering how this moment has come so soon and if there is a way, *any way*, that we could stay. It's a ridiculous notion. The house is sold, the decision is made. Plane tickets are booked, and the Uber driver is minutes away. But my feet feel fixed as if, like the oak trees overhead, I am rooted in this place. I want to stay on the red-brick doorstep of our home here on Shadow Grove, beneath the San Gabriel Mountains. I want to stand in the intensity of the light and let it burn me with the memories of the past eight years. Confident of only one thing at this moment: *this is home.*

There are several reasons for us leaving; the college Oliver works for in Los Angeles is tanking financially due to colossal mismanagement of money, which came to light a few years ago. And since they own the lion's share of our home here, we stand to lose the roof over our heads and the health insurance we depend on so heavily. Not only that, but our eldest daughter Liberty has a place at the University of St. Andrews, and with Oliver's new position as a Professor there comes with an undergraduate fee waiver. If we've learned anything about living in the U.S.A. over the last few years, it's this: higher education costs a fortune. California is a great place to live if you can afford the 'sunshine tax,' private health care, and have enough money put away to fund college-age children through the university years. I know on paper that the decision to leave makes the most sense given the circumstances. Still, I am dreading it.

Just thinking about what is ahead is exhausting—the logistics and demands of another international move and re-entering what now feels like a different culture, different systems, different politics, and different people. The energy required to navigate the new will be what drains me most. Things like memorising my phone number or recalling what day of the week the different bins are collected (the big-little things). I've already looked it up on the Fife Council website. Green for plastics. Blue for trash. Black for paper and cardboard. Failure to remember such fundamental weekly requirements will undermine my confidence in performing the most basic tasks. Inevitably, I will pull out the wrong bin on the wrong day, forget new passwords and PINs, and even the names of people I meet at the school gate. I will have to write it all down, set reminders on my phone, have a good attitude, try harder. It will take considerable effort to make this move work even though it is not the first time we have moved to St. Andrews. I am under no illusions; the move to Scotland will be especially tough. I've changed. I feel older now: tired; less adaptable. Less willing to put on a cheery front about the new home when ‘home’ feels like it’s *here*—in Southern California. I am also worried about ‘going back’: returning to a place where we once lived for a couple of years but that was not a particularly happy season.

The plan is this: Oliver will start a new job at the University of St. Andrews. This time, with tenure (or at least, as close as the British come to tenure in their understated way). Returning not as a junior staff member but as a professor, is a lifelong ambition fulfilled. Finally. After decades of chasing tenure, publishing papers, edited volumes and monographs, he has landed a job in the British equivalent of what Americans call an Ivy. If he wants, he could stay there for the rest of his career, which under British law stretches until he is 68.

Liberty will do her undergraduate program in International Relations and Arabic while Elliot and Mathilda start new schools in the town. I will keep my job, running a non-profit based in Massachusetts remotely, travelling back to the US for industry conferences and events, and register for the M.Litt. in the English department. Studying creative writing—another long-held dream. Being part of a cohort of literary students will, I hope, help anchor me in the community, and find people with whom I can connect and relate. The required reading alone will offer hours of escape. In fact, I have already purchased and read the list of books for the course. The essays, deadlines I cannot ignore, and the classes—all of these will structure my week, give me a reason to be there.

A few months from now, we will move into a house that we bought online but will not see until we get the keys. Looking back, purchasing a house in this way seems a little outlandish in more ways than one, but it means we will have our own place, eventually. Nine miles south of the city on a mixed arable, cattle, and pheasant farm surrounded by beech trees and dry-stone walls. There will be sheep in adjacent fields, occasional hares on our lawn, and a gulp of swallows circling the house furiously for the first week of June. We found the new home on Rightmove.com, and although we have not seen it in person from the photographs online it looks idyllic, like something out of a period drama—*Persuasion,* perhaps. A 220-year-old farm dwelling with a name but no number: *West Newhall*. It is a commanding Georgian property, and if you look out of the front bedroom window, head tilted at a slight angle, there are views to the North Sea. Inside, the house has been modernised with central heating, a new downstairs bathroom, and the kitchen recently installed by the previous owners with cabinets and countertops from Ikea. I have examined every picture, the floor plan, room measurements, even a 3-D image on Google Earth for enough hours that I can clearly imagine the five of us in turn, moving between its rooms, pulling up on the driveway, mowing the lawn.

What is *not* the plan will quickly unfold. Watson, our dog, will decline, dementia accelerated by more frequent seizures than he ever had back in the U.S. Oliver will not have an office for months, and will be so stunned by office politics that for the first year he will regret leaving Los Angeles altogether. Mathilda will be bullied at school for napping in class, in the changing rooms, and during break times and lunch. Pictures of her falling asleep will appear on social media sites alongside hashtags that label her lazy. West Newhall will be beautified sympathetically but impossible to heat. Damp will rise in the bedroom cupboards, the lounge, and the bathroom. By Christmas, I will be medicated for depression and the GP will be asking me to check in with her every two weeks. And then, in March, a week after Watson dies, the world will change irrevocably.

Before then, all five of us will navigate reverse culture shock while living in the town in a three up-two down narrow stone corner house that has been donated to the university. It also shares adjoining walls with a notorious student party house. When the end of the first week rolls around, we will discover our new neighbours are quasi-nocturnal. We will know their musical preferences and the names of girls they beg to stay in loud inebriated calls outside our windows. In the mornings, we will be greeted outside the front door by broken glass, occasional piles of vomit, used condoms, and an elderly neighbour who resents us for our excess in Amazon orders—dozens of empty boxes that will not fit into the single bin allocated to the house. She will also complain about the noise from our smoke alarm which we set off just by boiling the kettle.

If I wanted to stay put in Scotland at West Newhall, I could do so. It is a thought that is hard to comprehend after so many moves but not entirely unpleasant. Living out the rest of my life in one place—*staying put*. But what if I can't get over leaving Los Angeles and letting go of our lives here? What if we can't adjust back to British culture, and Fife never feels like home? Or what if the children decide at some point to traipse back to the States as adults because over the last decade, California, where they grew up, has become home to them—and they can’t leave it behind? That is a terrifying prospect: being back in a place where we might need to stay although we don't really belong, and which the children will ultimately leave.

During that first year, I will FaceTime and send Marco Polo iPhone videos to several close friends in California, letting them know how the transition ‘back home’ is going. They will see West Newhall, the grounds, inside the cowsheds on our WhatsApp video calls until the connection breaks and I resort to putting all the details in an email. Some, where I begin to describe how intensely isolated I am, I do not send.

I will check my inbox daily for their news and wait for their video messages to arrive, sometimes weeks later, until they inevitably become less and less frequent. One friend, Cynthia, a trauma therapist, who wears long linen tunics over leggings, tells me that this move is an essential part of our journey, and is confident that in time I will embrace it. All I need to do is ‘step into the light’ and ‘own this new reality.’ I have no idea what she is talking about, what journey, and what light she is referring to when I am engulfed in darkness by late November and medicated for Seasonal Affective Disorder (SAD) by December. Perhaps, she is talking about *her* journey, though she's only moved house a handful of times. Or the light that fills *their* home (opposite ours on Shadow Grove) almost every day of the year and can lift the human spirit in the darkest seasons of life. What I come to see is that in a short space of time, we share neither.

Mathilda demands I check the Uber app on my phone. With one hand, she grips the suitcase, the contents of which sum up her life; flip flops, Green Cards, young adult fiction, medical files bound in rubber bands, and four bottles of sodium oxybate—frontline night medication for narcolepsy. Despite her taking it for years and me having the necessary paperwork, there's a good chance we could get stopped by airport security in a few hours from now. It is, after all, a class A drug, better known in gyms as GHB and in clubs as the Date Rape Drug. For Mathilda, sodium oxybate is the only way she can sleep. But getting it out of one country and into another is never straightforward. Momentarily, I wonder if this might be the reason we could stay. And the thought of us being turned back at the airport, even if only for a few more days, cheers me just a little.

Agitated, she grabs my phone, which shows the driver's arrival is imminent. The app even displays his name: Sergio. We can see his every move on the map, his every brake or acceleration. The Prius sporadically shifts like a figure in *Game of Life*, such that we can track the vehicle moving through nearby streets. He is two blocks away when she unhelpfully begins a 60-second countdown. Mathilda's anxiety elevates mine and distracts me from the urgent task of mentally banking every detail of our lives here.

I desperately try to log the features of each empty room: ashwood floors, oversized lounge windows, chrome ceiling fans. Things we never got around to fixing, persistent irritations, like the broken sprinkler system and damaged closet doors, now seem like charming property characteristics. The new owners, a pair of investigative journalists, have already indicated that they intend to make significant upgrades to our Shadow Grove home. These include major remodeling projects inside and landscaping outside, including a pool and surrounding patio. It's all unnecessary (I think). Our home is good enough as is.

There's no time to walk back through the house where Oliver is sealing boxes, so I scout around its edges in my mind, creating a diorama that even includes the attic and the remains of nesting rats who also made their home here during cooler months. It is easy to conjure certain moments, slices of memories here and there, like Oliver and Elliot sitting on the sofa, wearing matching blue polo shirts, with matching haircuts. Thanksgivings with friends in the kitchen, half a dozen kids in the breakfast nook. Liberty, 16, looking 20 in a dark red evening dress, scooped out at the waist, heading to a prom. As if they belong to an observer. Someone who watched our lives unfold week by week.

Now, I wish I had taken more photographs. I should have printed them out, or at least dropped the ones I did take in the digital Cloud. The reason so few pictures ever made it into a frame, I tell myself, is because we were always so busy living. Living out the everyday-ness as the children moved through grade and elementary school, Oliver and I slowly piecing our lives back together after Mathilda's diagnosis of narcolepsy.

By the time Liberty and Elliot entered high school, I was forced to acknowledge their adolescent self--choosing photographic opportunities carefully, always in danger of becoming *that* mother—the one they roll their eyes at, thinking *here she goes again.* I also realised then that I *wasn't* that kind of person. I wasn’t sentimental, organised, nostalgic. We chose to live in the present. And pictures only represent the past. So out of all the boxes that will travel across the Atlantic, only one holds the memories. How easy it is to compress our lives, put them in a crate that will arrive months later and will wait weeks to be unpacked. I am most afraid of not remembering—forgetting how we lived here on Shadow Grove, unable to hold the years we belonged to each other in this space in my mind’s eye; that even the memories will slip away like time ... and be lost.

I give up searching for shade, and on the doorstep, try to slow it all down in the few minutes remaining. The years lived here, the moments bathed in a certain luminescence that now I work hard to lock away in my mind, to store, to draw on in the months ahead. If I look up (and not back) perhaps I can capture a thousand suns or more that touched us. Skies of cloudless, endless cobalt. All those fuggy, airless nights here when sleep eluded us in a moonless quietude before giving way to an early morning reset—I was grateful for those. But now, arrested on the steps of Shadow Grove, I wonder if I fought hard enough to stay. Why did I say yes to leaving?

Did I love this place enough in those tea-infused moments, lying next to Oliver at night when we talked, rationalising our small political and social world with all its uncommon ills? Mathilda's disease, work issues, finances. How it all could hurt our family, how we might fix it, between us, without damaging each other. So much work. We did all this here at Shadow Grove in the small broken hours and still later, as the dawn moved in through the patio door of our bedroom after Mathilda's second dose of Xyrem. When at last our resolve to take one day at a time gave way to subsequent, less troubled waves of sleep before sunrise we paused, this time with coffee in the predawn half-light that helped calm our night fears.

Our family was gifted this drenching light on Shadow Grove—a chromatic intensity that promised something brighter than where we had been before. Better than the last place, and if I'm honest, even the places before that in and around England, Scotland, the Midwest, and East Coast of the US in which we had sojourned. Under the evergreen oaks on Shadow Grove was a chance to abandon the old narrative and write a new one, and not just one with symbolic meaning. Because it was here in Los Angeles through our unrelated genres--Oliver’s academic tomes and my storytelling, that we wrote our way out of the past, not fully realising that publishing was a literary means of creating a permanence which, on reflection, was more for our ourselves than our (relatively meagre) audiences. That the words on the pages of our respective books might achieve durability was more than either of us could pull off emotionally, not together anyway. But the physical act of writing each day, the conviction that we both had the potential to leave something behind in our written work brought about a kind of unity of purpose. We found creative rhythms together, cramming a few hundred words in here and there on either side of our workday, and after years of raising children and searching for the *one job* in the *one* place, we also found a new intellectual connection as writers. With another move and all the pressure it will bring, I am worried we will lose this.

A new message on my phone comes through. As if I needed a reminder that the better part of the last decade is over, Sergio will be here in two minutes in his silver Prius, which is not enough time for me to comprehend how so suddenly, after months of planning, we are leaving. Watson, our dog, is leaping up and down the driveway as if something wonderful is happening. He doesn't know anything. He does not know that he too will leave in less than a week or why his epilepsy will worsen in the months that follow. More than that, Watson has no idea about the new house with stairs he will struggle to navigate, the wet and the cold that will deter him from walks and worse of all, his final sleep the week before Scotland's first lockdown.

Two minutes away. One minute. The car turns down Landfair Street, Greenhill, and then Shadow Grove and pauses at a stop sign 400 feet from the house. With the few seconds left, Mathilda says she has changed her mind. She doesn't want to go.

Together Oliver and I have done all the pre-moving prep with her over the last few months. This is our next family adventure (we said). One where we will, in effect, be going back to the UK; going *home*. So many upsides, I say. We will get to see our families from time to time, Down South. The grandparents and Lucas, her cousin in London. I tell Mathilda that she's bound to love her new school because there will be new friends, all internationals like her. Kids from Germany, South Africa, Asia. No one will care about her accent, which is at this point Mid-Atlantic—a term she latched onto so that she can explain why she sounds part-American and part-English, but not exactly either. Like Dick Van Dyke playing the cheeky cockney rogue in *Mary Poppins*. I go on and on, clutching at other small positives that present themselves here and there. (Wasn’t Van Dyke called Bill in the film, I wonder in an idle moment? Or was it Bert? Not very *Mid*-Atlantic either way.) There'll be the Christmas panto at the Byre Theatre in St Andrews, which I've shown her online. We can get fish and chips on Fridays or any other day if we want, new kittens on the farm when we move (again) in the Fall/autumn. Our first landing pad is a university rental in the heart of the ancient town, a tall medieval-looking building convenient to her new school, amenities, and everything else we will need. St Andrews is tiny, so it won't take long for it to feel familiar. It's all walkable, which is so much healthier—as if any of my rhetoric might swing it. Nevertheless, I go on about West Newhall. It’s the house south of the town that we are trying to buy online—remotely.

We have rehearsed this pep-talk with the kids each time we have moved, over and over like a mantra, and pull it out by default switching out geographical details. But no matter how convincing or upbeat I try to sound this time, I do not at this moment believe any of it myself, which makes it that much harder to articulate in any compelling way. It's a long time since our family has moved, and this place is the only home she remembers.

The Californian light has me stuck. Except for a handful of days, the heat and brightness at Shadow Grove came at us year-round—making the San Gabriel Mountains behind our house a kind of stark, brindled wall beyond which was the azure dome and the blazing sun that lifted our sagging spirits on a daily basis when a decade of sleep deprivation threatened to close us down with depression. Now I realise that the long fingers of warm sunlight had crept one way or another, not only into each room in the way outdoor-indoor living affords in SoCal, but also in such a way as to warm and quicken a part of me that might otherwise have lapidified. It had become a life source, and I was constantly under its influence. What I hadn't fully registered was how I craved its brilliance as a constant companion, and its warm touch on my face and skin. Looking back it makes sense of why I wrote and worked outside, in the front yard, and why I went about removing curtains when we first arrived there, stripping the windows of anything that might get in the way of this new solar relationship. Even the bathrooms didn't have blinds. There were times when guests who needed the restroom would comment on feeling exposed, rightly concerned that people walking by might look in. But I never really paid much attention to their recommendations for what they called window treatments, occasionally coughing up some excuse or other that I was too busy but should have it sorted out by Labour Day.

Perhaps, if I open my eyes, peel back every sense to the ribbons of light, the white-out will burn enough to numb what's coming—LAX, LHR, EDI, and finally, St. Andrews.

I will need to retrieve this chromatic power in a few weeks, and in months from now, once in Scotland. Once in our new home.

Urgent messages register on the Uber app even though he's only a few feet away, at the bottom of the driveway.

Is this the right house on Shadow Grove? Claire, right? Are you ready?

Sergio does not know that I will never be ready. He can't. He's on a timeline here and has already clicked open the trunk while checking his phone for his next client. Things move fast in Los Angeles, often at a pace that blends and blurs one thing with another like the lights of the traffic on the freeways at dusk. He is interrupting my attempt to fasten Shadow Grove to my psyche, buttoning up these last few moments before we leave.

I know this is what I have to do. Take Mathilda's hand, follow the driveway down to the street, drag our bags, drag us both into the back of the car. I should also say something to Oliver that will put him at ease, though I am not at ease and any words that might be helpful are already silenced, jammed in the back of my throat. In turn, I want Oliver to reassure me and bolster us up enough to get us to the airport. Perhaps, inwardly what I want is an apology. If not from him, then from an unnamed, unknown source: the universe, God—*something*. Who or whatever is the architect and author of our loss.

As I step out of our ranch house for the last time, I tell myself that this place is simply a construct of plasterboard walls and a wooden frame, with a low, shingle roof that gave eight years of light-filled life to our family, at a time when we were broken with grief. Surely, I can leave it and live anywhere and make it work? I can relocate again. Make the next house a home. Although we have dwelt here, paid taxes, educated our children, travelled the state, and seen dozens of doctors, we were not born here. None of us were. Legally speaking, we are permanent residents yet still aliens, our Green Cards tucked carefully inside British passports. We are a blend of cultures. Foreigners connected to parents in England, our ancestors European. It is easier to think of leaving if we never belonged.

I remind myself that our lives should never be dependent on the fabric of four walls or surrounding oaks that over the years protected us from violent windstorms, shade from the burning sun. The soil in which I planted lemon trees, Cyclamen, Lilies—it is just dirt. American dirt. I can plant again in Scotland, in the thick and heavy Scottish soil. I can write again, create a new narrative though I am more cautious of trying to belong somewhere only to have to uproot once again. The thought of leaving sometime down the line feels inevitable, despite tenure.

Home. Place. Soil. Light.

Now, more than ever, I am less sure of what home is or even means. Are we going *home* to the place where all five of us were born? Where Oliver and I met and married in our early twenties? Where our ageing parents are declining? Or is home here because this is the place where I was happy? Is home Shadow Grove because of friends and community? Is it Southern California because it was easy to feel accepted as an immigrant, a resident alien?

What now, and where is home?

As Sergio blasts the air conditioning and pulls up the tinted car windows, I suspect that the sense of home (for me at least) has a lot to do with *light*. However, I fail to realise the full significance of living beneath the Californian sky until months from now on the other side of the globe, when Scotland's darkness presses in, swaddling me in seasonal depression, and so constricts me in a kind of perpetual perceptual twilight that—for a time—I give up believing I could ever be happy again.

There, in that other place that I feel I should call home (an ancestral home at least), joy seems to be reserved for those who somehow deserve it. But somehow, somewhere between our home in America and the UK, I fell short.

THREE

Lost

> Maybe this isn't home, nor ever was—maybe home is where I have to go tonight. Home is the place where when you go there, you have to finally face the thing in the dark.
>
> —Stephen King

It is near dark when Mathilda falls asleep on the train from Edinburgh to Leuchars. Her head is on my lap, and as I slip my fingers through her thick hair, I allow myself the full realisation of not having a home. It is a terrible feeling of betweenness. Of not belonging. Not to the last place, or the next. And, although the sense of dislocation is familiar, it comes at me again with an emotional force that is difficult to contain. I sink further into my seat and look out of the window to the rows of houses where, I imagine, families have lived for years. I cry quietly. They are all home. What comes next is predictable. Mathilda plunges further into REM sleep, her legs and arms twitch, her chest rises and sinks with deep-drawn breaths. Her pupils, dilated, dart under half-open eyelids as if in a frenzied escape; she is trapped. These daytime naps, irresistible to a child with narcolepsy, are repeated reminders that she is brain-damaged and stuck in malfunctioning cycles of sleep and wakefulness.

The train stops before we make it a mile out of Waverley Station. It waits—but for what? I look around the carriage. Everyone is on a phone or laptop, heads down, unperturbed. This must be normal for the fast train to Leuchars. There is an announcement. I learn that the snack trolley is on its way, but here is where my memories mix. Was it on this train that a cart with goodies arrived? Or was that, a year later, on the polar express from Miami to Palm Beach? A carriage fully decked out in oversized Christmas ornaments, the November sun streaming through the windows.

This train, rattling its way towards our new home, judders forward by only a few feet (it seems) and then stops again. Already we are late for Oliver who has hired a car, but without cellular data I cannot tell him that we are crawling between towns and villages. They bear names I forgot long ago. A guard arrives. She holds out her palm and flicks her fingers as if to say, *give*. *Give me*. Handing back our tickets, now punched with holes, I ask the reason for the delay and expected time of arrival in Leuchars. Her toneless reply: *we are west of Edinburgh*.

I have put off this moment. Punted it—sought distractions. A week in London, sightseeing here, a show there, even stayed an extra two days at my parents on the South Coast. What took months in the planning, arranging meticulous details that only an international move for five people and a dog demand, has brought me to a *pont de non-retour*. I knew it would happen. But, so quickly?

Now, grinding North, I am gripped by questions that have accompanied me with every move: What am I doing here? Where do I belong? What or where is home now? The ties to the last place will soon work themselves loose. Relationships that anchored us to one community or another will be untethered. There will be new connections and new routines in time, but I have done it enough to know that it takes several years before the betweenness and the limbo lifts. Yet I cannot say when the shift comes or how. It's nine years since I last went to the UK, seventeen to

St. Andrews. Now, we are moving back. We are moving back and buying a home, and all I can think is that I do not belong here.

Now, just outside of Kirkcaldy, Mathilda's feet flick in spasms. I think how beautiful she is. Then the sense of loss kicks in. Her daytime sleeping is an inescapable shutting down. No matter where we are or what she is doing is another hour where she is not listening, seeing, speaking, reading, learning, living. Not for the first time, Poe comes to mind: ‘Sleep, those little slices of death. How I hate them.’

The hallucinatory spell of narcolepsy plunges her into sleep and hypnagogia. Mathilda has gone to a distant place. One that is inaccessible to the rest of us. It is as if she had left us for a time—if only I knew where she goes.

A friend of mine, Steve, whose child died twenty minutes after birth, said his grieving focused on not knowing where Samuel was once he had passed. That he, as the father had not been able to go before his son; go *first*, as it were. Not even to imagine whatever dimension it was that Samuel inhabited was the thing that kept Steve locked in destructive patterns of loss. I understand that now.

Samuel was buried in a white coffin, not much bigger than a shoebox in a lot half the length of a shovel. That was twenty years ago. And every few years, when the family can afford the flight and time off work, they return to pay their respects and conjure up the memories that lasted half an hour. They might talk aloud, bring him up to speed on what he has missed all this time, ask what it is like, where he is, so far away. I know I would.

A child's suffering feels unnatural, wrong. Inherently so. Their death disturbs the fundamental order of things because it is premature, and we do know have the words to tell them they are dying. Steve put Samuel’s story on a website called *gonetoosoon.com*. It serves as a digital memorandum where others could comment, leave their thoughts, well wishes, prayers. It is also a tragic collection of thousands of young children, babies even who have recently died. A digital cemetery. There is talk on there of unexpected loss, heaven, babies being taken by angels, living in paradise. The grief is palpable. Though narcolepsy is not a terminal diagnosis, the slices of sleep each day are death-like as Poe says. Or so it feels.

There have been mornings when abstracts from Mathilda's world appear on paper scattered across the nightstand. Lines of words are written one on top of the other. Layers of images in drying felt pens, undefinable scribbles that I found taking the sheets off her bed. Always sinister. Haunting, disturbing. Some pictures and dream stories are so intelligible that we wondered if we should find a therapist. One in particular, which I kept for several years, showed Mathilda bleeding from her mouth and stomach. Small knives plunged into her legs. The paper ripped through the centre where she had used a pencil with too much force.

Once, I asked a sleep specialist why Mathilda's hallucinations involve such dark images. Why did I never pick up a picture of her riding a unicorn, or building sandcastles with friends? In the early days of her diagnosis, I hoped for picnics and birthday parties on those pages, something other than menacing ghoulish swirls above her bed. He told me about an artist in New York who painted pictures of the images he experienced during sleep paralysis. I looked him up later—drowning images of human heads covered in sheets, tied around the neck and bobbing in water. Broken bed frames, crumbling worlds, floating teeth, ropes, nails. New York, the city that never sleeps, the perfect place for narcoleptics. New York was the last place we visited before Mathilda succumbed to the condition—a three-year-old, catching snowflakes on her tongue in Central Park.

And now, the spell is cast again. This time, Mathilda's nap has overtaken her in a safe place, but we are also between homes and that feels important. As her mother, this might be the time to offer some preparatory insights about our ‘new family adventure,’ the phrase we use pre-move. It seemed to work when they were younger; the pep talks on how lucky we are to experience living in distinct cultures, making new friends, trying new things. But now, lurching toward Leuchars, I am sceptical. After 20 years of regularly relocating, I am also tired of the rhetoric. Mathilda is about to hit high school age, and is becoming harder to convince about the upside to a transatlantic move.

The train staggers to halt, and the woman opposite smiles in my direction.

‘Someone had a late night.’ She says. I return the smile, leave thoughts of how lost I feel and look sideways. Cupar. Some commuters get out. Others take their places and bring with them a draft of chilly air, and dusk. The carriage lights twitch on, and Mathilda begins to wake.

What, I ask as we trundle through the low hills of Fife, are we doing here? Where should I be? The immediate nowhere-ness translates to nobody-ness. I am *nobody*. I wish I could shrug off the sense of needing to belong to a place, but even the thought of our family being altogether an hour from now isn't enough. I must learn to connect here, to feel rooted for it to work.

The brick houses we pass are familiar as are the 40-foot gardens fiercely protected by chain fences and hyper-alert guard dogs. I grew up in a similar neighborhood, on the west border of London. Nudging towards Leuchars now, I think on what passes for life here: the lives lived out in these rundown semis. I see a girl—she must be around seven or eight years old—springing on a trampoline. Oblivious to the rain, she waves in what seems to be our direction. Mathilda sits up, waves back to the girl and asks where we are. I want to know where she has been this last hour. Did she dream and go somewhere, or was it just what I saw, the shutting down, a dark void of nowhere? Does she even know?

In real terms, we are minutes from our destination. I tell her this and that it is a short drive from the station to the Dower House owned by the University, where we will stay. We will see the rest of the family; she will sleep this evening in a new room. Daddy has already unpacked her things. Her new bed is made.

'I am tired,' she says.

'I know you are,' I reply. 'I'll carry your bag when we get off the train. Did you get some rest?'

'Not really. Where are we?'

'Almost there. A couple of minutes and hopefully Dad will be waiting.'

'Sometimes, when I take nap. I'm not always sure what's really happening. Or where I am. My dreams are so real. How do I know this is not fake?'

'Being here you mean, on the train?'

'Yes. I know I am awake now but where are we?'

'Between places Mathilda. But heading home.'

FOUR

Back Story

Bristol, 2009

The year we celebrated our seventeenth wedding anniversary, I counted our moves over lunch with Wendy, a friend in Bristol. We had lived there almost five years. That was a long stint by our standards back then, which may have prompted her to ask where we were going next. Being the overconfident, glass half full type, I told her that actually, no, we had no plans outside of staying put and finding secondary schools for our two older children. I spoke that day about Liberty applying to a local music school, possibly being accepted on a violin scholarship. We laughed about Elliot, then eight, becoming a chorister at the Bristol Cathedral, something he would have hated, and not just for the cassocks or early morning starts. But when she went to the bathroom, I did a little maths on a napkin. Nineteen. Nineteen moves across three countries in seventeen years. My mind went further. Almost all of the transitions until then were in pursuit of tenure or another interim situation while we waited for the new rental to become available. Some of those stays during transition lasted several nights—some months. Oliver was a junior academic at the time, and, by default, he was constantly striving for a way to climb the pedagogical ladder. But after a childhood centred in one location, within walking distance to my grandparent's house and primary school, the two most centring aspects of my life, I was looking for something similar in adulthood: community, proximity, and purpose.

That's when I knew we were living outside the box, chasing an ideal that exceeded our financial and emotional bandwidth. Given our track record, Wendy's question was not unreasonable, but I suddenly felt exhausted. It was as if her passing comment had popped a balloon that until then was inflated with optimism. The hope for a permanent job and a place where we could live, if only for more than a few years.

The conversation left me recognising disappointment in an academic system that took advantage of a junior staff member when the role demanded so much of him and us as a family. On top of a gruelling teaching schedule, he was working on getting published in peer review journals, writing monographs, editing philosophical volumes. There were also various administrative roles he took on and grants he applied for, in addition to absorbing a mounting list of PhD students.

Organising conferences and serving on various committees were additional commitments he called *service to the guild*. We laugh at that phrase now, but at the time, not one of these was enough to secure tenure, and, if I am honest, the process baffled me. The rounds of failed interviews between colleges in London, Scotland, and beyond were disappointments so crushing, so politically motivated that it often took months to reset our resolve. But, there is a job out there, we told ourselves. It's just a matter of how long we can hang on.

Early on, the temporary postdoc positions scattered around the US and UK became places where I envisioned something more long-term, even when I had marked the calendar with the end date, which was usually early Summer. It was necessary to make the crappy rentals cheerful, familiar even, and I went about it with increasing fatigue that took me to places that felt foreign, like Walmart in the Midwest where they sell guns in the aisles adjacent to baby wipes. We never shipped our stuff overseas, always trying to limit the expenses but at the same time foolishly paid for storage in various domestic locations between London and Edinburgh. When we returned and unpacked containers the futility of storing items like Ikea wardrobes, which we later learned never travel well, struck us. It seemed essential to keep our things then, even if we had no idea when we might unpack them, or worse whether the mattresses, sofa, dining table, and other domestic paraphernalia would even be needed in the next place. Some of those items ended up in the recycling or at the local dump. Other things we gave to incoming families who, like us, were passing through town. Whatever way we planned it, moving was expensive and exhausting though the children always loved reuniting with their toys, which kept them occupied for the better part of the first month back. Eventually, I understood this: aside from the immediate convenience of having essential items like kitchen utensils to hand, or the relief in knowing our photo albums were still intact, unpacking, for the most part, amounted to piecing together fragments of one life, only to find they didn't fit very well with the next.

I remember specific arrivals, like showing up at Notre Dame, Indiana, back in 2004 during a tornado so damaging that we spent the first three nights in darkness, sleeping side by side in the basement. By contrast, several years later New Jersey offered a different kind of welcome. It was mid-week, mid-summer 2008; I don't remember the date exactly, but I do remember the wall of heat and humidity stepping off the plane, the air feeling thick with anticipation. We were wearing British clothes, unsuitable for this new climate, and spent the fifteen minute cab drive to our new town house sweating. Later, we would learn that in order to cool off in side a car, it was necessary to close the windows and allow the air conditioning to run. I fell in love with Princeton during that ride—struck by the great green canopies of trees over along the winding streets, the sound of birdsong and cacophony of cicadas. It marked the start of a series of local adventures as the distinct seasons passed like something out of a children’s book, until, inevitably, the time came for us to leave. From time to time, the children talk of our time on Ross Stevenson Circle—the chipmunks under the house, chasing fireflies in June, snow days with friends. Looking back, I think it may have been one of the happiest years of our lives. Each of us, for different reasons, felt settled there. And that happiness was enough to make it feel like home.

With every arrival, I would pull children's books that we had previously read from the local library, replace whatever piece of children's equipment we needed with a similar brand so that some things felt familiar. And then do whatever else it took to acclimate to that environment. It mostly meant making friends but depending on the climate and contents provided in the new home, it was necessary to purchase additional items.

Moves around the UK were more manageable than the relocations in the US. We were both committed to creating new lives in new towns and cities, even in a place like Bristol with its dismally wet forecasts. But over time, with every upheaval, even that notion began to lose its force. Falling in love with a place or the idea of making it home was like being in a story. Sometimes I was the main character, though more often, an observer, permitted to listen and watch only—never really owning the narrative. By the time we had to leave I was usually falling or had fallen out of the story, the tale of a home that I very much wanted. Too much, probably. And the wrenching loss that came with leaving almost derailed me in the following months. Simply put, I didn't know where I belonged.

Back in 2005, there was a spell between short-term contracts when we were both out of work which coincidentally was well-timed with my parents renovating a tiny two-up-two-down cottage in a hamlet tucked away in the New Forest. It was a place rich in natural resources like firewood and blackberries and local entertainment if you counted the wild ponies and pigs that lingered on the grass Infront, often coming up to the front gate. Generous too, in that the local authority wrote to inform us that while we didn't qualify for unemployment benefit we did qualify for free milk, white bread, and of all things, eye tests. It was also the place where we almost returned to our previous professions: high school teaching for Oliver; physiotherapy for me. Then, just when our only asset, a ten-year-old Ford KA, was totaled by a neighbour, Oliver secured a job: a permanent position at the University of Bristol.

If probability were the only indicator, our time in Bristol could soon be up, and although I had no reason to suspect another move was imminent given that Oliver had finally secured something long term at the University of Bristol, Wendy's comments amounted to a foreshadowing. We would leave Bristol eight months later, working the same rituals before and after departure—sell, pack, clean, leave, arrive, clean, unpack, buy. Another move, then. One that brought us eventually to Shadow Grove, but not this time for tenure.

Since then, people have commented on what a risk it all was. To sell up, wrap up our lives in the UK, drag the older children across the world for the sister they could no longer play with, to a place where they'd never been. But if I knew anything back then, it was that our lives in England were physically unsustainable. Mathilda needed treatment and expert care, and that commitment took us to the US. By the time we watched Atlantic International drive off with a crate load of books, I had closed the front door on a place that had essentially failed Mathilda. In fact, it had failed all of us.

FIVE

Identity

Only memories are left:

—the container from the US arriving a month late, held up in customs in Portsmouth. It may be a regular delay, but I wait for days, wondering if the authorities found the bottles of Xyrem tucked away inside shoes, wrapped in towels and bed linen. At night, I imagine our boxes torn open inside the crate and constructed what I think might pass as robust arguments for bringing Mathilda's medication illegally overseas. Various hypothetical lines of questioning by customs come to me at 1am 3, 5. All of them are incriminating—all my responses inadequate. In the mornings, I go through her medical notes, printed prescriptions: all the paperwork that showed she needs the ‘date rape’ drug at the age of twelve. The files stay beside the phone. Should customs call and question us, we would have the answers, and they would be satisfied. I would not go to gaol. I would not write a book about the three months spent with women dealers in prison for drug-related crimes, sharing a cell with a mother who would cry at night from the top bunk, ‘I did it for my kids.’

—on the fifth of October, the mover's, a team of young men, carrying boxes and beds in the rain. Dozens of cows watch and shuffle anxiously in their stalls because the lorry is wedged between them and the ruins that border the garden at West Newhall. Our children find boxes with their names written in black Sharpie and politely share the scissors, moving in the silence of their new bedrooms. Oliver prioritises the unpacking—kitchen first. Sheets on mattresses. Clothes into cupboards. I leave the house for an MLitt class in Kennedy Hall on editing a literary journal where we role-play in groups and return to our new home hours later with food from Tesco.

—months later, I search for a small cardboard box with the words 'valuable' written on it. It contains photos, an old pink and white clock from Marks & Spencers, my christening bracelet, a green peg bag hand made by my friend Suzanna and a birthday card from my Grandmother. But I am most panicked over losing a small set of photographs of my mother when she was seventeen holding me, a fat baby.

—the clock is rusted at the back and edges. Its hands fixed at 3.25. I am unsure now how it qualified to be in ‘the box.’ There is nothing special about it, other than this: it was given to me when I was thirteen, around the time my mother got her first paycheck as a secretary for a small company that made pewter ornaments.

—the green peg bag, handmade from Laura Ashely fabric that my friend Suzanna gave me. I saved to use in Scotland once she recovers from breast cancer.

—a birthday card with twenty-one-pound coins stuck to the inside cover and arranged in the shape of the number twenty-one. The card had faded, the floral patterns barely visible, but my grandmother's shaky handwriting was there wishing me well when she was already bright yellow with liver cancer. To our granddaughter, on her special birthday. Lots of love, Nan and Grandad. I should have remembered everything she wrote--the notes she sent to me at college. Some contained sets of second-class stamps. I remember that much. She would have walked to the post office for them. But her messages folded on notepaper inside the box are gone, and no matter how hard I try, I cannot recall one line.

—I should have spent the money and bought something memorable instead of leaving the coins stuck to the card, but I could never think of what would be worth her loss. What could I buy to restore her to me? What could money buy to match the sepia photos of her?

—Sepia photos of her, dancing in a white dress on a stage in London, black hair tucked under her neck. Curled and pinned to her forehead. A program from the production she was in, soft with age. 'Babes In The Wood' at the Beck Theatre. Listed as one of the Babes, her name just about visible. Dorothy May Wylds. Then the war came and her dancing days were over.

—November 1991, six weeks after my birthday, my grandfather took the engagement and wedding rings from her still warm fingers. Her feet swollen with water. Legs heavy to lift when moving her in the bed. We turned her every half hour, this way and that to relieve pain and avoid bedsores. Her body jaundiced, the yellow of a sunflower. Someone in the room that night said to pull up the blankets, keep her warm.

—fireworks in the street lit up the dining room, where she lay cooling in a hospital bed. Her eyes closed with one penny pieces to the colours flashing across the walls—the sound of a Catherine Wheel nearby. Rockets charged through the November darkness. Dazzling waterfalls of light finding their way through the curtains of the room where we stood, not knowing how to let her go.

—in the morning, when she was cold and under a sheet, Grandad handed me her engagement ring. Eight small diamonds arranged in a flower shape—one each representing her children. She once said that the large centre diamond was me, her ninth child. I have worn the ring for thirty years but cannot locate the box with her pictures and letters in any room of West Newhall.

—what I am looking for specifically is a series of black and white prints dating from early 1971. They are glued onto embossed cardboard with scalloped edges that show a serious-looking young woman holding a baby when unfolded. The photographs are almost identical unless you study the woman closely—a slight shift in the tilt of her head here, a slight smile in several of the images.

She has thick dark hair dragged into a large bun, no parting, no makeup or jewelry and a simple white top. A skirt in darker material covers her uncrossed but tightly drawn knees. The mother's hands hold the baby's chubby arms and legs in places that allow the short lace dress to hang without creases. The baby is fat and hairless with a large round face, and on her left wrist is a thin silver bangle. In all the pictures, her plump fists are closed. This christening bracelet that would fit a doll was kept carefully inside a silk handkerchief sleeve in the box. Under the last photo in the row and written in gold are the words ‘Hampton Hill Studios’ with a postal address and phone number below. The last time I looked at these pictures, both the black and whiteness of mother and child were muted with age, the gold lettering on the back unfaded.

—Another photo. Again, black and white show the same mother and child several years later. This time, they are outside in a garden under a cloudless sky. My mother, still a teenager, sits sideways on a lawn, watching me examine a plaster on my knee; her hair sweeps below the straps of a swimsuit and in her left hand is a small mug. I am somewhere between two and three years old and have a headful of hair, white blonde and curly, evident from this image. It will be tamed and detangled with daily brushing not long from now, scraped back into neat ponytails before it is cut short, like a boy. We are both barefoot in the grass, but in the far-right corner cut off by the photo frame are the legs of a man wearing bell-bottomed jeans and shoes. It is the most relaxed I remember my mother being, a memory, prompted by this moment bathed in light, barefoot on a summer's day. In this piece of a family archive, it is difficult to tell if she is happy. It is impossible to know who took this photograph or who stood watching them, though she married the following year.

—all the images and letters have disappeared. I have looked in every room, every cupboard. The small cardboard box has followed me to each place where I have lived—South and South West England, Northeast, Central and the South West coast of America, but this time, in Scotland, I have failed to keep words and images between the cradle and deathbed safe.

—I should not have labelled the box ‘valuable’—it was the wrong word. I should have left the box unmarked or better still carried it from Shadow Grove to West Newhall as hand luggage.

—The Grandmother who would have been a dancer in 1939 has gone. So has her daughter as a young mother. The baby and little girl, lost on a crate or between ports on either side of the Atlantic Ocean. Their traces of happiness, captured in a moment, must be committed to memories that pair the living with the dead, dreams with reality, past with the present. No matter where I search, I cannot find these women, one dead for a quarter of a century.

—Hundreds of words are deleted, vanished all at the same time. The ones used to name all the things, the feelings, the ones written to make meaning of our lives, the places we lived, the words that made my heartbeat with belonging.

—And the memories follow me all the way to sleep, where we three women are the same age and sit, talking like friends in the heat of a Sunday evening. It is hot, the screen door to the porch is open and a prairie can be seen from the lounge where we sit. I own this house that is somewhere in the Midwest, a place that in the dream I have lived all my life. My mother and I, both in our thirties are talking, drinking, waiting, while two children play in pools of light on the wooden floor around our feet. A ceiling fan overhead competes with the constant chorus of cicadas until the room falls silent and my Grandmother walks in. She too is a young woman who we have been expecting. After being gone for years, Dorothy opens the screen door and casually explains her absence, why she left. We let her talk, my mother and I and ask how she finally found us. It was the house, she says, I knew you would still be here. The dream feels like a scene in a movie set in the 1950's. The night comes, the children are put to bed, the women wearing floral dresses go out to the porch and watch the last line of light drop behind the horizon. In this dream, I forgive Dorothy for leaving. There is space, time when we talk for my mother to say all the things she has locked away—because, on the porch I am a woman she loves and not the baby that bought her shame.

I do not know how it is that we three women exist in this timelessness, where the generations contract into an evening shared between lifelong friends. Dorothy doesn't explain herself but the thirty years since she left are forgiven. She is back. My mother is happy. The children sleep. I am home.

SIX

Thinking as Writing

Another dead mouse, sodden, rigid on door mat. Still raining, so wet, even on the outside of the watering can. Bubbles of water on its green handle. Long green-leaved plants with no flowers. I don't know their names. Mum would if she was here and she would tell me why they haven't flowered. They are bent by the rain and wind and look like an apology. Their ‘sorry’ is my ‘sorry’ for not being happy here. A pang of shy guilt—Hilary Mantel said that once. What book? Her memoir? For now, at least, I can't seem to recall. I am reading. I want to escape into words and ideas. Other people’s are better than mine. I need the pull away from being here. Give up the ghosts (Ah! It was the Mantel memoir!). Sink asleep, dream, wake, cry, read, leave.

I was so wrong about the farm in Fife being about living somewhere that is life-giving. That is the word now: *life-giving.* This is what we should do with our time—only life-giving things. The lawn and all the fields from here to the sea were beautiful in the pictures online. Bright green grass. Wide-angle lens made it an acre back then. A lie. Not like the front yard in LA where our sprinklers were broken. Parched and patchy grass under the oak trees. Nine oaks on that property, protected by the city. The water there is expensive. A moral issue too. Better to understand that it is a desert (or desert-like). We did. We understood. That's why cacti thrive there. Our neighbours Nord and Cynthia had huge cacti in their yard, although they could afford a lawn like a cricket pitch. They are still there at Shadow Grove, probably doing laps in their life-giving saltwater pool.

Wait. No. It's midnight in California. There they are. I am here with a dead mouse on the mat. Where is home?

Get the dustpan. I will have to chuck the mouse somewhere. Neck extended. Don't put it in in the flower bed because in the Spring we will find their skeletons. One of the girls will scream. So, over the wall, into the field it flies. Little mouse body. Returning bones to the earth. Dust to dust.

Ed and Julia (who sold us the house) never mentioned mice or rats. Ed, A.K.A Mr. DIY, and Miss Leather Trousers—landed gentry types. They left long holes in the walls covered up by a towel rail. It's heated, but it costs the earth to warm a few towels. I remember the pictures of each room downstairs joined in the middle by the black and white tiled hallway, just like Alice in Wonderland. How many times did I look at those pictures? No, I didn't merely *look* (too passive, too fleeting). I *studied* them—like I studied the housing market in St. Andrews. All the rooms at West Newhall connected and made sense on the floor plan, scrolling across the page for every picture: bedrooms; landing; the conservatory (which needs work); the kitchen. But why on earth would you put an Ikea kitchen in a Georgian house? Eye roll, and then back to tapping on the keyboard. What estate agent site was it? Galbraith? Savilles? Hah! No, it was *rightmove.com*.

It's bold to buy a house online, like an oversized Amazon book order. But it was surprisingly easy too. Read reviews and click. Checkout. Thank God some things I can do quickly here, online. Life is *all* online, or so it seems sometimes. A never ending digital labyrinth in which one can lose oneself for hours at a time. I hope the internet works today. If not, I might lose my job; lose it when the Board find out that calls are dropped every day out here on the farm. I charge up the Broadband booster hoping it will help. Why hasn't the weed killer arrived? I ordered it. Can't remember the day but it was last week. I should check the Amazon order history. Another thing to do. Should I write it down? I do seem to forget things. If I go to the order history, it will be on a*mazon.co.uk* and not *amazon.com*. Different sites. Different credit cards. I need the weed killer. The weeds are everywhere because I can't look after the place. Not really.

Local people know this house and the Erskines, the aristocrats who used to own it and still live across the road in Cambo House, which is the family seat. It is set in Cambo Gardens, with lovely tree-lined walks down to the North Sea full of bluebells in the Spring. Blah, blah, blah. It’s not open now; wrong time of year. One of the elder Erskines died here when West Newhall was the Dowager House. I can only guess it was the mother-in-law who expired in Libby’s room. I Mustn't tell the kids this, and I must stop thinking about death. Inside *and* outside.

People don't know that outside, in the garden, I am lonely. They only see the pictures on Instagram. They give a digital ‘like’ and a ‘thumbs up’ for the vegetable patch, our old gate, stone walls to the *#piggery*. I take good pictures with the filter and portrait mode on my iPhone, but never in the rain. Take beautiful images to remind people that life can be beautiful. Maybe it's *just* a beautiful image. After all, how do we know what is real? The cows in the cowshed—I hear them, smell them standing on straw when I drive past the barn. They seem real enough in the Spring when they are birthing. Months later, we count four or five nights of crying when their calves are taken. Where did they go? Do cows cry? I cried a little with them, and for them. For my children already leaving. This Erskine house is over two hundred and twenty years old. I can pay the mortgage, touch the walls, keep the pictures on my phone. I could leave. Soon. I would like to; I would like to go back—back to California and our ranch house under the oaks. 3795 Shadow Grove Avenue, Zip Code 91107. I couldn’t help being happy there. It came to me in slices, photographic memory stills like when I saw the kid’s flip flops on the front door step. The teenagers in the kitchen, changing their plans. Chasing new ones but only for that day. In they come, out they go, reversing on the driveway. Fifteen years old with a surfboard and a driver's license. Happiness and suffering make the memories. Anything in between, anything ordinary I have forgotten, and all those memory stills are lost.

Remember the seed planting with Mathilda on Sundays last January? Little pots from Aldis. Very cheap. We watched them grow around her lollipop wooden labels. She has terrible handwriting. Tomatoes spelt 'Tomatos' on her stick signs. the mint is in pots because it spreads, which reminds me: Gin and Tonic tonight. Celebrate Wednesdays. Celebrate every day.

My birthday yesterday went well. Relief is setting in. I don't need to talk about *nudging toward* 50 anymore. I *am* 50. But is that right? I'm stuck at 14. I think of school and dancing on the sewing tables in the Home Economics room at lunch, which was during the summer of 1983. Something about the light and heat made me do it. Was it in June? Try and recall; try and guess. 1983, perhaps? Did I jump up? Yes, I was leaping all around the room. Table to table. Was that when I loved Marc—60 Almond Drive, Hampton Middlesex, TW—something? I recorded all his Valentine's kisses in a notebook and can still call up the memory of his name without effort. His kiss in the hallway close to the school dining room: our teeth touched. He's on Facebook, and this is how I know that Marc, with a 'c', is in Market Harborough. He is a chemistry teacher. Two kids, a wife called Emma who is a buyer for M&S. Probably, she earns more than I do. Wears Per Una every day; looks good. I bet she's not too lazy to wear makeup.

I must address my lazy traits, use hair products for my unruly curls, do ab crunches. Fifty sit-ups a day would be a good start. Back in 1983 I didn't bother with floor exercises. Only dancing. I guess I must have been *thriving.* This is another thing we should all being doing now. Thriving. A better word is: *flourish.* We should be flourishing; in 1983 I was flourishing. For some indefinable reason, I prefer the idea of flourishing to that of thriving. Am I still that girl from the 1980s?

The hollyhocks at West Newhall are not flourishing, nor are they thriving. They are being eaten by something. No tall pink, cabernet red, or white flowers to be seen. Turning to a white-lined page for today's list of things ‘to do’, I scrawl, *will help them with their success*. The children are not flourishing either because of COVID. Had a panic attack in May when I couldn't find paracetamol anywhere. Counted four doses a day for the five of us and sealed them up in labelled clear polythene bags with zip locks. The same rigmarole for the ibuprofen tablets I could scrounge from the household cupboards. ‘Only for adults, and to be taken every six hours.’ Oliver has asthma. He is at risk of COVID complications. We went all over town in search of medication. There is no paracetamol at Tescos or Boots. Toilet roll doesn't matter (despite the fact that everyone is hoarding them).

I hear myself saying, ‘After all, we are *resourceful*. This means, children, that we as a family have lots of options. Also, we need to bear in mind the need for *Gratitude*. We are grateful for what we have. Remember that?’

Worry comes back. I bought an oxygenator from Amazon just in case. We tell ourselves Ninewells Hospital in Dundee (our nearest medical facility) is an excellent place. It's 999 now, not 911.

‘Everyone use the landline for *999* calls when necessary,’ I repeat to myself.

Truthfully, we are trapped in a gilded cage, though we have done nothing wrong. No one can come to the house. But who did anyway? Margaret did once, I suppose. She wore a tired blue Barbour jacket but looked fresh. She said we were in her *bubble*, so it was okay for her to be here.

For some reason, I want to call her Maggie after our last cat. Maggie slept with me. I knew her habits well. Loved her much. Yet we left Maggie with Nord's parents who are ninety-something. We went to their ranch house to drop her off on our last day, before leaving LA. Crying, leaving, and loss. Maybe when they die, I can have my cat back. Maybe then, I can go home.

Margaret said life now was all about bubbles, just like champagne. I felt a slice of happiness then, two weeks ago, sitting outside. Surely I could like it here if she came around more? We both drive Hondas and are the nearly same age, which might mean something if only I could grasp what that might be. I should ask her some things. Next time. Conversational questions over tea, such as: Does she like her step-children? Is her marriage to Alan what she thought it would be? OMG, she has a daughter-in-law called Julie! One of those garrulous types. She does Crossfit and Sunday school—never shuts up. I must think about how to approach Margaret with care. These needs to be done right; she could be the one friend I need here. Maybe I love her a little already. Margaret/Maggie. I have a capacity for love. Get the questions right. Don't call her Maggie just yet. But maybe that will happen in due course, and maybe sooner than I think.

Only a year ago I was with the feline Maggie in LA. Yes, next week it will be a year. The truck with our LA things came on October 5th, 2019. Oliver says it was the 3rd. On this occasion, it doesn't really matter which of us is right. Los Angeles, the City of Angels. I thought when unpacking that what we had transported was mostly junk. Little things had gotten lost or broken. The *stuff* of life. Things like beds that don't fit in a new context, or mattresses that were stained. Perhaps some of the stains were from the transit, but not all. Girls have periods, after all. They're not little anymore. Some books were weathered and ruined in their cardboard houses. Sea air destroyed the batteries that I had left in my book light. Things are still missing, like my peg bag from Suzi and photos of my mother and me—the bottle-fed baby. Suzi is Down South, in

Englandshire. She is doing better, having finished chemotherapy. We've been friends for thirty years but when did I last see her? Probably back in 2011 when we left for the US, and she made me the peg bag. I never used it there. I've lost it and she's lost her breast. She wants to see her boys get married. Get settled. Waiting for the results. I must WhatsApp her.

Next to our truck came the cows. The same day. One by one they were unloaded into the shed. I count twenty steps between their home and ours. Lowing cows, separated from their calves. They go on and on for four nights without ceasing. When will they stop crying? When will I stop crying on waking? Tears stain my cheeks. A weighted blanket pins me down so I can put the day off for a bit longer. Let me stay awhile and rest. When I get past this, I will *thrive*, I will *flourish*.

How many cows are out there now? One hundred? Two hundred? I've never been good at guessing or math/maths. How many chocolate Smarties are there in the Smarties jar? I remember guessing at a primary school Christmas fair. I went alone up to the table and gave 10 pence to make my guess and win all those colours, all that chocolate. It felt brave at the time, even though my guess wasn't even close.

The cowsheds are full again now, cleaned with something white, a white powder. I think of cocaine (perhaps and obvious urban association for a city girl transposed to a farm), but it's bound to be dairy lime. The pigeons and the pigeon poop all gone. I was stupid only a year ago when I thought they came in for the winter to stay warm. Straw. Piles of broccoli stems. Cabbage smell for days. The birds got fat and left suddenly in the Spring. Into the fields they went, but only for a while. How long are their lives? How long is mine?

This winter I know what to expect and so will do better. Less crying. Less fat. Less sadness in the house. Still, there is the dark and the silence. It's October now. Then will come the November winds and rain. Still, at night, I hear the screech of the owl. Still, as I lay there in the pitch dark, the scurrying of the mice and the lowing of the cows.

SEVEN

Writing as Thinking

Today is Monday. I am distracted by the pain in my mouth. There is a large lump on my gum and when I push my cheek it feels like an electrical current is shooting up into my left eye socket. Over the phone, the dental receptionist says they could take a look but will not treat the problem if any water spray is needed. This is because of the current COVID regulations. I am conscious of the fact that I am running out of time to get this sorted out. On Friday I am supposed to fly to Florida for work.

‘I have to see a dentist,’ I hear myself say with some conviction.

Monday blues. Feeling blue and blackened by the weekend—all rain and quiet conflict. Yesterday, I walked to Cambo House with Oliver. We are not on the same page, wanting different things. Your work is everything I said, and whatever happened to the so-called work/life balance?

Could we go out with the girls on the weekend? This is what I want. To be a typical family on Saturdays. Yet, nothing about our situation is typical and anyway, the children are all grown up. That would be weird.

Human: aching for so many things.

I'm afraid to ask anything else, like choosing paint for closet doors before the painter comes on Wednesday. When is a good time to talk shades of grey or green? I have a Pinterest page with pictures, ideas. Boards of Georgian colour schemes for the bedrooms, hallway and carpet. If we default to white doors and walls, we might as well live in a hospital, or back with my parents. They only conceded to a hint of yellow to unrelieved white (Dulux Easy Care, to be precise), because of a neighbour's comment about the lounge looking like a waiting room. A sterile childhood: every room had white walls. To bang in a nail and hang something would ruin the house where I grew up. No pictures, paintings, mirrors, or family photos. What did Amanda and I look like at 7 years of age and 4 years, or at 13 or 9? She is beautiful now. Cured of childhood Eczema, and working for Honda in Human Resources. Her only son, Lucas, is ‘on the spectrum,’ as they say. He is brilliant with numbers but can't read. Her husband James works as a project manager in the City, and eats roast dinner rolls for lunch from a stall in Borough Market. Amanda's dark blue hallway and fox print WC is an interior design inspiration. Her friends have done the same. They all have comic foxes in the downstairs WC, and hedgehog tea towels in their kitchens. So *very* London. Some took it further and put up Marvel decor in the kid's rooms and, with the first lockdown, rescued a puppy. Amanda and James followed suit, of course, and called their new dark-coated springer spaniel, Oscar.

Online, everyone is happy, everyone is rescuing puppies, running 5Ks, eating Keto, losing weight. It's all pictured on Instagram and reported on Facebook. There it is. Everyone can go on a walk and be happy.

On our walk, I bring up the colour themes for the house. We are sitting a bench facing the ocean when he says, 'I just don't have the bandwidth, Claire. I'm like a desktop with hundreds of windows open.' And follows that up with, 'we could have bought a flask of coffee.' We *could have* done a lot of things.

I give up the Pinterest Boards I created. Paint charts for West Newhall: Farrow and Ball Lichen, Pewter by Zoffany, shades of my first world problems. It's all gone before we reach the bridge at the foot of Cambo Gardens by the sighing waves, where we pause again this time in silence. The closets will be white after all, and our home whitewashed for years on end, or at least until the next family takes ownership of West Newhall. I am thinking of being back in SoCal and want to turn and walk the 50 miles to Edinburgh airport. It feels like something I could do.

Oliver, cursing the mud on his new cords (that have just been taken up by an excellent tailor on Church Street), wonders why I am sad when we live in a big house. Wasn't this what I always wanted, the very nice, very big house in the country? I know why I have morning tears and need to retreat in the early evening. I could say. Perhaps now *is* the time to be honest about our history and where we find ourselves at this juncture in life. But the walk through Cambo is long, and I don't know how to do the next hour. The stream and stone steps drain us.

At intervals, we try to say something constructive, but despite our best efforts the words cut and only succeed in generating more pain. We want the best for each other. He loves me.

Respects me. Admires all that I have achieved. Long term relationships are tough. We know how to hurt each other. We wouldn't want to end up like our parents: Married and chronically miserable.

On the farm track as we approach the house he says, I will always like you. I say it back, which is as close to a resolution as either of us can get.

Back home, the conservatory leaked, and the rain ruined my new book of essays on Stories and Storytelling by Philip Pullman—red cover and black page edges—Pullman's Daemon is the crow. I sit out here on a green garden desk to write and get vitamin D. Writing is personal and requires privacy. Everyone is still home all day, all week. We scatter each morning to different parts of the house, searching for a WIFI signal. Liberty in her bedroom, pages of A4 foolscap on her bed and floor. Curly words in Arabic script. Mathilda is studying online too. Her French book, Mythology text, and biology homework are on the kitchen table. Oliver is in the drawing room, various tomes scattered on the sofa—titles that indicate works on atonement, legal theory, and metaphysics. Some of them he has written, others he's merely endorsed on the back cover—blurbed, as they say. He knows most of the authors in his small, inbred academic world. Craving light, I work in the conservatory with its cold draughts and patchy WIFI--a hot water bottle tied to my back with apron strings. Very classy. Mathilda appears in the doorway. I close the document I am working on. She says: you can look up your Daemon, Mum. Online.

I shouldn't have left my books on the windowsill. Perhaps I should have known it might rain. She goes to make tea and I re-read what I wrote last week. A few hundred words. A friend who writes enormous volumes of material once told me I need to write faster. I must reach my daily word count, get up earlier, find an extra hour where I can be alone.

Mathilda comes back and tells me her Daemon is a snake. Mine is an Arctic Hare: compassionate, curious, craving close connection, energetic. I guess that might be me on some days (the good days, perhaps). But not here, not today. Mondays at West Newhall are darker than other days of the week.

As usual, we are up in the night with Mathilda for her second dose of Xyrem. After she was drugged to sleep at 1:00 am, I lay awake. Bedroom or tomb? I can't see my hand in the blackness. Shutters let nothing in and nothing out. It is hard to breathe. No air. Beyond the shutters in the rain is an Owl that sounds close. My heart thumping against my sternum, but turning would mean disturbing Oliver. He is ‘over’ my night-waking. He has his schedule, which involves being up at 4 or 5 am to do the work of the Director of the Logos Institute. New emails appear as if by digital magic in his clotted inbox each morning before dawn, and displace the backlog of work and promised publications for another day. Twelve new postgrads are arriving soon. These are good numbers for the department. Some have sold their homes in the US and are trying to find schools for their children here. It's tough for them, he says; huge sacrifices. Spouses unhappy, children whining, cultural challenges, yet (somehow) they are all aboard for the PhD. Without pulling up my mental file on our first time here twenty years ago, before Oliver's stream of other academic jobs, I say, *I know.* But I am thinking, *this is also how it was for us.*

One of the new families at St. Mary's need uniforms for their sons at Madras College, the local high school. Can we give them Elliot's old blazer? As Oliver talks over my thoughts, I wonder why anyone would bring four teenage boys to St. Andrew's during COVID. International students are a significant stream of funding for the School of Divinity. But on the domestic front, another PhD student that means Oliver doesn't have time to cut the lawn or fix his bicycle, move his weights upstairs or go out on the weekend. His job here is a Big Deal; I get it. The Institute and his work. The new students, such interesting ideas for research. Yes, all of it is *terribly* important.

I find Elliot's School blazer screwed up in his backpack in the corner of his old room and call him in California. Throw it all away, he says. For the first time since he left home, I go through his things. History books, notes on Mythology, Moby Dick, and RMPH. All of it represents work for his Scottish Highers, the exams that got cancelled in June. He thought he wouldn't get into college here. He had wanted to study Game Design at Abertay University in Dundee. Instead, he left for California in July with his Green Card and a sense of failure not knowing if he passed, if he was good enough to stay and go to college.

Once, when he was 7 years old, Oliver's mother, Julia, had said Elliot had appalling handwriting. That year I bought him books on cursive and a King Arthur fountain pen after we hiked Tintagel.

For years, we believed Julia went to Cambridge University. When carving Sunday roasts in the dining room at St. James' Avenue, Hampton Hill, Julia held forth. When I was a student, she would opine, my roommates and I would punt along the Cam and meet up at The Cambridge Blue, near the Botanic, where I met your father. Oliver's Dad looking down at his food. His brothers sat there waiting to eat. I was Oliver's girlfriend back then.

After the advent of Google it was easy to locate, ‘Cambridge.’ It transpires that it was a regional teacher training college called Huntingdon, North of Cambridge City Centre, off the A1. Somehow, because of those Sundays, with Julia going on about her Cambridge years, we knew. She never had any university friends, no career capital from attending an elite school and Oliver’s dad was always silent. I want to show her Elliot's schoolwork hidden in his clouds and blue skies backpack and say, *Look at this! Look at him now!* But she is drowning in a deep valley of grief, somewhere between Tooting Bec Psychiatric Hospital where one son is an inpatient, and a couch in Birmingham, where her other son has relocated.

William has paranoid schizophrenia and tears electric wires out of concrete walls. He's done other things like jump in front of a bus, rip out stairs, and refuse to brush his teeth in twenty years. Jeremy, Oliver's other brother, has been unemployed for the last six years but says he works through the night with the CEO of Apple on his new business idea, which means he needs to sleep until two in the afternoon. On FaceTime calls with Julia, I hear a slanted reality. Jeremy is encouraged, he is quite on the cusp of something. Any day now, all his hard work will pay off. He has a new website coming, it is all awfully exciting. Jeremy has always worked so hard.

In the dark, I take Elliot's school files to the bins by the shed where the cows frown in judgment. Tomorrow I will iron his school blazer for another mother and her son.

After Oliver had gone downstairs early, I tried reading *American Dirt,* with my book-light, but couldn't put away the conversation with Wendy yesterday. I also tried meditation and positive thinking but failed; her family is crowding my mind. Years ago, back in Bristol, we raised our kids together when Oliver was a Reader at the University of Bristol. Another important job. Wendy said Heather Rose, her daughter, is now 17 and is cutting herself, leaving blood on the carpet. Emily Georgina, another daughter, is bulimic. She overdosed last weekend on Codeine on her 15th birthday. Emily Grace, a third daughter, is back home and now Wendy shadows her to the bathroom whenever she eats a meal, if she eats, which is about four times a week. Emily Grace and Heather Rose are under CAMHs. CAMHs is the Child and Adolescent Mental Health unit at the Bristol Hospital for Sick Children. Our conversation is triggering, but I carry on listening anyway. CAMHs, Bristol Children’s—I know it only too well. Mathilda was sent there at three years of age when she was sleeping all day, and hallucinating at night but the consultant neurologist declared it couldn’t be narcolepsy because she was too young. In 2010, after the H1N1 vaccine, he was proven wrong. I carried her back through the heavy doors of the A&E unit. While carrying a partially paralysed child and several bags I learned how to walk through without us being hit. How many times did I do that, I wonder? Let me count them:

After she couldn't stop vomiting.

After she became incontinent.

After she lost her sight.

When she wouldn't wake up.

When she went ‘floppy.’

When we could no longer reach or help her.

When I wouldn’t give up.

In the eyes of the law and the NHS, Heather Rose and Emily Grace are still children. Wendy only makes their beds now when they jump through their bungalow windows. She prays for them with a bottle of carpet cleaner in one hand and a tracking App open on her smart phone in the other. Part of me tries to think what happened to make the little girls who I also bathed and read to each week now starve and cut themselves.

Heather Rose still plays the piano; music is her thing. But she won't get her A-Levels in English, Maths, History, and Classics. She is intelligent. But now she is also very anxious. Emily Grace sneaks out late to the skating park behind the school. Wendy lit up about Emily's mastery of skateboarding. Then we both went quiet. It was hard to slide the head lice from Emily Grace's tar-black hair when she was five. Do you remember the two days of combing? I ask. We made the others wear hats so that wouldn't get lice.

Now, through new tears, we both laugh a little ... can it be ten years ago? How did *that* happen? Those days when we built garden ponds and made marshmallow molecule-models with toothpicks. We called it science, and didn't care about the national curriculum or our children not going to school. Over Zoom today, Wendy smiled at the time when it took us a day to find frogspawn at Dyrham House, a National Trust property near Bath. The children used to swing in turns from the oak beside the orangery, and found a deer horn for the nature box. Which of them did that? Libby? The children made fairy houses and crowns of fallen leaves in the grounds. Then they all lined up on a fallen log for a photo. That was a great picture. Sticks and golden and red leaf crowns. I can see their breath and flushed faces, feel their cold fingers in mine, on the walk back. I do not know what we spoke of that day, watching the kids run, fall, shout, laugh, cry. Something that day was within our parental grasp. A promise perhaps, like love.

A month later Mathilda had a wheelchair. A year later, the photo of her with Emily Grace on the fallen tree was on the front page of *The Daily Mail* next to another picture of her, bloated in the back of the car.

Sleeping Beauty.

This new thing, Emily's draw to suicide, all started when she got a smart phone and when Heather Rose started using a private account on Instagram. Wendy says that Heather Rose is an internet star now, as a 'cutter.' She has lots of followers on social media. To get more friends, be more liked, her girls slice their skin and bleed and vomit breakfast and the birth control pill.

One day, our kids will see that we did our best. What other words can I pull out to help Wendy, who is both disoriented and losing ground? I tell her that COVID is the tipping point for kids and marriages. It will soon be over.

* * * *

The dentist on South Street attempts a root canal. The lump on my gum has been there for some months, though he's not sure why but his colleagues in the Dundee office have a CT machine and this will show if anything is growing into the bone. Now I also need to see the oral/facial surgeon. 'Yes, I do plan on giving up social smoking and drinking' I manage to mutter, exhausted by it all. He checks a box and we both know two things. First, that I have underestimated the units of alcohol I am consuming by around 50%; and second, that I will probably give up smoking *provided* I really do have cancer. At this point, I am seeing more than a root canal happening: I will have a face like Lucy Grealy.

The dentist and assistant move to the back of the room and put on COVID required surgical gowns, gloves, and shoe coverings. They peer over me both looking and sounding like Darth Vader. I can't hear them properly, which is a problem for someone who needs to know what is happening. (George Lucas never seems to have considered this in his cinematic saga.) ‘Please explain the procedure as we go,’ I ask. ‘I do better when I know what to expect.’

Lying back, with a piercing, cold dental light in my eyes, there's the thought of what's coming. The yanking of four nerves that are bent at 90 degrees, implants, or a bridge later down the line, and now the prospect of jaw cancer. I realise this has not been suggested but already I cannot control the dribbling. I can almost see Oliver holding my hand one-night in the next week when I break the news. He cries and my diagnosis means there will be no more fighting. He will drop his hours and take me to chemotherapy, each week. His work won't matter anymore. Or ever again.

Wearing a surgical mask under the Darth Vader headgear the dentist is sweating and being wiped by the assistant, his visor already steamed up. Calmly he injects the gum with something and half of my face tingles and before it goes numb, I weigh up what might be better: having a stroke which seems more immediate, or facial cancer, which is more long term. They cannot use water to wash away the tooth pieces in my mouth. In the end, the procedure fails, and all I feel is a relief, despite the fragments of broken tooth I have swallowed. I know the CT scan in Dundee will take months to come through, and, this time, I welcome the inevitable long wait.

Tomorrow I am going to Florida and then on to Los Angeles, with a cracked tooth that is covered by dental composite. Working and visiting Elliot already means no stroke, cancer or chemo. My trip will be webinars, board meetings, breakfast with my son and the echoes of a child who cannot sleep.

EIGHT

Borderland

> The Internet gave us access to everything, but it also gave everything access to us.
>
> — James Veitch

No matter how much I want to see people—actually see them *in person*, as it were—we meet as two-dimensional representations of ourselves on the screen of my MacBook Air or iPhone 8 Plus. Flat images of real people crammed into little boxes on a grid. We are the ‘Multiple Participants’ flung across laptops and desktops, granted access and screen-sharing powers by The Host. We are visible from the waist up, raising a digital hand here or commenting in the chat there when we can't otherwise get a word in, opting on bad days for audio-only—camera off.

I do it all the time, choosing to use an old headshot as a placeholder in meetings when I would rather not be visible online. Because if I am seen, so is the room, and so is my home and the private interior of our lives, which during Covid is not a place I want to share. Particularly not with colleagues.

My online image, a photo taken almost ten years ago, is a brighter version of myself. Younger, of course, but also more put-together. Happier, even. As time goes on, I notice colleagues do it too. They switch off their computer cameras. It’s a privacy bid when meetings could expose the fact that life has taken a difficult turn and your family is falling apart less than six feet from the kitchen table.

What makes connecting online confusing, regardless of the visual background, is that I am at a loss placing individuals in Cyberspace. Or, perhaps it is this: that in a way we are bi-located—meeting up in a virtual space and at the same time, sitting in front of the screen, physically located in a room at home. I know where colleagues are precisely situated in theory, whether in the UK or the US. These are people I've worked with for years, met at conferences in lobbies and elevators, sat next to in meetings, shared cabs with to and from convention centres, stood shoulder to shoulder with for photographs. But never have I been in their homes or have access to much about their private lives. Before COVID, many meetings were already online but usually from an office, in an office building. I rarely invited colleagues over to my house, not even those I liked or the few that lived within striking distance. And yet, here we all are, hanging out in the ether, showing up from our sacred places, giving the boss access to our most protected spaces.

Last week, in my personal Zoom room, I met with Dr Ong. He was calling in from his bedroom. He was sitting at a desk, his bed neatly made to the right of the screen. Talking with him took the usual format. Beginning with a polite catch-up, and a brief update on his mental health and mindfulness research, he proceeded to outline his upcoming presentation on narcolepsy co-morbidities. It was all business as usual, unsettling in that he seemed not to be bothered by the awkwardness of his background. I tried to focus on his face, smiling and nodding here and there, hoping he couldn't read the awkwardness I was feeling now that I knew the colour of his bedsheets and his taste in artwork. The piece hanging above the headboard was a messy juxtaposition of stained glass and children's comic characters. The paint was splashed everywhere as if the artist was a 6-year-old who couldn't stay within the lines. He said it was an anniversary gift, which his wife purchased on a weekend cruise event off the coast of West Palm Beach in Florida. They love the artist and are planning to buy more originals. More pre-school designs to complement the pre-teen zebra rug. I now know this about him and cannot *un-know*.

On Zoom, there is another bedroom background. This time I see a cluster of orange pill bottles on the nightstand of the upbeat and meticulous Dr Grandner from Arizona State University. His whole room is a mess, and this meeting feels like an invasion on my part. I shouldn't be here, so close to his bed. It's like I've shown up uninvited and walked through his house while he was gone and discovered some terrible secret. Something I won't be able to shake off when we next meet at a conference (if the world ever opens up again). I had Dr Grandner down as the obsessive-compulsive type, with everything in its place, his tie never off centre—not even the teeniest bit. He tells me that now, he only bothers to be smart from the waist up, and that COVID is making him reassess things. Not rushing out of the house for the early morning commute has made him slow down, and relax. Immediately another image is conjured in my mind’s eye. Maybe he's wearing sweatpants or even pyjamas. I've heard people are not bothering to get fully dressed doing this during lockdown, as well as not showering either. Yet neither of these details is as disturbing to me as the half dozen or so pill bottles visible in the background.

He keeps talking. I keep thinking about the possibility of him self-medicating for depression, my thoughts drawn irresistibly in that direction given that it's his area of expertise. Or maybe something equally serious is going on and his life is unravelling. Or something worse. Eventually, the conversation moves to his research topic, identifying sleep disorders in displaced immigrant families on the Mexican border and his recent appearance on the *Dr Oz Show*. The white-capped pill bottles are catching the Arizona evening light by the time we both click the toolbar tab labelled, ‘leave the meeting.’

On Cisco Webex, during a summit with a Congressional committee, the executive director for a large charity based in New York who was scheduled to speak before me joined from what looked like a dorm room. I had driven into town with the keys to Oliver's office searching for secure WIFI, and not wanting to risk our internet connection cutting out at home just when I was about to speak to representatives of the Federal government. Our home wireless internet provision had inexplicably dropped the signal in more than one recent board meeting. Such things tend to be noticed. By the time the Congressional committee meeting came round, I was sufficiently concerned about losing my job due to internet issues that I was prepared to stand outside St. Mary’s College in St Andrews at 11 p.m. in order to dial in to the meeting in Washington D.C. The University internet portal, eduroam, was as secure a connection as I could find within a ten mile radius of the house. At least I could access that relatively easily with my student credentials. The purpose of the Congressional Sleep Forum was for patient advocacy organisations to make a case to the National Institute of Health in the U.S. for more research funding to investigate sleep disorders, and expand provision in American sleep medicine more generally. My counterpart, Evaline, who was the Executive Director for another medical non-profit Narcolepsy Network, appeared with the thirty or so other attendees at the meeting. Except that, unlike the other virtual participants she was sitting on the floor cross-legged (enviably flexible for a 65-year-old) beside an unmade futon. Behind her was a dresser covered in stickers and a pink poster on the wall that bore the legend, ‘Babe Cave.’ This made me wonder whether she had split from her attorney husband, and left the family home in Central Park South. But it was the items of clothes on the floor that triggered an image of a weeknight fling with a college jock. It didn't help that Evaline was late-actually late for the meeting with the members of the Congressional committee and hadn't even done her hair.

My spiel about children with narcolepsy needing better access to medication went well enough, but I'd gaffed the ice-breaker. It turned out that I couldn't get into Oliver's office. The University had changed the outside locks on the side door that he'd told me to use, where there were no cameras. Neither did I have the time to drive back to the house. Instead, I opted for propping my laptop up on a bin in the alleyway between St. Mary's college and a narrow row of student housing, close enough to use eduroam, but far enough away from the main street to avoid being seen or worse, interrupted. Still, I was distracted by only having 56% battery power left for a potentially two-hour meeting with no way to recharge my laptop. The evening had been mild, but it suddenly turned windy and wet. The rain was battering the bins, and the darkness was drawing down like blackout blinds. I stood, holding onto my nerves and pad of A4 notes, which was by then a wad of blurred ink, only an outline committed to memory.

When asked by the Congressional moderator what I have been doing by way of self-care during COVID, I said—trying to focus—something about taking my daughter for a walk each day, which lacked imagination and made her sound like a pet. Others, patient advocacy leads and reps from the biopharmaceutical industry, had found new interests over the last eight months during lockdown—Peloton, Poker, that sort of thing. Evaline said she had taken up Macrame which jarred with her current online image. In a previous email, I had been asked to submit my bio. It stated at the very end that I lived on a farm in rural Fife with a hundred cows, not far from the North Sea. This jarred rather strikingly with my virtual background that evening. What everyone saw and heard was an alleyway littered with trash, drunk students singing within earshot. Turning my camera off may have looked like I was dialing it in, checking my email or surfing the internet, so I kept it on, like the other attendees, though I'd never been more grateful for the mute button.

On Google Meets, I accepted a meeting with Maria Frivida at Jazz Pharmaceuticals about a recent grant application I had written to fund online support groups in the narcolepsy community. She appeared from the shoulder up, apparently lost in tall grass, giant green blades crowding around her from the top to the bottom of the screen. Her virtual background was a filtered cornfield, somewhere between Hoosier Hill, Indiana, and Dayton, Ohio. This, though she lives in suburban Virginia and has been working from home for six months. ‘Where are you?’ I asked. She told me she was at home, in the lounge, her office in Philadelphia having been closed for the foreseeable. The digitalised field image taken from her family album was where she spent vacations as a child, she explained. It conjured a pleasant, homely thought. An eight-year-old version of the glamorous Chief of Medical Affairs, legging it back through shimmering summer grass at dusk to her grandparents who were ready with homemade lemonade and s’mores on a clapboard porch that needed sweeping. When after half an hour we closed the meeting, her head still bobbing between verdant blades, it was not without relief. Apart from the obvious distraction of trying to reconcile our discussion on funding research with placing the digital field scene background, I had half expected a predator to pounce and bite off her head, as if she was some country insect crouching in among the tall grass. Maria may have been equally disoriented. At the time of the call, I was in the drawing room at West Newhall, floor-to-ceiling bookcases behind me. ‘You have a library?’ she inquired in surprise. ‘Don't you live on a farm?’ And looking back, it is a room that could easily impress an American who had earlier confessed to binge-watching *The Crown* and, before that, *Downton Abbey*.

Maria and I were both where we said we were: Virginia and Scotland, respectively. But it also felt like we were film set versions of ourselves elsewhere, in the nebulous realms of cyberspace.

*   *   *   *

On Microsoft TEAMS students in Mathilda's maths class take screenshots of her falling asleep. For the past seven weeks we have been oblivious to these pictures being posted on Snapchat, each with its own caption: Blobfish; Gross girl; Lazy bitch; Fat Cow. Charlotte, Mathilda's friend, has taken screenshots of the posts on her phone, but it's her mum, Jo, who calls.

‘I'm so sorry; I think you should know about this. It's been going on for a while. Charlotte would rather you not mention her name to the school when you report this.’

I ask her to send them to me, all the images, all the messages. As they begin to pop up on my phone, I am told that they no longer exist; they've disappeared, as with all Snapchat posts 24-hours after going live. But here are the screenshots Charlotte captured, as evidence. In one image, Mathilda is pictured slumped asleep on her desk. In another, she has her head cocked back, mouth open. Then there is one with her head on her chest, a wet patch of dribble on her t-shirt. All show her napping through class, the unavoidable sleep attacks that are a sure sign of the narcolepsy she has had since the age of three. As much I am used to seeing her like this, it's what is said by her classmates in the text-threads that is crushing.

Narcolepsy is a fucking joke. LOL! So convenient to sleep in class! We've all got Narcolepsy! Who isn't tired? What's her excuse, exactly? The hashtags used with each image say more about what they think of her: #comic #lazyass #fake #lazyasfuck #disgusting #sougly #wasteofspace #wishshewasdead. I am angry with these children at their ignorance, their wickedness. I am angry that they are all healthy and that Mathilda will never be able to sustain wakefulness and never know what it is like to feel rested. Weeks later, the anger gives way to sorrow and the answerable question: Why her and not me?

Because the original Snapchat posts no longer exist in real-time, there's little recourse with either the school or the thirty or more students involved in writing the comments. Not only that, but her classmates use handles and not their real names, so there is no way for me to tell which is which, or who is sharing the post across the internet. And it is the sharing that means multiples of people see the images and engage with them online. Who knows how many? Some say nothing but drop emojis in the threads: a thumbs up, a laughing face with tears as if to say, yeah, this is hilarious. Another emoji shows a sloth lying on its back in the high branches of a tree: lazy, checked out. I give all this to the Head of Year on Monday morning, who is very sorry and would like to know more about when this all started. She listens to my reporting as I email her the images and comments.

It is impossible to express what I *really* wanted to say: You have no idea how hard life is for her, living with narcolepsy. You have no clue about what she goes through every night and day. You cannot imagine how miraculous it is that we even manage to get her to school some days! *Find out who did this. Tell me their names. I want to see them. And hurt them.*

What I heard over the phone was predictably asinine. COVID is hard on everyone. We will try our best to get to the bottom of it, but with no real names to identify the culprits and no in-person teaching, It will be challenging to determine who is involved. And on a loop that replayed for months, kids can be mean sometimes. Such is life.

Several months later, by which time school has finished for the Summer, I received an email.

Dear Mrs Crisp,

How is your Summer going? I was able to identify several students who are in part responsible for the unfortunate incident with Mathilda. Since then, I have had two letters of apology which both stated that neither pupil thought about the upset they could cause at the time and were deeply remorseful of their actions.

Unfortunately, I still haven't discovered who took the photo images but remain hopeful. During assembly (online) at the end of term, I highlighted the rules of VLE and made it clear that bullying will not be tolerated.

If we had been in school, these pupils would have been issued a series of detentions. Unfortunately, this is not possible at this time. However, I have written to their parents and asked that they discuss the matter with their child.

I hope you are both well and if you have any further questions, please do not hesitate to contact me.

Kind regards,

Ms. Jennifer Watkins

I learn that VLE stands for Virtual Learning Environment, and that the school has a code of conduct that outlines appropriate behaviours online. This is news to both of us; Mathilda says she has never seen it, that the school didn't mention the code in the transition from in-person teaching to classes online. In another email, Ms Watkins refers me to a government website on cyberbullying. It lists common-sense rules, like ‘change your privacy settings to friends only,’ ‘don't post personal information online,’ ‘never let anyone have access to your passwords’ and ‘Google your name now and then.’

None of the advice is relevant as Mathilda does not have any social media accounts, but I action the very last point: a Google search of her name to check for cyberbullying content. What comes up isn't surprising because they are publications we were involved in after her diagnosis: an NPR podcast that featured her diagnostic journey; newspaper headlines about the H1N1 vaccine causing early-onset narcolepsy; book reviews of *Waking Mathilda;* and in advanced searches, scientific data. In this way, she is heard, seen, recognised as the little girl that cannot wake up—a Sleeping Beauty. Charlotte's mother was right. The posts from social media no longer exist in the ether. It is as if they never happened. So much for government advice.

A week later, a card arrives at the house addressed to Mathilda. Inside, the word sorry is printed in large cursive and underneath, an indecipherable signature, a scribble in pencil. We have no idea who sent it, but she hazards a guess. A boy called Felix.

Every time I go into town, which has few remaining inhabitants on the streets, I look for his face.

A year later, Mathilda is in a new school where all the students are anonymised online—known only by an icon they choose to appear in the chats, such as an animal or Anime character.

Even the teachers are invisible though the courses are synchronous. They are voices arriving through headphones over a deck of slides during class or a name at the end of an email. She can be anyone or anything she wants to be in this school when typing questions in the chat, conversing with her virtual classmates, sending in homework. I see the need for her to hide behind the headshot of a kitten, even in this virtual space. I understand she never wants to return to a traditional school setting or have in-person teaching where she might be seen falling asleep again and again, which still happens despite new medications. But I don't know how she will flourish in a world so contracted, so isolated. An almost entirely digital education in which she is profiled as a cat and talks only through typing, her voice unheard, and with few opportunities to explore and own who she is as a young woman with narcolepsy. Or, for that matter, with little real social interaction as a teenager like any other, who is trying to figure out who she is, where she belongs, and what life is all about. Inspired by reading a collection of essays By Ann Patchett, on one balmy day in May Mathilda begins what she calls her autobiography. It's a painful read except for a few light moments around friends and the coastal views from her bedroom at West Newhall. But the first chapter begins not in her early years but with what she describes to me as *the Snapchat Incident*. The title of her work is, ‘Judged When Asleep.’

* * * *

On Bluejeans, a tele-health appointment with Dr Urqhuart at The Royal Hospital for Sick Children in Edinburgh assures me that Mathilda's recent dizzy spells and headaches are the consequences of her sedentary, reclusive life. Under normal circumstances pre-COVID, her blood pressure would be taken at the clinic. But that is impossible given the current lockdown. In any case, he says, it is unlikely that her medications—even sodium oxybate—would cause cardiovascular issues in a person with narcolepsy who is so young. He advises that she find a friend who might go running with her, or at the very least, that she should download the 'Couch to 5K' app on her smart phone and start there.

We try the app more than once, but the results were short-lived and the process painful. On one particularly miserable attempt, I dragged her out across the back of the farm for a repeated cycle of 2 minutes of walking, followed by a 30-second sprint. The two of us set out together, but soon I was some distance ahead. At the time, I was upbeat mostly because I could see she was trying, and the panoramic views were life-giving as always: sheep in the fields running off as we drew near; cows coming towards us as if we had something for them; and when you looked up, the North Sea right there like a blue-grey ribbon on the horizon. Then, just as the voice on the app told us both to walk again, I looked back and saw her, head down like a stubborn horse, refusing to go any farther. Gasping between breaths, she shouted, 'You don't love me! You've never loved me. Mum, wait! Please. I am trying to tell you something!'

Three weeks after we ditched the Couch to 5K idea, we flew to California to see Elliot, who had already moved back for college and had been alone, self-isolating for several months. And because some things are easier there (like having your blood pressure taken during the lockdown), and faster (like getting a referral for an EKG), Mathilda was found to have heart issues resulting from a nighttime medication high in sodium. By the New Year, she was under the care of the paediatric cardiovascular team at the Los Angeles Children's Hospital.

*   *   *   *

On Skype, in Southern California, we meet up with our friends Jill and Clint. It is January and Jill's 50th birthday. It is also a year since we have seen them both. Clint, her husband, has already sent us the game the four of us will play, a travel version of Yahtzee. It is so tiny, I need reading glasses to see the dice. An hour before the virtual birthday party, something else is delivered. This time, it is a box of cupcakes. A dozen beautifully decorated party bites from a local bakery. Jill and Clint have an identical box for the birthday girl who asks to open them together, not now but later. My heart sinks. Several of our cupcakes have already been eaten. If the online celebration wasn't awkward enough, Oliver hates board games, and it never occurred to either of us to buy balloons or candles, something Clint organised their end. Jill appears on screen in a party dress and full makeup, as if we were all headed out to eat somewhere fancy, while I haven't so much as taken a shower that day.

I am sitting there feeling bad, wondering why we hadn't thought this through, and made more of an effort when we had the time. Jill wins the Yahtzee game, which is fitting since it's her special day. But then she requests another round because this is the most fun they've had in ages. As much as we want to celebrate Jill, it's another online meeting, and being the weekend, it is hard to summon the enthusiasm for a virtual party. Squeezing into the screen next to Oliver, I sense him trying hard to sound upbeat when really the whole thing felt too distant to have any real meaning. We both want Jill to have a great time. Truly. To feel celebrated. It is just that neither of us knows how to pull it off in any convincing way when we are burned out on Skype, Zoom, WebEx, and TEAMS. When the time comes to sing and open the pretty box of cupcakes together, I quickly angle the screen to hide how many are missing. Jill blows out her candles and claps with delight.

On Skype, two months later, we meet again. Jill's mother, Jean, has died. Not from COVID or something COVID-related. Rather, she had a fall and a broken hip as a consequence of which she had a minor post-operative stroke, followed by a full-blown heart attack at home. Jean, I learn during the online funeral, had loved gardening and regularly wrote letters by hand to friends and family. These days, that seems such a quaint thing to do. Jean is why thirty or more of us are here, boxed in our digital islands, muted on a Saturday afternoon in March. COVID is why we are doing this online. COVID is why Jean is alone in a chapel in Carlsbad, the casket open.

The Minister leads the service robed up in his home office, candles and crosses in the background while images of Jean's garden scroll across the screen. I show up from an open plan lounge wearing black, hardly knowing what to do when asked to stand and sing for the first hymn. Elliot walks behind me half-naked to the bathroom, making it all the more awkward just as I am trying to feel sad about Jean. I know the pain is there. It is a collective grief that goes beyond the unattended coffin and Jill's loss and the bewildered faces on the screen. But somehow, I cannot place it. My sorrow needs a location, just as I need to feel rooted in a place to belong.

By that time we had been back in Los Angles for several months, facing new health challenges with Mathilda that required treatment outside (I should say, *outwith*) Scotland. But it was also a year since COVID began its global threat, and if my grief also needed a purpose, this was it. Despite seeing Jean's beautiful handwriting and the moving tributes during the online service, not knowing her personally somehow made space for reflection on something much larger than a single loss. I cried then.

I cried for Jean and Jill at first. Then, when the virtual display noted ‘Meeting Ended For All’ I closed my laptop, and fierce tears filled the space we all inhabit in the isolation of our homes, in the context of our communities, in the places where we were born and where we dwell, where we are trapped—COVID occupying all of it.

NINE

Crashing

> It was a feeling in the present that arose from a vision of a future that was no future, one with no way forward, from a conviction that what is terrible will always be terrible, that now is a flat, featureless plain that goes on forever, with no forests relieving it, no mountains rising from it, no doorways inviting you out of it—the dread that nothing will change, that somehow coexists with the dread

> that something terrible is going to happen, that what is joyous cannot be trusted, and what is feared is lying in wait for you.
>
> —Rebecca Solnit, *Recollections of My Nonexistence*

When I wake, I want to be asleep. When I am sleeping, I am an observer of myself. When I dream, I am somewhere else.

Once, I crawled army-style to the west coast of England. It took months to drag my body, stomach and chest open, organs dragging over roads, fields, streets, hills. Looking over the Atlantic Ocean, I saw the east coast of Florida and a crocodile that took me there. On his back, I felt the promise of something which could have been hope. Or light. Or home. It wasn't strange that the crocodile talked and told me how it was he was there, gliding through the saltwater waves in the pitch blackness. The hardest part was the last leg—running without water across mile upon mile of continental America, from eastern tree-lined slopes to the rugged deserts of the West, my body changing each day until I looked like someone else. The sand and cacti of the West populated the dream; but they are not a part of my life. The sun burnt my skin, but I am cold. My chest is not bleeding, but on waking, something is pressing down, diminishing each breath. I am whole *and* broken.

Upon waking, Oliver tried to comfort me and tell me it wasn't real. But the desire I feel about returning to California is otherworldly. I want that other world, as in the other life I once lived there.

Another dream: we were walking around a large pond filled with underwater vines and algae. Oliver says that it's me who must get in and look for what is missing. In the water, I am struggling to swim, legs tangled in green plants. It's deep and dark, the water is almost black, and although he is telling me what to look for, I can't hear him. What I hear is the sound of water on the other side as Mathilda sits on the bank and slips in to find me. I am screaming at her to get out as I try swimming towards the other side, panicking. She will get tangled, sucked in and will drown. The algae have me stuck, and as she turns to lift herself out, her legs are large and bulbous, like those of a giant frog. Mathilda pulls up onto the bank, her belly bloated, crying—*I can't do this!* Then silence. I watch her sink as if something invisible pulls her down. Slowly, painfully, she slips below the green, algae covered surface. Not even the water makes a sound.

I think: this is how it is in waking life. *We cannot save each other.*

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When the day comes to be vaccinated, there is no knowing what the new adjuvants will do to us. No data is suggesting the Pfizer, Moderna or Johnson & Johnson vaccines will trigger an extreme immune response like the H1N1 vaccine did with Mathilda. But equally, there's no data to say it will not. The fear of contracting the virus becomes contagious in our home and halts our decision-making, delaying our individual decisions by months. In the end, my fear of COVID and developing secondary complications outweighs fears around contracting narcolepsy or blood clots or any other unknown side effect. Each of us decides to have it—except for Mathilda. In turn, we go to get the vaccine and report various side effects: aching arms, fatigue, fever. What I look for in Liberty, Elliot, and Oliver is the lifting of post-vaccination sleepiness. Also, I wait for the sounds of nighttime hallucinations, and the early signs of cataplexy.

When my boss M—— in Massachusetts calls to discuss why I am not a great success at fundraising, I sit in the old conservatory in West Newhall with my hot water bottle tied to my back by apron strings as usual. She wants me to pull back from providing support services for people with narcolepsy next year and switch to donor relations. This means asking for money (large sums of money!) from people I do not know. *You need to be bold;* she says. *Ask, Ask, Ask! It is, after all, the American Way. We need a big donor—someone with narcolepsy who is famous. Do what you need to do.* She wants me to reach out to Big Names. People like Isiah Thomas, whose daughter has narcolepsy. He was a huge Basketball star, and friends with Michael Jordan. Then there is Ginger Zee, a meteorologist at ABC News. She is a national treasure who has narcolepsy. *Can you get an interview with her? Jimmy Kimmel—he has narcolepsy too. Do you know his show?* In our meeting, she shelled out instructions about to take courses in philanthropy and donor relations, a paralysing thought. *If you work from a social media angle, you could get on the Oprah Show. Take more selfies, like when you are about to board a plane, that sort of thing.* In my inbox this morning, there were a dozen links to resources M—— had found through the night. Courses I could take, certificates in corporate philanthropy, leadership strategy, articles to be read on running online fundraising campaigns. One link is entitled 'Asking Is Not Evil.' I almost gag on my coffee.

When I drive Mathilda to the Children's Hospital, we join a long line of parents and their offspring in the foyer. It must be chemo day because almost all the children are bald. No eyebrows. Some can stand; others are in wheelchairs or oversized strollers loaded with equipment to help them survive. Tubes going into different parts of their bodies: nose and neck; stomach; arms. We are lining up for admission, moving forward to the next coloured circle on the floor marked by the outline of an insect. We move from a butterfly to a dragonfly and wait six feet behind a boy who is on a ladybird. He does this thing with his arms, a tic, a spastic motion that never stops. It is exhausting, just watching him move rhythmically, and impossible to not overhear his mother when she talked on the phone to someone, making evening plans as if this day was like any other; as if we were all queuing up for a museum or theme park.

Mathilda changes into a paper gown on the red level. She undergoes an echocardiogram and ultrasound by a man called Moses, who calls her Martha throughout the hour-long procedure. Neither of us corrects him because he doesn't stop talking about arthritis in his hands, the exercises he's been doing for twenty years, and how he plans one day to return home to Egypt. She glares over at me with that look in her eye as if to say, ‘I hate this,’ the man's hands moving the ultrasound head under her left breast. The room is cold and dark as night. The door is closed. The hour is long.

When the consultant cardiologist tells us the results of the morning's scans, she brings in a giant ostrich puppet on strings, introducing herself in a squeaky voice as Noel's best friend, explaining how the two of them together help kids with hearts that don't always work as they should. Noel provides an overview of the heart's anatomy, lifting his legs to words like pump, chambers, gates, blood squirting through tubes en route to cells as far away as fingers and toes—delivering them lunch (oxygen), and picking up their trash (carbon dioxide). *The heart is one hard worker,* the ostrich says, dancing. It is as if I am not in the room until the end when Noel is done with the lesson and the doctor makes eye contact with me. Now, there's talk of higher-than-average P waves, elevated blood pressure readings through excessive sodium intake causing idiopathic right atrial enlargement. She will need to come off Xyrem and be monitored. Mathilda's sleep specialist will need to find alternative treatments—that do not contain sodium.

When I think I am writing the story of my life, I do so (at least in part) in order to reframe the past, to put it in order, and find its meaning. But I cannot write this week without thinking of

Ben and Meg on their date night, their bodies burned into a hole in a road in Fort Worth, Texas. I've read that writing is a legacy, that words have power. But what message could be written to their four children to make meaning of their parent's death?

A few of Oliver's doctoral students followed him to various institutions—like Ben, who went to Bristol University. He got his PhD in analytic metaphysics but weighed up taking an academic job against being a sales rep for CarMax in Texas instead. The Obits say he was a leading young voice, a devoted father, and a pillar of the Fort Worth community. A good car salesman, who was also teaching adjunct at colleges here and there. Yesterday, two drag racers tore into Ben and Meg's car causing it to flip and explode within sight of their driveway. The local council has already called an urgent meeting to address how traffic might be slowed on the street where they died. *Fox News* runs the images—a shockingly small pile of burnt metal but none of their young children or their house or of the two boys who sped off. One journalist speculates: *drag racing is growing as a pastime as young people feel the pressure of COVID, which is having catastrophic effects on mental health.*

Their memorial service is tomorrow and will be live-streamed. Someone has decided attendees must wear blue and white because Ben and Meg had bought new jeans and shirts for their family photo shoot next week. $111,000 has already been raised on GoFundMe for the family's financial hardship.

Date night. Death night. Darkness. Orphans.

Oliver: *What's the point?*

When we went to dinner with Todd and Elizabeth, you could tell he wanted another job, another life. *Lizzie is the star here,* he says, serving up Coq au vin. *Head of Teaching. Under contract with Eerdmans* [a publisher]. *We couldn't turn down this job, not when the University of St. Andrews said they wanted her. Eight years later, and we are still here!* That night, Todd said November was a bad month. Very cold, very windy. Worse than that is the dark. *Days will get shorter until December 21st*, he said in a way that might prepare me as if I didn't know and hadn't lived there before. *It's all uphill after Christmas.* Between courses, there was more: *Get a diagnosis, get antidepressants, get a SAD lamp and close the door, let the light fill the room and warm you up. SAD light therapy lamps: only a hundred bucks on Amazon!* Todd has a year-round tan on the upper half of his body. A red face but white hands. Three days a week, he holds the hands of blind kids and teaches them to walk around the schools where he works—Madras College and Bell Baxter. One of the students has eye sockets that are shriveled like mushrooms. He will never see Todd's red face or the faces of friends or his classrooms or the light and but at least he doesn’t need a SAD lamp.

When I think about language, I go back to the classrooms at Castle House and Kennedy Hall, when as MLitt students, we had discussions on the works of Walser, Kierkegaard, Kafka, Kleist. Students talked about building the tone, non-narratives, and deliberative neuroticism. Professors taught on Ekphrastic writing. One student wanted his work to be more layered, more tonal, and not have a storyline. One workshop on life writing was about a girl who starved herself and hovered for years on the brink of vanishing, thinking she would only be beautiful if she took up less space—until she was diminished enough to need hospitalisation. Her mother stayed beside her at night to watch her breathe, exist. Another submission for the workshop was entitled ‘Penis Caught in Zipper’—a true story in which a twelve-year-old boy feels such humiliation on a train that his mother responds by writing a parenting manual on educating teenage boys about wearing pants. On the drive home after class, I think about all the ways I could have done better at parenting.

All the books that we read, the worlds into which we escaped in Kennedy and Castle, came before we knew the word COVID.

All the technology we have to connect us living remotely, but no app for belonging.

All the words, all the terms, and no telling the way forward, no explaining how we should live, what we can trust.

Upload

Download

Swipe

Scroll

Surf

Drag

Drop

Charge

Trash

File

Find

Copy

Paste

Post

Pay

Print

Press

Plug

Cut

Tag

Check

Edit

Add

Open

Close

Reply

Rate

Click

Delete

Update

Scan

Send

Forward

Shift

Scroll

Command

Chat

Join

Dial

Meet

Enter

Leave

Lock

Start

End

Schedule

Cancel

Share

Print

Pause

Zip

Unzip

Test

Respond

Record

Escape

Erase

Mute

Burn

View

Virus

Search

Save

Help

TEN

Present Self

Touch has a memory.

—Keats

I keep trying to remember the touch of strangers—the hand of the bearded barista in Costa when I paid in cash for a takeaway latte and millionaire bar. I was on my way the English Department, weaving behind St. Salvator's, eating from a brown bag and drinking from the cup he handed me. I thought nothing of his hand touching mine. Nothing of a deadly virus, or a global pandemic. In Kennedy Hall, we lined the stairwell before class, waiting in rain-wet coats. Shoulder to shoulder, outside the Barbara Murray Room. Then, a class full of poetry and prose students who sat down next to each other. Close. Near Christmas, we passed round a box of Quality Street, sliding it up and down the table, touching the tin. Two dozen unsterilised hands.

I keep trying to remember the time before we wore masks. When did we start to use the phrase 'socially distanced?' April? May? When did the marks on the pavements appear, that keep us six feet apart? June? Later, perhaps. Now, we stand on our spots in silence outside Tesco's and Sainsbury's—the only food shops open on Market Street. We do not make eye contact. We could kill each other with our breath. And those we love.

I keep trying to remember what my mother feels like—when I cupped her face in my hands at Edinburgh airport. More than a year ago. She looks older, thickset now on FaceTime, though I cannot be sure. She tells me that my father has his own bedroom, his own lounge upstairs, full of photographic paraphernalia—over-sized lenses, mounted images of sailing boats, wild horses and pigs roaming the New Forest, a gaudily dressed cast of actors at the Bournemouth Palladium propped up besides old copies of Attenborough and Wainwright books. Our earlier selves are on his bookcases too, remote moments of my childhood faded and framed. The 5-year-old version of me is a girl giggling inside a cardboard box on the balcony of a high rise flat in Feltham wearing a dressing gown for a superhero cape that was years short on her arms. The same child several years later is half crouching, hands covering knees, on a day trip to Brighton Pier. We drove down one Sunday in our new Cortina and met a man who took photographs of his squirrel monkey sitting on children's shoulders. One pound fifty for a picture of the two crouching sisters in their floral dresses with lace collars and sewn-in petticoats. That day my parents were proud of their gold car, and proud of their girls in sepia tones. The happiness is still there in the photo on my dad’s bookcase, but it is a room that my mother never enters. I remember asking to take the monkey home, suddenly feeling desperate for it. A tiny thing. Something to care for, something to love. I knew myself then, knew what I wanted—a monkey that was mine, and a mother who did not withdraw into monthly cycles of bitter silence. I wanted a mother who stood visibly at the school gate and was not afraid to talk to the other parents instead of turning on her heels as soon as she saw me, dragging my sister through the estate, as if we did not belong there, or to her. On those afternoons I ran to keep up with them, though I never wanted to reach home—49 Winchester Road, Hanworth Middlesex.

I wished that weekends did not exist. Saturdays were for lessons when my father taught her to drive, whacking the window over her failure to stop at traffic lights. ‘You could have killed us … you stupid b—-.’ I am 10, 11 years old, sitting in the back seat, fingers tightly crossed behind my back willing Mum to stay in her lane, or all the other cars to disappear. I wanted there to never be Sundays either because that was a pub day. Dad, his brothers, my mother's brothers, her father, and uncles met at the Green Man in Bedfont, Prince Blucher in Twickenham, and the British Legion in Hounslow. By 2 pm, around the time he got home, the meat was ruined, vegetables overcooked, and often the plate of food was thrown at him from the hallway or kitchen. In the lounge, with its orange faux leather couch, indoor plants were hurled too, later to be rescued and re-potted. Before the evening, the two of them blacked out under sheets of *The Mail on Sunday* with the beginnings of bruises on their arms that would change colour over the week—red, blue, yellow. I did not know then that they were just trying to cope, to make it all work. They were doing what we do as parents … doing their best. I understand this now. These days, the only rooms they share are the kitchen and the cupboard under the stairs where her jackets, clean and crease free, are on the left. My father's all-weather gear is pegged on the right. Their clothes have not touched for years. ‘He can live in his own shit,’ she says.

I am trying to find a picture my sister took when she brought her son Lucas to West Newhall. I rode the lawnmower that weekend with him on my lap. Scrawny legs, squeals of laughter when he steered the two of us up the track, through the empty cowshed, across the lawn—it was the last cut of the season. I held him tight, half pretending that he might fall. It did not matter to me that Lucas could not write, or was two years behind at school in reading, maths, spelling, or that he has ADHD, OCD, ODD and Spectrum Disorder. We drove up the farm track scattering pheasants into the fields under a circling hawk, the October sun like a handprint on our backs. It was not illegal then to see your family, or travel beyond a 5-mile radius of your home. He is taller now, and on winter walks he will not hold his mother's hand.

I keep trying to remember meeting people, shaking their hands, and embracing friends in the street. When I got home, I would say 'You'll never guess who I bumped in to …'

I keep trying to start the day with yoga. On YouTube, Adrianne tells me to move through the poses as if I love myself. We pause in the Goddess pose. Hands on heart. 'Protect your heart. Be the Goddess you were born to be. If ever you doubt yourself, come back to your mat.' A new pose is lying on your back, hands wrapped across your chest. Love yourself. Focus on the breath. Leave aside COVID. Inhale. Exhale. Let it out.

I keep trying to recall the times when we left the house at eight in the morning. Every weekday we drove to school, work, libraries, cafes, Morrison's, or Aldi's. Rushed breakfast, scrambling for lost shoes and last night's homework. So many questions: What time do we all finish today? Who will collect Mathilda from school? Elliot, do you have bus money? I was often irritated when Oliver came out of meetings late, making me wait, watching for him to come through the iron gate of St. Mary's. Now I am searching for him with words. 'Will we do that again one day? I will not mind waiting for you outside in the cold and dark when the world opens, and we can live in it.'

I keep trying not to buy things. Amazon orders abound: cat toys, colouring books, pens, paracetamol, and an oxygen tank. Things we already have or may not need. Trapped at West Newhall, a gilded cage where I wait for a van to pull up and listen to a delivery driver crunching across the driveway with a box, a package like it is Christmas. If I spread out the orders, someone might come every day. Someone I don't know but who will say hello.

I want to get things locally, pop into town where they know my name and I know theirs, but the 5-mile rule means the only shop we can go to is the Co-op in Crail. It’s a tiny store not much larger than our lounge that sells flowers on the verge of wilting, day old donuts, and expensive dog food. Several times a week I buy supplies there—cheese, eggs, milk, and Cadbury’s chocolate. Seeing the rows of Pedigree Chum stings. Watson has been gone for a month. We have moved his lead, plaid winter jacket, and dog bed into the garage. Indoors, memories of him exist in every room. The kitchen table he bit into with the last seizure. Urine stains on the carpet on the stairs, his hair still in the vacuum bag, like finding Christmas tree needles in June. I do not want to remember his final walk on Kingsbarns beach before his final sleep at the vets on Largo Road. We could not tell him what we were about to do to him. We could not tell Watson where he was going after Janetta's on South Street, where we gave him a whole ice cream and sat on the bench watching him. Two scoops of vanilla in a wafer cone. Tears down our cheeks, watching him eat and wag his tail when a tourist asked what breed he was and if they could pet him.

I keep trying not to think about food, or being so cold, or drinking. If I wait until 5 pm I might love myself. Then, it’s five o'clock somewhere, and with a gin and tonic the conservatory in which I write warms a little. There is colour in the sky, blue tints squeezing between clouds. Rays of light that have chosen me, touching my desk and books. With another glass and a slice of lemon for fun it all seems bearable—work, the evening ahead, being here. Even writing is doable, and I am filled with the belief that none of us will contract COVID. We will not get sick. The universe assures me in these moments that this is not the end times and for the next few hours, I am convinced of it.

I keep trying to understand, to keep up. In March, schools are closed and learning is moved online. Boris Johnson contracts COVID. By April, he is in the ITU. He survives into May, and the

‘R’ Ratio is below 1. Nevertheless, lockdown will not be eased until the summer. By June, school exams are cancelled. Elliot will not do his final exams, and has now been home for three months—no classes, no friends to see, nowhere to go. He is awake all night, asleep all day. In July, obese people are identified as being more at risk and more likely to die from COVID. Technically, twenty pounds above your BMI puts you in the clinically overweight category which means Oliver and I should start dieting. By the time July rolls around cases have risen to 2000 a day in the UK, and in New York thousands of bodies are being put into mass graves. In October, the Oxford COVID Vaccine is reported to be effective. By November, I can no longer write. I come religiously to the desk and the screen, and wait. Type, edit, re-read, delete. Another day passes when my word count slips. I tell myself it is because I do not have space at home, or the postgraduate library, or privacy. Perhaps restrictions will lift soon, and the girls will stop peering over my shoulder and reading their names on the screen.

I am trying to un-learn. Too much news, obsessing over rising cases, deaths, and restrictions may lead to an increase in depression. We have a new rule which is to watch the news three times a week, not seven. Enforcing it is hard because after dinner it is dark, and we have all been alone, flung to the peripheries of the house occupying spaces with no edges and worlds inside headphones. Occupying different rooms, and yet together under one roof.

I am trying to remember when I went out—traveled to work, to sleep industry conferences in San Antonio in Texas, Vancouver, Minnesota, Oregon, and Philadelphia. Doctors, sleep specialists, and patient advocates were packed in elevators that took us from our hotel rooms to the main lobby. I listened to researchers, gave interviews, presentations, and signed copies of my book. We did not wear masks. We did not talk about COVID or vaccines. World leading doctors did not know what was coming. When I try and locate myself in the present, these are the places to which I go. Rooms where I take notes on new medications on narcolepsy and find hope.

I am trying to stay here, at West Newhall. I go to bed early, sinking into sleep and dreaming. When I dream, I am either in California or trying to get back there. When I dream, I am always alone. I do not know where my family is or if they are alive. We are separated and changed. Our lives have transformed, and I am afraid that we have become unrecognisable to each other.

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