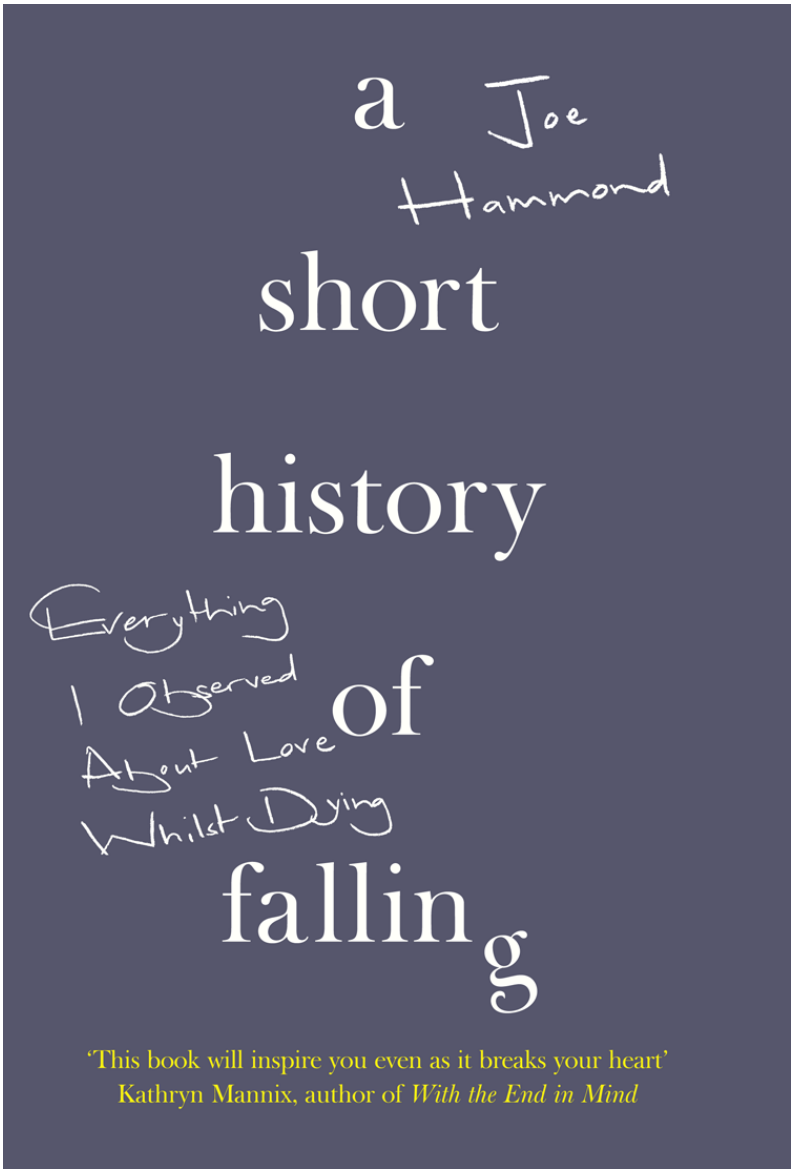
a short history of falling
Joe Hammond
Everything I Observed About Love Whilst Dying
'This book will inspire you even as it breaks your heart'
Kathryn Mannix, author of With the End in Mind

Joe Hammond

A Short History of Falling: Everything I Observed About Love Whilst Dying

«HarperCollins»

Hammond J.

A Short History of Falling: Everything I Observed About Love Whilst Dying / J. Hammond — «HarperCollins»,

A Short History of Falling – like The Diving Bell and the Butterfly, and When Breath Becomes Air – is a searingly beautiful, profound and unforgettable memoir that finds light and even humour in the darkest of places. We keep an old shoebox, Gill and I, nestled in a drawer in our room. It's filled with thirty-three birthday cards for our two young sons: one for every year I'll miss until they're twenty-one. I wrote them because, since the end of 2017, I've been living with – and dying from – motor neurone disease. This book is about the process of saying goodbye. To my body, as I journey from unexpected clumsiness to a wheelchair that resembles a spacecraft, with rods and pads and dials and bleeps. To this world, as I play less of a part in it and find myself floating off into unlighted territory. To Gill, my wife. To Tom and Jimmy. A Short History of Falling is about the sadness (and the anger, and the fear), but it's about what's beautiful too. It's about love and fatherhood, about the precious experience of observing my last moments with this body, surrounded by the people who matter most. It's about what it feels like to confront the fact that my family will persist through time with only a memory of me. In many ways, it has been the most amazing time of my life.

Содержание

A SHORT HISTORY OF FALLING

Everything I Observed About Love Whilst Dying

Joe Hammond

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Dedication

for Gill, Tom & Jimmy

Contents

Tumbling

If I could just stop falling over, this would be a funnier book. I'm a big man and I'm starting to cause a lot of damage. I've just written off a kitchen cabinet, and two weeks ago I dislocated my shoulder on the bedroom floor. Quite recently I fell into my son's empty cot, but that was a peaceful experience. The sides of the cot snapped inwards, swaddling me in very fine, soft, white mesh. Given

how unsafe I am at the moment, this felt OK. I decided to remain there, looking around. It was quiet. It would have been nice to sleep, but then my other son – my six-year-old – walked in.

If I'm near other people and I sway this way or that, it can seem balletic – like one of those trust games when a person is encouraged to tuck their arms inwards and let others prevent their fall. But often I find myself alone or out of reach, and from a height of six foot three falling always takes so *long*. Or it feels like it. I seem to have plenty of time to think and notice and worry in that quiet moment before impact. And that's been quite frightening. Just observing the slowness of my descent and picking both a landing spot and part of my body that seems most capable of taking the impact. And whenever I hit the floor, or something on the way down to the floor, it's never a funny thing or a funny moment. Never something funny that I want to write about the next day. Last week I fell and split my head open in the shower. And I just lay there. Because if I fall, I can't use my arms to get back up. I lay there, beached and soapy on the white-tiled floor, with the water raining down turning pale pink around me. And my wife running in like a Greenpeace activist to a seal cull.

I'm getting to the point when I shall look back on these falls as moments of luxury. From a wheelchair or a hoist or a hospital bed, I'll view these early days of motor neurone disease as a time of freedom. A time when toppling or tripping or tumbling was actually possible. Because I can put my finger through the place where muscles used to be in my legs, right through to the tendons, and can feel something like the substructure of myself emerging. And it's not a particularly good sign, but it's not everything. It's just the physical body. This book is everything – the experience of my body as it changes and declines. The experience of saying goodbye to those I love. I'm scared – I know I am. But it feels strangely OK. And surprising too. I'm going to tell you about it. The story of my end, or as close as I can get to it.

*

The first I knew was about fifteen months ago. It was the sensation that I had a fresh piece of chewing gum stuck to the sole of my foot. Feet feel bigger when they don't lift properly. My big clown foot, and the funny slapping sound as I ran for a bus. And perhaps I could have fixed this by attaching a piece of string to my big right toe. But where do you stop with such things? How much of a marionette can one person be?

I was walking like a passenger in the aisle of a plane going through gentle turbulence. It's the walk someone would make just prior to the seat-belt lights coming back on again – that medium level of mid-flight turbulence. But not on a plane: on the ground. On the way to make a sandwich or brush my teeth. Just walking. With my palms face down, as if steadying myself on the headrests of non-existent passengers.

My first fall was when I was walking Tom to school. We had joined with several mums and their children and it was a cheerful occasion. I made my way to the edge of the pavement to widen our group so that I could chat alongside what was now a phalanx of mums. But as I put my right foot down, I felt only the very edge of the kerb. I'd expected more underfoot. And the rest of my foot fell away from the group. Not off the edge of a cliff, off the edge of a kerb, but somehow I kept falling. There was no correction from either leg, as if each were too polite to be the first to move. So the whole structure of me went down. It all landed between two parked cars. About five or six children looked over me, including Tom, and a number of the mums. Something about the choreography perplexed – I think we all felt that. After the briefest of moments, most of us started laughing. And then I got up and we laughed some more. We laughed about it again when our walks next coincided.

But Tom laughed the least. He wasn't particularly upset; he just didn't find it funny. He's logged quite a few falls since then. Several weeks ago he was with a friend as she listened to an account of her aunt's recent fall and then remarked that adults don't do such things. My son corrected her immediately. It was a factually incorrect statement, and he is good at spotting those.

*

I next fell while trying to do an impression of a pop-up toaster. This was some months later. Actually, there had been other falls in the intervening period, but nothing calamitous. Nothing I remember. By this time we were living in Portugal, where the tiled floors are so shiny that I can't think of anywhere less suitable for a man with my predisposition towards falling. And this was just part of the adventure. A new life on shiny floors. On this occasion I fell and slammed the back of my head against a radiator. Tom and Jimmy, who was then just over a year old, were sitting on Tom's bed wrapped in towels after an evening bath. Tom had just correctly identified my washing machine and there had been other white goods, as well as a vacuum cleaner. With the toaster, I keeled over because my left leg achieved the elevation my right one couldn't. It was a buckled-cartwheel move, and when my head made impact it was the deep vibrating sound from the pipes that shocked us all. I lay back with my head wedged uncomfortably forwards against the steel pillow. After a few moments, Jimmy started crying; then Tom. I looked over at them. Their tears. Their crumpled faces. And a nasally sound like two interlinked air-raid sirens being squeezed out through their ears.

There's so much more indignity in failed silliness. The thought of no longer being the clown brings me as close as anything to feeling defeated. A lot rests on being able to impersonate a toaster. I don't think I've ever wanted to spend more than five minutes with anyone who isn't in some way capable of being a clown. And my feelings of loss are at their most profound when these opportunities evade me. If I can't brush my teeth in the style of a camel. Or getting dressed in the mornings and no longer being able to chuck my discarded pyjamas at my children.

I've noticed that nothing can trigger tearfulness quite like an unexpected sound. This was the case with my toaster and the deep clang of the radiator, but also with the time I wrote off the kitchen cutlery drawer. I'd grown weaker, but was reluctant to give up my role as house cook. In the kitchen I needed to hold on to the counter to keep myself upright. So it was all quite sloppy; a little desperate. I'd chop an onion by throwing a knife at it or chuck a used spoon at the sink from twenty feet away. On this occasion my energy was particularly low. We had guests and I should have asked for help. I remember I didn't bother counting the cutlery. I just shovelled it up and left the drawer open, then spun around towards the dining table. I shouldn't have been spinning. I shouldn't have been manoeuvring in such a casual way. But I doled out the correct cutlery at the table and spun back towards the drawer with the spares, catching the left toe of my rubber trainers on the shiny tiled floor and my right spastic foot on the heel of my static left ankle. Having reached tipping point, there wasn't a chance my legs could save me. By this stage of the disease, rather than legs, my upper body was being supported by a creaky twin-set of large Victorian steel stanchions. I knew I was falling. It's passive knowledge. Knowing it's about to happen; knowing I can't prevent it. In a cartoon, I would be whistling at this point, or checking a wristwatch. But actually, in that moment, I was gauging my total 'arms outstretched' length, my distance to the cutlery tray, the fixed position of my feet, and had calculated that my hands would become parallel with the cutlery tray at the point at which my falling body would reach an angle of thirty-five degrees from the floor. And I had judged it well: that's exactly where my hands were. But I had not allowed for the velocity with which my hands would be travelling through the air, and this was considerable. My upper limbs crashed through the open drawer before I could reasonably subdivide into forks, knives and spoons, bringing the drawer and its contents down with me, in much the same way that simulated films show the collision of an asteroid into Earth, bringing an end to the age of dinosaurs.

*

My role as house cook began sixteen years ago. I'd known Gill a week, so we weren't even living together by this point. I was lingering outside her kitchen, trying to catch sight of her as she prepared a meal. I didn't know what to do and I was a little nervous. A little expectant. I heard clattering sounds and moved to take up a better vantage point. I remember the excitement of then seeing Gill through the frame of the doorway. She was holding a tin of tuna, trying to get the contents out. She was thrusting it downwards, the way a person might try to get some very stiff ketchup from a bottle, the

way someone would do this when they don't know the technique of slapping the base of the bottle with the palm of the hand. She was trying so hard. And I have always remembered the repetitions of the despairing downward plunge of her arm. That repeated, forlorn, hopeless, futile, beguiling, beautiful movement of her arm through the air.

*

It's hard to live the losses moment to moment, accepting them as they arise, dispensing with pieces of the self fluently like a bag of birdseed strewn into a flock of pigeons. Lying on my back on the shiny tiled floor, I was struck by the amount of metal and detritus that can be loaded into one cutlery drawer. I was turning as I hit the drawer, so my hands and wrists connected side-on to the open drawer and the impact turned me completely. I couldn't necessarily see what was lying all around me, but the sound of falling metal seemed to continue like hail on a skylight. And I lay, arms outstretched, on this sea of steel and crud. A friend and her sister were staying with us, and each got up and took my arms, raising me to a marginally more dignified seated position. Directly in front of me were Tom and Jimmy, standing side by side. Three foot tall and two foot tall. Their lips were beginning to agitate, like four pink caterpillars rippling across a leaf. Sitting on my bum amidst the debris, I watched as their faces crumpled and they again began squeezing air-raid sirens out through their ears. Once they had levered me up, the two sisters began gathering in all the items. It was a job I desperately wanted. I wanted to be down there, on my knees. Putting it all back together again. The spoons in one place, the forks, the knives. The masher, the crusher, the bashers, the smashers. The togs, the bottle tops, the skewers, the openers. And then a dustpan and brush for all the accumulated dust and dirt.

*

From an early age I dreamt of falling. For many years, this simple dream included nothing more than a matchstick or a marble or something small like that. It was just me and these little bits and pieces suspended in space. It was something like the very beautiful children's television programme from the 1980s called *Button Moon*, which told the story of Mr Spoon and his friends in a bits and pieces universe. My own version wasn't quite as charming. There was no ground or environment – just these items – and in the dream I would be concentrating on these little things. My hands were there and in this dream my job existed to make sure nothing fell. And this really was the crux of it – that nothing must fall. Because if it did, everything would end.

I used to listen to my parents fighting at night. It was dark outside. And if you're an older child, you turn your music up, or you open your door and shout down the stairs, slamming the door back shut behind you. But if you're young – or very young – nothing seems separate from who you are. Sounds settle on the skin and are then absorbed, as if they are your own, as if these problems are your own.

I had this dream in largely the same form, for many years. Always the same task – to keep the world in place. I think the pressure was something like a bomb-disposal expert might feel if they were somehow forced to experience their job as a child. And, of course, within this dream something would always fall and I would wake with the certain knowledge that not a bit of the world remained.

*

As my legs began to weaken, and my right spastic leg began to stiffen, I was excited to find that I could improve my balance by walking around with a book on my head. Tom had a Paddington Bear book that worked best. It was hard and heavy and square and I seemed more conscious of my movement with this book. Less likely to fall. It was the story of Paddington's journey from Darkest Peru, his arrival at Paddington station, and his early home life with Mr and Mrs Brown. I made this discovery about a month or so following my diagnosis. At around this time my arms began a spontaneous adaptation to the heaviness in my legs. I widened my gait and began purposefully reaching out with my arms, and breathing out with each movement. It was loosely inspired by a session or two of t'ai chi that I once did, but it felt like my creation. Or an evolution, perhaps, towards life as an anthropod.

I cherished this time. I felt more aware of my body than at any other time in my life. I wanted to feel my body and be in my body because I knew I was losing it. I think about this time and often wonder what would have developed had I not caught a leg on the strap of a bag I'd left on the bedroom floor. Part of me wishes I'd decided to make impact with my face, not my shoulder, because I later decided that the disablement of my shoulder accelerated certain aspects of this disease. But I think all this fall did was to create a kink in the line of my body's development. The perception of acceleration, maybe some actual acceleration, but not much. The abrupt end to this fertile period helped me to mythologize my short life as an insect. That's all.

Because the truth is that I was actually declining through this period. I just enjoyed the thought that I wasn't. I think the fall ended one kind of hope, but it didn't end all kinds of hope. The creative life gets harder and darker and more real. But life is not worse than it was before. It doesn't have less value. It's not less interesting. Not at all. As I get weaker, less a part of this world, or less a part of what I love, less a part of my family's life, I can perceive its edges with fantastic clarity. I can lie against it, lolling my arm over the edge, running my fingers around the rim. And this is where I am.

*

I might now notice that I haven't fallen for a while, rather than that I have fallen. This normalization is just taking shape. I had one of these quotidian falls last week. As I was heading out of the kitchen, I caught my sandal in the indentation of the grouting between the floor tiles. My wrists were attached to crutches so that, falling through the door, my body and both arms behaved like three portly figures bustling to be the first out. I was aware of a lot of jostling between these separate components of my body. The momentum took my torso through ahead of the other two fat fellows, with my arms pinned back behind as they followed. As these three oafs who comprised my body clattered through the doorway, what landed first was my chin. And because of the order of my body, my shoulders splayed out and my palms landed with a splat on either side. One crutch was still painfully attached to my wrist, cuffing me to the ground. And my body transmitted to me the physical impression that I had been pinned to the floor by an arresting officer. I didn't initially attempt to move. I wasn't particularly hurt; it was more the feeling of profound dismay at having to work out a way to get up from the floor.

Having previously described the siren sounds of my children after they witnessed one of my falls, this fall provided further evidence of the transition along the scale from horror to tedium. There was a brief sound of upset being squeezed out through Jimmy's ears, but nothing like the previous episodes and nothing from Tom. They had seen it all before. Daddy had now been seen on the floor on a number of occasions, so the sound on this occasion was something like that brief attention-seeking pulse from a police siren that makes you wonder why they bothered. I think Jimmy soon thought better of it and he continued emptying the recycling out from its various containers. Gill came to help, but I told her I was OK for the moment and, dribbling into the carpet, suggested she finish grilling the fish fingers. Tom stepped over me on his way up the stairs. I could hear supper being plated up and I wanted to stay put – perhaps for ever. I was seriously considering the possibility. And nothing about that thought felt in any way abnormal.

*

I now spend a lot of time in my pants and people come and go. It's getting harder to put my clothes on and the heating here is quite good. As I write this, I'm in my pants, and I'm looking down at my T-shirt which displays the remains of two splodges of the beetroot and squash soup I had for lunch. A lot of me is not as decorous as it once was and it's in this unvarnished state that I now tend to find myself, groaning on the floor, after the latest fall.

Having fallen, it's now impossible for me to get myself back up. That's been the case for months, but now Gill and I can't quite manage it together. The most recent example resulted in quite a lot of pain and the unfortunate reprisal of my recently healed rotator-cuff injury. On this occasion, Gill was the first to arrive and I was able to roll over on to my back to have the usual conversation about

whether I was or wasn't OK. I spent a minute or two being aware of the furrows on Gill's brow, but then Jimmy swung in through the door. He was smiling broadly and, having not actually seen me fall, appeared simply tickled by the experience of looking down at me.

A visiting friend of ours was the last to arrive. I suppose I mention all this because, with this particular episode, I'm partly writing about dignity and how I just don't bother with it any more. Attending to my dignity would take too long and would consume a vast amount of Gill's time. Behind every sponged and smartly dressed disabled person has to be someone else's considerable and uncredited commitment.

It took us a few minutes, but the mechanics of raising me up were extremely effective. I'm no engineer so I cannot explain the considerable biomechanical benefit of a single hand placed lightly under my bottom. Under normal conditions I struggle to raise myself from a chair but, with a hand inserted just under my bum, exerting marginal upward pressure, I seem to experience very little upward difficulty. On this occasion we were trying to raise me up from the floor but with the compensation of six hands. I found it particularly affecting that two of them belonged to Jimmy – the boy I should be cradling in my big Daddy arms. My wife, my son, a friend – all managing with my near dead weight. I could never previously have conceived of six hands seeking upward traction from my bottom. But the operation worked. In yesterday's pants and a dirty T-shirt, I'd made it to sitting – on the edge of the bed – relieved and looking out at my trio of helpers.

*

For almost six months we'd been living on the side of a mountain in rural central Portugal, and then I was diagnosed and we fell all the way down to the bottom. We fell through the pines and the eucalyptus, bumping and clattering against the trunks, brushing through the foliage. We cartwheeled and bounced and slipped – an eighteen-month-old baby, a six-year-old boy and a mum and dad. And it was remarkable that we fell a mile downwards from high up on the mountainside, with the speed of falling objects, but sustained no external injuries – no cuts or grazes. Nothing visible. Everything that hurt was on the inside – the disappointment and the shock and the sadness.

It had been Gill's idea to come to Portugal. She had been on maternity leave with Jimmy and dreamt up the idea, and we carried through with it. Our flat had been rented out and we were experimenting with a different kind of living. Tom had not enjoyed his start to school life in the UK but now found himself in a tiny bilingual school surrounded by cherry trees, where he spent half his day constructing shelters from old tractor tyres and mud and fallen masonry and discarded timber.

And Gill and I spent our days together in the sun, learning a new language and eating the oranges and cabbages and potatoes that neighbours would leave on our doorstep. And I don't know how long this life would have gone on for, but I do know, if my diagnosis had been for something sweeter, something fixable, that our journey home to the UK would have been slower – not off the side of a precipice, with the rocks, the stones and the blood-red earth flashing by.

*

I had a moment yesterday when my fingers went reaching for the finial on the banister at the first landing. I looked at my fingers. They were playing a little piano melody in the air. I could feel the slightest sense that my body had moved backwards, rather than forwards. That my hand was doing the opposite of reaching; it was withdrawing. And that this worried me. It was only a faint sensation at this point. The very gentle transitive feeling that a treetop must feel just after the axe has finished its work on the trunk. A subtle movement at first but with full knowledge of the carnage that will follow. It's the worst kind of terror, the one that begins with such gentility. Knowing what it means; what it would mean for my body. The steepness of the gradient behind me and the hardness of its edges. The damage I would do to my limbs if I were to fall back in that moment. Falling back and needing to take it. The quiet minutes and hours and years of the falling moment. And the thoughts of my wife as she would come running. What all this would mean. Of lives disturbed. By a set of fingers flailing short.

This is a special subcategory of falls – perhaps the worst kind – because they linger and they haunt, they spill and they drift. These are the almost falls – the ones that never happen; the ones that nearly happen. The moment of knowing a fall is happening. Not fearing it. *Knowing* it. Even if that moment is fractional, and then snapping out of that space. It's the waterboarding equivalent of falling, because it feels like it's happening but it's not. The heart turns inside out like a rubber cup and then pings back into shape. It's time travel, or two parallel moments coexisting: the disastrous one and the banal one, with thoughts rattling helplessly between them like a pebble in a bucket. The finial was out of reach, but the banister rails weren't. I never forget the almost falls. Not the bad ones.

One pebble has been rattling around for the last nine years, getting more clattery with each recollection. I was on a path on the edge of a ravine. I must have stopped for something. A view? Maybe I needed a piss. Gill was ahead. I could see her disappearing as she traversed the sharp cliff along a loose, flinty path. We were trekking on the Indian side of the Himalayas, without a guide. We were alone. And as I skipped forward to catch up, my toe caught a rock and my two insteps collided. After a stumble forwards, the thick sole of my right boot skidded flat and I came to a stop. I was on my own in the silence. Gill was out of view, with the precipice just ahead. I thought of the degrees by which falls can happen: the strength or slightness of the connection that one toecap might make with one heel, in the process of stumbling and clattering. And how close I came to a more prolonged stumble, and then to nothing, to disappearing over the edge, in the silence, out of view. Imagining the experience of Gill as she stepped back on herself into a mystery. To an empty path. It's the silence of that moment that concentrates this memory. The fitting stage that it was for an ending. The intimation of an ending, even though it wasn't.

Every thought I have had about that moment has been more profound than the one I had at the time. I shook it off, but it has stayed with me and has grown in the dark with each recollection. I didn't mention it to Gill when it happened. I just trotted on and caught up. Because nothing actually happened – nothing that I felt I could communicate.

I'm falling now. But this time it is real. Unlike you, perhaps, I *know* I am dying. And because of that I fear it less.

The Body

As I progress down the upstairs landing, holding on to my four-wheel disability rollator, I invariably glance through the open door of the bathroom. It's become a pattern. Glancing through the door at the metallic frame that holds my raised plastic disability toilet seat. This momentary experience reminds me of the times in my life when I've walked past specialist disability shops, gazing absently at all the unlikely paraphernalia from other people's lives. This world of experience in one

shop. And this is what it feels like, seeing this contraption installed around my toilet. It's other people's lives; not my own. But each time I remember that it is mine, and that's quite shocking.

I think I feel the same level of original shock on every occasion. And these are largely the same feelings that I have about every disability item I own: the cone-shaped device for putting on my socks, the grabbing and reaching implements, the rails, the splint, the stroller, Dr Seuss's fantastical self-washing wires and brushes. New items arrive almost daily and I am unexpectedly becoming the curator of the Museum of my own Decline. How did this happen? Because it wasn't so long ago that I was walking past these shops. I was on the pavement looking in. And now I am inside.

*

If you're disabled, London beggars don't ask you for money. They don't even make eye contact. I discovered this whilst visiting the UK at Christmas, travelling through London on my own. This was a few months before we had to move back permanently, and I was being disabled all by myself. I must have seemed quite unsteady because it was my first experience as the recipient of help from strangers. I found this exciting. I don't feel excitement any more. But at that time it was exhilarating in the way that all transportive experiences can be exhilarating. Like an acting student with a begging bowl or a celebrity in a fat suit. Except that it was me. The most complete version of me that I would ever be.

I changed trains at East Croydon and deliberately trailed a woman with a crutch who had a spastic leg like mine. I sat quite near her but realized she was much younger, with MS. Then I felt like an older man stalking a younger woman, which I briefly was. I gravitate towards people with a bad leg like me. At Three Bridges station there was a man of about my age with an even slower walk than me. He was dressed smartly and clearly trying to sustain some kind of job. I was coming from the other direction and had enough time to become excited by the way his leg was swaying wildly – just like mine. It was rush hour. Not an easy time to be thrashing your leg around. I wanted to wave or to say something; or communicate to my brother with an upward turn of my eyebrows. And because we were heading in opposite directions I knew our unacknowledged time together would be fleeting. He needed help, from crutches at least, but he had nothing. I was impressed by his lack of speed. I should have been going a little slower. Or I should have stopped to think, but I ended up doing the opposite. I picked up speed and felt momentarily jaunty. It's what I must have wanted. I was racing along. And that was it; the moment for connection was gone.

He's not the first person I've picked out, wondering whether he or she is the same as me. Wanting to ask. I fabricated a notion that this man's symptoms might have been further on than mine. Perhaps he had been slow to refer himself, and was soldiering on. A man who was continuing to work in the face of considerable difficulty – wondering why his foot wouldn't lift off the ground. Wondering why he was always toppling over like an old wet tree in the rain. And waiting for it all to stop, for the body to return, to heal, because that is what the body does.

I don't think I'm looking for my comrades any more. Not with quite that expectation. Or with that sense of shocking newness I want to share. But still, when I'm with a friendly physio or occupational therapist, I often end up asking about their other patients. I must want to find someone like me. Someone out there with children who is where I am with this disease. Someone out there who is writing about it. Wanting it to be OK. Willing it to be OK. I want to meet this person.

*

It's shocking to me that I have a spastic leg. I'm struck by its arcing trajectory, its banana-shaped inefficiency, and by the sticks I use to compensate for it. And by the wheelchair I will one day be consigned to, the toileting aids that await me, disfigurement, the premature ageing. These are all shocking to me; I'm calm about it, but still shocked. I'm calmly shocked.

All my life I've convinced myself that I have a remarkably striking physical appearance. Unfortunately, I have been capable of believing that almost anything about me, or almost anything I've done, might be remarkably brilliant. I have been afflicted by this delusion for my entire life. There's nothing unusual about this. It's just the dreariness of narcissism. Only the route towards narcissism

is unique. The real stuff. The narcissism itself, the affliction, is dull, boring and predictable. And as with all narcissism, mine has an obverse side which is equally true and equally present: the unrelenting conviction that when I'm not being remarkably clever and beautiful, I'm being remarkably stupid and ugly.

But now I'm living with a concept that is neither. It's not life at the end of either of these two extremes. It's not even on the same linear scale. These days I'm preoccupied by the surprises in my life. The way the body reminds me of myself. The saliva I'm now collecting in my mouth. It's this. It's all the tiny signals I experience. The not swallowing. The lagoons beneath my tongue. These pools of saliva don't interest the narcissist in me. In the presence of such novel details I've finally found a way to bore him. With my actual body. The volumes of swallowed juices that sluice away like the downpipe from a toilet stack. Sometimes when I inhale they inadvertently skim backwards with a splutter and a choke. Or, if I'm lying on my front, a small amount disappears over the curve of my bottom lip. Just a little for now, over the side of the bed. Just a tiny stream from a toy teapot. A darkened dot on the carpet. Everything starts as something small. There are no shocks. This is a gentle kind of devastation.

When I was a much younger man I spent a year or so not being narcissistic. I had found God, briefly. I knew him for a year. He loved me and I loved him and my narcissism ebbed away. I felt the tension in my body release. I felt my 25-year-old body open up, after many years of tightness. When I no longer felt I knew him, my narcissism returned. My body closed again, as if a season had passed. This sounds glib, but it's the truth. And even though I lost hold of what I had found, I don't think a person ever completely loses what they have had. I'd lived with a level of shock and confusion my entire life, but something had been lifted that was never completely pushed back down again.

And now, being a man with a spastic leg, finding myself being wheeled through an airport in a wheelchair, as I was earlier today, I realize this is the culmination. It's finishing something, finally and decisively. I'm a man with a disability. My body is the truth now and it's saving me from myself. I have all these losses, and feel a kind of freedom in that. With each awkward, spasmodic movement, or the difficulty I have wiping my own bottom, or with the slur developing in my voice, the narcissist recedes. There's nothing for him here. Not any more. It's death to him. The phoney.

You wasted a lot of my life. Nothing you did was ever real.

*

In the weeks and months that followed my diagnosis I received dozens of suggestions about how I might combat my decline. Some fell into the category of *tonic* and these included several exotic examples, such as a paste made from mixing water with powdered scrapings from reindeer-horn velvet. I was also advised to start my day with warming spices, so that I might have a ginger or a cinnamon tea. Or I could have eggs for breakfast and cook them with turmeric and cumin.

Other suggestions have been less to do with ingestion than the functions or processes that I could add or alter within my body. In one of the loveliest examples a friend espoused the medical benefits that singing could offer me. A more prosaic example was that I could slow the progression of the disease by chewing my food more slowly.

In some cases, these suggestions have been delivered with little confidence. Perhaps they're offered if a person feels awkward and wants to think of something positive to say – so that it might be something they'd heard about from someone or caught as a snippet on the radio. On one occasion I received a text from a friend to inform me that a new drugs trial in India had yielded miraculous results. I texted back to ask for more details but, unfortunately, he was unable to be more specific. I wondered if he might have the name of a town or medical institution so that I could narrow it down a little but, no, it was just something that was happening broadly within the nation of India.

Others have been far more confident in their approaches – strikingly so. I'm particularly thinking of two parents from Tom's previous school in Portugal. In both cases, I didn't know the people involved that well and they had first learnt of my condition from chatting to another parent in

the playground. In the case of these two women it was interesting to note some common attributes to their communication style. Both times the initial engagement involved gently touching my elbow and very sensitively, very earnestly, leading me away from a mingled group of parents. What I then noticed was the closeness of the physical space they occupied, so that the intensity of the eye contact lent the exchange a certain gravity and seriousness.

As for the suggestions themselves, they were both to do with diet. I have noticed that people can be at their most fervent when making claims that this or that diet can combat my decline. I group these two approaches together because each person espoused a dietary regime which, as far as I can tell, appeared to be the diametric opposite of the other. So that one of them was suggesting a diet based exclusively on fats and animal protein, whilst the other suggested a vegetarian diet of brown rice, sea vegetables and pulses.

As these two separate discussions continued, and the volume of parents surrounding us thinned significantly, it became clear that these two women weren't actually prescribing a bespoke cure for my specific neurological condition; in fact, it wasn't entirely clear that they knew what my condition was. It didn't appear to be the case that the diets could specifically prevent my motor neurones dying. Instead I was offered the reassurance that they themselves, and their family – as notably healthy and flourishing individuals – were also following this dietary regime and that anyone else in their right mind should be doing the same. As time went on, and we met repeatedly in the playground – and it became clear that I wasn't following their guidance – the looks on their faces conveyed a saintly form of disappointment. I had been offered *the way* but clearly lacked piety. In this respect, it seemed that I hadn't been approached by two friendly and knowledgeable parents but by two variants of the same religion.

The list of cures I receive continues to grow. It seems important for some people to feel that they can do something about what's happening to me. Sometimes this is offered in a caring or despairing way and sometimes it's evangelical. But in all cases it feels like a frustration with the idea that things *happen*: the idea that we all might grow old or that any of us might contract an illness or a disease and not be able to do anything about it, or the idea that none of us really possess control over our lives. For many people this is clearly unbearable and intolerable, so that just *being* is frightening – and that the only possible sane response is to be *doing* something.

*

The loss of motor neurones begins with a display – something visible just beneath the surface of the skin. You could watch my wrist and observe tiny pulsing movements working their way up my arm – like a trapped cricket trying to find its way out. Or if you were to place an open hand on the side of my neck, you might wait there for a moment and then suddenly squeak or let out a little 'Ooh!' as you snatch your hand away.

These are the flickerings of a light bulb before the plink and fizz of a blown filament. Tiny faltering premonitions of loss – a kind of panic or disturbance in a muscle that is losing its sense of purpose within the body. For some reason, these twitches make me think of earthworms after the rain – when the soil is claggy and they come to the surface for oxygen: the way they blindly pop out of the soil, flailing and wriggling in the unnatural habitat of the air.

When I hold Gill's hand the sensation transmits through the ends of my fingers or through the muscle at the base of my thumb. It's hard to feel her flinching from the movements of my body – from the subcutaneous crickets and the earthworms popping up for air. Hard to reassure her that at least the fibres are still looking for connection – that they haven't given up – that it's not the end.

But these fasciculations are beginning to get less frequent now – like that moment at the end of a garden fireworks display when the nostrils are pleasingly filled with sulphur and the last firework in the box fizzles out and someone hands you a sausage roll, and you're standing by the embers of the bonfire watching the ghost of an image from a burnt-out sparkler.

*

A couple of times in the writing of this book I've discarded more extended metaphors that attempted to convey what this disease is – and its effect on the body. In the first, I was describing a steel suspension bridge: the way the bridge appears to function normally, whilst up above, and out of view of the traffic, the cables supporting the stanchions are snapping one by one. Over time, fewer of the cables are taking more of the strain until, finally, a steel stanchion begins to creak and wobble. From this point, decay continues much as it did before but now visible and obvious.

The second of my abandoned metaphors employed the image of a corner shop, in which shelf items mysteriously disappear through the walls or the floor. Increasingly, the stock appears sporadic and the shop becomes less useful as a place for anyone to reliably buy their groceries. Sometimes the shop door opens and the visitor looks around, having arrived here through habit, forgetting that the place has fallen into decline. Others still choose to come, if they have the time, remembering what it was – or they maintain their shopping habit out of nostalgia and affection.

It's so easy to reach for these metaphors of loss and decay, and I think this has something to do with the absence of concrete information about what this disease actually is, or what causes it. No one appears to know why or how or when motor neurones die within the body; why the line of communication between brain and muscular tissue breaks down. It remains a mystery, so that in thinking and writing about my degenerating body, imagery and imagination can be everything. This is the reason why, despite writing about the removal of extended metaphors, I'm nonetheless tripping over smaller, rat-size examples of imagery darting in from every angle.

But when reaching too far into metaphor, the experience of what something *actually* feels like becomes lost – and because I feel this experience so profoundly within my body, it's description that really matters to me. I've had my moment here – descending into metaphor – to help explain the little I know about how this disease works. But I don't experience the disease, I experience my body, and this is what interests me. I know enough not to think that sea vegetables or reindeer velvet can delay its course. Of course, somewhere out there, a reason exists for why these neurones die, and there's probably something out there that will stop this. Maybe it *is* sea vegetables! But these dart-throwing investigations can't be anything to do with me – not whilst the shamans are still shaking their sticks at the moon. They don't interest me.

All that interests me is being with people – and with my body as it dies – and writing about it.

*

On the other side of the room Tom and Jimmy are flapping on our bed like unnetted herrings on the deck of a trawler. Gill's laughing and the boys are squealing, but I'm over here with my recliner all the way back resting my tongue on the floor of my mouth. It's unusual to be this much on the outside of an escapade, not even to be enjoying the fact that my children are so happy. I could be in an adjacent hotel room or in a split time frame. There are other moments when I will sit and enjoy: laughing or smiling at acrobatics, or boofing a pillow into someone's face. But on this occasion my recliner is tilted back and I'm interested in the difference between the roofs of the two terraced houses I can see through the window. The slate on one roof is clean and new, but where the roof becomes another property the roofer has left the moss-barnacled slates unchanged. It's the same roof. A shared roof. But the two parts are cared for as if they exist in different continents.

Gill and I can still talk and talk when we get the chance, and I can still read books to the boys, but this evening my facial and tongue muscles have grown more tired than usual. I spent the day on the phone to estate agents, solicitors and various health professionals. I became hoarse quite early on in the day and then the susceptible muscle at the base of my tongue began to ache. I used my reserves and now I'm spent. So I've tilted myself back in this moment and taken myself away. To a time, perhaps a year from now, when the voice is gone and the face is gone. And my hands can no longer make signs. Preparing for disability is like going on holiday somewhere new and wondering what clothes to pack. For now, I'm scouting it out. Just temporarily – just for an hour or two. Being elsewhere, in an expanding private world; a world I will get to know. I'm glad to feel it first. Preparing

for when I will be looking out at the life of my family. Knowing that I was out there once. The clown. The protagonist. The herring.

Doctor Tiago's Hydroelectric Power Plant

In the moments before Doctor Tiago called me in, I was propping up a wall with my shoulder. When you spend a lot of time in hospitals being undiagnosed, you start propping up walls and lounging about and picking your nose in waiting rooms. And not being prepared for certainty when it comes.

An hour or two before, Doctor Tiago had been scratching away at my body with a pin. But before all this, I'd been lying on my front and waiting. I could hear him scrabbling about, trying to find

something. I heard the clasp of his bag. I heard him stirring the contents around. The thin metallic sound of a cabinet door being opened and shut. A drawer sliding open and then slamming shut. He'd been searching in the room for something sharp. I realized that later. I don't know where he got the pin from. Thinking about it, I was lying face down: it might not have been a pin. What was it? This wasn't the first time he'd taken to me with something sharp. He'd made some preliminary etchings on my last visit, but this time he was dragging the pin rapidly across and around my back and legs in wide swirling motions; an impressionist holding their brush at the very tip of the handle, standing back from their canvas and operating in broad strokes. He'd stop for a moment and then start again. Then he'd have another thought and drag the pin wildly in a different direction. And when I sat up he was holding his chin and thinking.

'Your face is lopsided.'

'Is it?'

I really like Doctor Tiago. His smile is perhaps the broadest and most expressive smile I have ever encountered. It is so broad and all-encompassing that it seems to subsume his entire face, right up to his eyebrows. A couple of months earlier he had found me wandering the corridors, having arrived at the hospital for a non-existent appointment. He seemed much more like a very young and enthusiastic uncle than a doctor. On that occasion he set up an impromptu clinic in what seemed like a stationery cupboard and we went from there. In all my time with the hospital, I was never really aware of how appointments happened. They just did. It was all quite miraculous. And so I don't mind that he put so much effort into trying to find a brain tumour. He was clearly misled by my face. Even the neurologist who did my CAT scan said I had a brain tumour. They couldn't find any evidence of a tumour. This didn't matter. They remained convinced. Cheerfully so. Apparently a brain tumour is great news.

I wonder why it is important to know. It always seems so very important, particularly for doctors. But surely they seldom know. Or they seldom *really* know. Doctor Tiago 'knew' I had a brain tumour within five minutes of meeting me. But this wasn't knowing; this was confidence. We'd have had a better conversation without confidence getting in the way. There's so much to simply not know about the body. I'd prefer a person who really knows about something (like Doctor Tiago) to tell me all the myriad fascinating things they don't know. Because however much a person knows about something, that *knowing* is minuscule compared to what they don't know. A scale demonstration of this would involve standing next to a mountain and pouring a kilo bag of sugar on the ground. Standing back and comparing these two mounds would give the onlooker a visual comparison between the little that is known about anything by anyone (the sugar) and the vastness of what is unknown about everything by everyone (the mountain). None of us know. Even the most knowledgeable amongst us don't know. Doctor Tiago didn't know. I'd like to have spent more time with Doctor Tiago not knowing.

This was the third time I had seen Doctor Tiago. Each time he would make me clench my teeth and then he'd nod with certainty. This time I clenched my teeth and he seemed less certain. He was smiling less. I watched him chew on the end of a biro, weighing up whether to buy me a fantastic new train set or book tokens. Instead he sent me along the corridor to a woman who inserted much more serious and painful needles. I asked her about the brain tumour, but she wasn't particularly interested. I liked her as well, but at no point did she give me the impression that she was my relative.

It was about an hour later when we walked back in to see Doctor Tiago. He was now seated at a desk fiddling with a piece of paper and this was when Gill noticed that his leg was twitching. Not that he wasn't smiling any more. It's just that on this occasion his frown needed to be displaced elsewhere within his body. In this case, to his right femur and the quadriceps that were supporting it. And this time he had a medical student with him who stood squarely and uprightly by his side, reflecting an air of high rank on Doctor Tiago to which, to his great credit, he seemed entirely unsuited. Because here was his smile again. I wonder if this is all a doctor needs. Just an engulfing smile. Its irradiating and

detoxifying effects. He had clearly decided on the train set. Of course! Doctor Tiago would never fob me off with tokens. We were all back together again. But, actually, there wasn't much of an interval between this smile and Doctor Tiago telling me that I had motor neurone disease. Or not that exactly. Not that I had this disease. Just that it would be impossible for it to be anything else. I like that. It's perfect manners when handling bad news. It's not that it's the thing. It's just *not* all the other things.

I had placed motor neurone disease on the same shelf in my brain where I keep the phone number for Dignitas in Switzerland. This was on a high-up shelf in the outhouse with a broken tricycle and an unused bread maker. Immediately prior to receiving the diagnosis I had been slouching in the corridor. I was holding my phone and browsing inanely through online drivel with my thumb. This was just a few moments before.

When I started crying my head was parallel with the desktop. The sob I experienced was just like the deep vibration of a kitchen tap after the mains water is turned back on. A series of metallic shudders through my spine. A chug. A gurgle. And then water. I remember looking up at Gill. She was crying more gently as she looked down at me. I was over her knee by this point, with my neck arched up towards her. And on her face was the shock of sorrow. Not for herself. For me. I will never read a face like that in a moment like that again. It's a wonder to know, that with all the muscular variation the human face is capable of, some permutations are as unique as fingerprints.

We said our goodbyes. Doctor Tiago came out from behind his completely inappropriate desk. His hug confirmed that he was indeed my uncle. I hadn't been imagining this at all. I'm glad that I was diagnosed in Portugal. To be amongst these warm-hearted people. In most other places, doctors seem to belong, or aspire to belong, to the notion of a particular caste or stratum. But doctors in Portugal carry themselves like people who just walked in off the street and put on a white coat. Which is what they are. Which is exactly what all doctors are. It's just that doctors in Portugal appear to know this.

In the corridor, Gill and I ran into Paula, the medical secretary of the neurology department. She'd been expecting us. She stood there in her white coat, with her eyes moist, and her hands clasped as if she was cradling a young chick. I owe a lot to Paula. If it wasn't for Paula, I'd still be limping around the ground floor of Coimbra hospital, somewhere near the impenetrable network of lifts. The Portuguese health system was a little tricky for me to understand. But I had Paula, so I didn't really have to understand anything. By that time in Portugal, after my wife and boys, I'd talk to Paula more than anyone else. She'd push me around the hospital in a wheelchair and drop me at the train station after appointments. For some weeks Paula had been perfecting her version of Leonard Cohen's 'Hallelujah' on the ukulele. She'd been sending me various versions as MP4 files. And now I understood. She'd known about my disease long before Doctor Tiago. I later spoke to her about this and she confirmed my theory to be partially true, but not entirely. In fact, she said that Doctor Tiago knew; he just didn't want to *admit* he knew. It made him feel too sad. Maybe he was better at not knowing than I'd given him credit for. After hearing this, he went up even further in my estimation. I already loved him; there wasn't much further up for him to go.

'You will suffer. You know this, right?'

We'd rented a very old car whilst in Portugal and it had a cassette player. We just regarded it as an artefact and told Tom all about this strange device. And then a month into having the car, Tom was fiddling with the buttons and out popped a cassette. Of fado music. It had been raining all winter and we'd been driving around in the rain playing it ever since – unaware that our car had been thoughtfully preparing us for tragedy. So it felt like we understood this moment. This moment with Paula.

'It will be hard, you know? It will be very hard.'

Paula dropped the tiny chick on the grey-tiled floor.

'You must be happy, Gill. Oh, Gill, you must be strong!'

She cupped Gill's face in her hands.

'Because Joe will be handicapped. His body will stop working. Almost completely. You will see.'

She was a little closer now. Almost nose to nose.

'He will die. You know this, right?'

She took both of us by the hand.

'You must love life. You must be happy!'

As Gill and I staggered along the concourse I felt I had to try and mention this thing about Dignitas. Or something like that. I'm not so brand-orientated that I would have insisted on Dignitas. I needed to admit to this general idea – to spit it out – but it felt like the mains had been turned off again or someone's boot was stuck in the pipe. I was trying to talk. I was trying to cry. My hands were on my knees. I was trying to communicate but only spit came out. A thick, gloopy spit. Down my shirt and all over my trousers. And I was sweating. I was trying to say what I had now just remembered. My Dignitas plan. But Gill was pulling my arm, as if she thought this was not a plan but instead something to do with the piece of tarmac I was standing on. So that if she could pull me away from that spot I would be OK. How unlike tourists we must have seemed in that moment. Pulling and wrenching as doctors and porters and patients in hospital gowns parted around us.

*

Really bad news is a little like medieval weaponry. It isn't precise like a bullet or a machine-sharpened blade. Part of its brute effect comes from blunt power, so that extensive collateral damage is caused to areas already weakened for a variety of other reasons: areas that are sometimes quite a long way beyond the originally intended location. In this sense, they both destroy and clear away. They bring forward endings in a more timely manner – tidying away what had already grown weak. And I think it's not possible to be properly aware of such quiet, broad-reaching devastation, so that it's only discovered later when performing an innocuous task – like reaching for some tinned tomatoes in a cupboard – and you notice some white part of the bone revealed in a place you would have never expected it.

I couldn't have known it at the time, but a lot more became visible to me in the days following my bad news, and I don't think I'm alone in being someone who walks around with all kinds of weaknesses that go back many years – almost as far back as it's possible to go in a life. In the hours after Doctor Tiago diagnosed me I would not have been aware of this, of the soreness and the calcification that had existed for all this time. And that's why the very worst kind of bad news – whilst seeming, of course, really bad – can also perform the same function as a brace applied to wonky teeth, or metal pins through the spine. It can take some time for its brutal benefits to become clear.

When I now look back at that early devastating comprehension of my condition, I see that it was necessary, in a way, to dig and scoop away at an area that should have long ago been knocked through – like a section of blown plaster after a leak; as if this wasn't simply bad news, or advanced notice of a premature end, but also a long-overdue resolution.

*

I spent five days crying. There were intermissions when I could build fantastical, ornate wooden tower blocks with Tom. These periods enabled fresh fluids to be taken in, so that I could begin again at night-time or during the school day. During those nights I awoke several times to cry. Often I had just been dreaming of the diagnosis. And then, sitting up in bed, the expectation was that the day would flow in to dissipate and dissolve. When it didn't, it was as if dreams had lost their function. It was an unschooling of the ways in which bad dreams are meant to be dispersed. Sleep was diminished. And waking was never quite achieved.

I had no previous facility for crying. No track record. I think I could take the image of Doctor Tiago in his white coat and replace it with one in which he wears a white hard-hat. Tiago the Engineer, overseeing a vast hydroelectric power plant. He had pressed a button or pulled a lever, because it began in that moment. It swelled up somewhere from a series of large, loosely fitted metal parts. So that I was just a vessel. A pipe. A tap. A drain. I was not the beginning and not the end. Something

is running through me. I'm in the car or lying in bed and all the metal parts of Tiago the Engineer's vast hydroelectric power plant burst and split, and then the water comes.

I now realize what Doctor Tiago and the other neurologists were doing. It was quite an artifice. I admire it now because it helped me a great deal. They dispersed my fears with their wonderful array of smiles. They needed me slouched against walls, bored, complacent. Because if I had been led incrementally towards diagnosis, I would never have gained entry to this vast hydroelectric power plant about which I had never previously been aware. They have to lead you towards it while simultaneously keeping it outside your field of vision. And suddenly, there you are, with other people who've made the same journey. Other recipients of this sudden violence. Perhaps they feel it in other ways: as a conscious fall from a high place or perhaps a sense of having misplaced something important, like the whole universe. In this place of vast latent power and unfathomable depth. And without this place, or outside this place, loss is never really felt. Outside, loss is dispersed, and becomes a kind of unseen haze. But here, down here, it's felt. I found this out. Down here there is nothing but feeling it. The power of it.

I can walk for miles in this underground cavern and remain as I am. And I do. But up above my children are growing older. They're living a life with Gill in a place I don't know. And all the time I can see them from here. A life that works. The boys older. Life happening. I'm not getting closer to any of this. It just gets smaller and darker and fainter as it disappears into the distance. And then the water comes. And then it comes. And it does.

*

I was eating scrambled eggs, watching the milk pump out from Tom's mouth as he spooned up his cereal. It was a natural and effective overflow that meant he didn't have to regulate the amount of milk or cereal he was shovelling in. Gill had her back to us, making packed lunches, and over Tom's shoulder I could see Jimmy trying to mount a sofa that was several hands too high for him. I got up and went through to the bedroom to lie down on my side. I pulled the pillow into my bottom lip and squeezed my face together, wringing it out, so that the pillow became damp around my eye socket. I could hear Gill telling Tom to get his shoes on. Then my diaphragm started chugging. It felt like hiccups but was more rapid and rhythmical. More like a pulsing. I rolled over on to my back and pulled the pillow into my teeth. There's an ambient, wheezing noise that accompanies this kind of sobbing – a layer of treble that makes it sound as though I'm pleading for some kind of mercy. I had a toy once that made this noise when you turned it upside down. It was supposed to sound like a cow, but it was more like a smoker's wheeze. I was tucking my knees into my chest and breathing more steadily now. I heard a door open in the next room, and Gill was stating something assertively. I knew that she was gathering up Tom's schoolbag and I wanted to say goodbye. I could tell the episode was almost over and I sat up on the edge of the bed. This was the functionality of tears that I became used to in those five days. I knew I needed a moment after the exertion, like knowing when I need a cup of tea. I had my hands on my knees and looked around. Nothing had changed. Then I went back into the kitchen.

When the crying came at night, I'd be squeezing the duvet in my fists and thinking very acutely of the physicality of Tom and Jimmy. It must have been something close to focused meditation because I would imagine their current form, then focus in on the changes that I imagined would take place in their bodies in the years to come. I would imagine the lengthening of Tom's lean legs and the broadening of his V-shaped jawline. I imagined the fine, fair hair that would appear on his face. I imagined his length and strength and the cheekbones that would one day underline his gaze. With Jimmy, I love and marvel at the width of his feet and hands. I imagine him continuing to be broad and solid. His shoulders would thicken and his jawline would be rounder than Tom's. I imagined him shorter than Tom but more burly. In Jimmy's case I also felt guilt that I knew his physical shape and form, but that he would never remember mine. He would often nap on the bed with his chin cupped in his hands and I would talk to his sleeping body and tell him how sorry I was.

Over the Portuguese winter it rained continuously in the mountains, and the eucalyptus that burnt all summer now smelt green. Descending the mountain, we'd wind down through these forests and the warm microclimate inside the car created ideal conditions for precipitation. Any thought or awareness or reflection simply switched it on. The road snaked and seemed to further dislodge all the salty snotty liquid within. I could have leant forward and found the button on the dashboard. And it would come, rising up through the pipes pooling inside my head. Then I'd hit the button again and it would stop.

During those days it felt like some figure was cutting around me with a pair of scissors; moving me with the blades to cut close and accurately. And as the paper turned, more of me would drop down and I knew that it wouldn't take long for the scissors to have made their whole way round. I would be imagining the boys and Gill. Living in a place I might not know – a life that worked but which was alien to me. The boys older. Life happening. And I was looking at all of this from the outside. I clung to Gill, but I saw her and Tom and Jimmy connected by something that I wasn't. They seemed somehow in place and as they should be. And though I was holding on, I wasn't connected in the same way. Until this time I'd just assumed that we were formed from a single piece. That something like this could never happen. A little family of four pinched into human form and then hardened. Set. Finished. So that one figure could never be the person outside observing all these parts. That it would necessarily become a complete form made up of three figures is one of the things I discovered in this cavernous place. This is a concept that I looked at and looked at and looked at and looked at again and again, and I could not understand it. And all the moments that had upset me in the past were in one place. And this moment of upset was in another place. It was an entire physical feeling. And when it came my body curled inwards like a fortune-telling fish on a hot palm.

*

When the five days of tears came they filled the spaces I had never known. Unused rooms. Forgotten rooms. The places where I might have been. It crashed through barriers and washed away impediments like they were blades of grass. It carried me away – it carried everything away. I bobbed on the surface of this rising, moving water, my arms outstretched – a little man being carried away. There was no need to call out; there was no other way to travel; only water. Nothing was left behind. No selves in tiny corners, no scary thoughts left buried. A bowl of chocolate ice cream, which I ate when I was five, went by upon the surface of the flood. A teacher half remembered, a scrap of brown carpet, the car I crashed when I was seventeen, a painted wooden block – all bobbing in the water along with me.

Конец ознакомительного фрагмента.