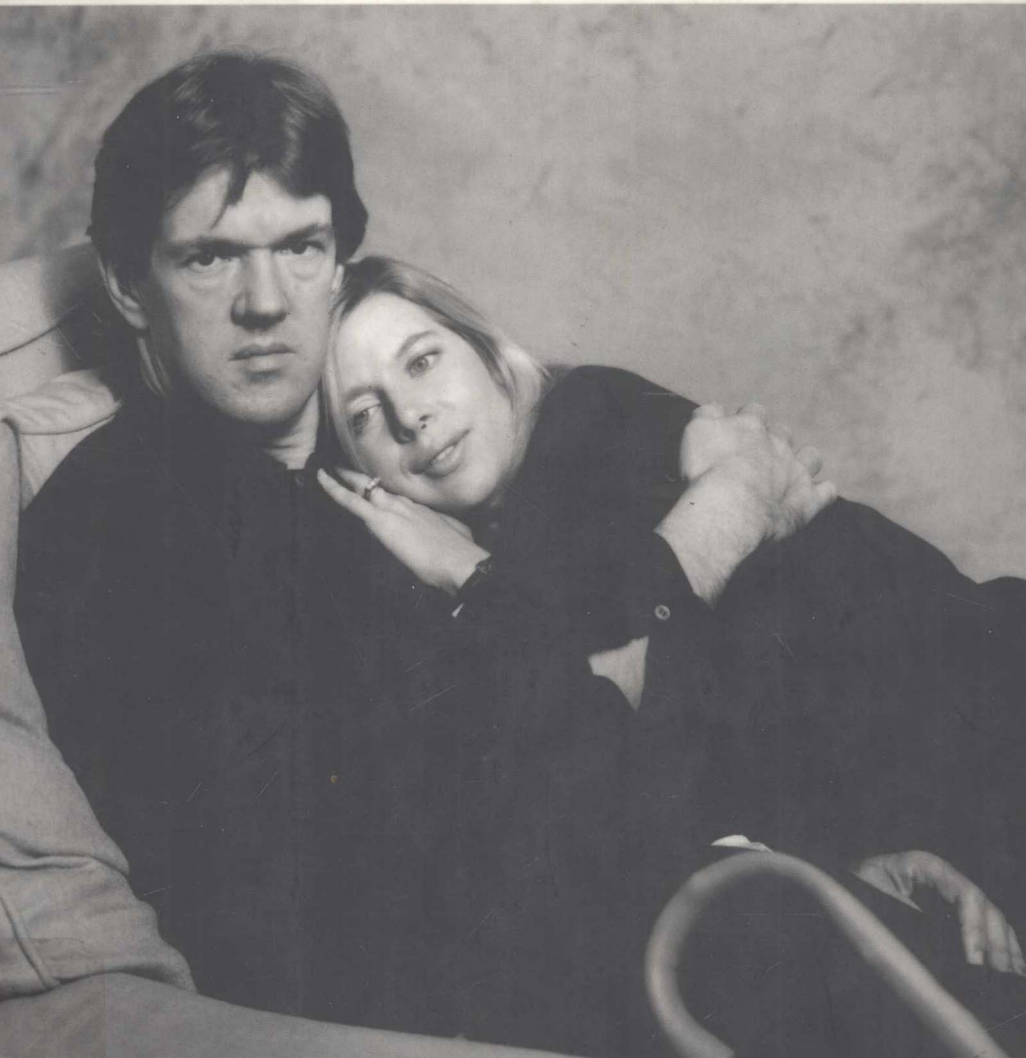
MY YEAR OFF

Recovering Life After a Stroke

ROBERT McCRUM



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TO SARAH

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INTRODUCTION

A Severe Insult to the Brain

Wo aber Gefahr, wacht das Rettende auch.
(*Where danger waits, salvation also lies.*)
Friedrich Hölderlin

When I was just forty-two I suffered a severe stroke. Paralysed on my left side and unable to walk, I was confined to hospital for three months, then spent about a year recovering, slowly getting myself back into the world.

When I was seriously ill in hospital, I longed to read a book that would tell me what I might expect in convalescence and also give me something to think about. There are many books about stroke in old age, but I was young and had been vigorous and there was nothing that spoke to me in my distress.

I have written this book to help those who have suffered as I did, and indeed for anyone recovering from what doctors call 'an insult to the brain'. I've also written it for families and loved ones who, sucked into the vortex of catastrophic illness, find themselves searching for words of encouragement and explanation. People

express every kind of sympathy for stroke-sufferers, but the carers are often the forgotten ones. To all concerned, this book is meant to send a ghostly signal across the dark universe of ill-health that says, 'You are not alone.' It's also intended to show those of us who are well what it can be like when our bodies let us down in the midst of the lives we take for granted. Some will say that it's a *memento mori*, and that's undeniable, but I hope that it will also be heartening, especially to those who have given up all hope of recovery. I don't mean to offer false or cheap optimism, but I am saying that, if my example is to be trusted, the brain seems to be an astonishingly resilient organ, and one capable, in certain circumstances, of remarkable recovery.

The other audience for this book is, of course, myself. The consequences of my stroke were simply too colossal to be ignored or shut away in some mental pigeon-hole. Writing the book has been a way to make sense of an extraordinary personal upheaval, whose consequences will be with me until I die. Besides, I am a writer. Communicating experience is what I do, and quite soon after I realized that I was going to survive the initial crisis I also realized that I had been given a story that made most of what I'd written previously pale and uninteresting by comparison.

Whatever you, the reader, take away from it, there's no escaping that it is a personal book, my version of an event that changed my life. The philosopher Wittgenstein writes, 'How small a thought it takes to make a life.' Throughout my period of recovery I was often alone with my thoughts. When, finally, I came to record these, this book became the mirror of an enforced season of solitude in the midst of a crowded life. I've called it *My Year Off* because, despite the overall grimness of the

experience, there were, at every stage, moments of acute irony and, even, of the purest comedy to brighten the prevailing gloom and chase away the clouds of melancholy. P. G. Wodehouse, one of my favourite writers, once said that 'There are two ways of writing . . . [One is . . .] a sort of musical comedy without music and ignoring real life altogether; the other is going right deep down into life and not caring a damn.' There is, I'm afraid, not much 'musical comedy' about having a stroke.

At times, my year off was one of all-pervading slowness, of weeks lived one day, even one hour, at a time, and of life circumscribed by exasperating new restrictions and limitations. The poet Coleridge observed that it is the convalescent who sees the world in its true colours, and, as a convalescent, I have been forced into a renewed acquaintanceship with my body and into the painful realization that I am, like it or not, imprisoned in it. I have learned, in short, that I am not immortal (the fantasy of youth) and yet, strangely, in the process I have been renewed in my understanding of family and, finally, of the only thing that really matters: love.

[1]

One Fine Day

29 July 1995

Things do not change; we change.

Henry Thoreau

My year off began with a headache, a glass of champagne – and a question. As it happens, the first two were not connected and the truth is that no one will ever know exactly what happened inside my head on the night of 28/29 July 1995, but probably it went something like this. First, for reasons that are still mysterious, a surreptitious clot began to form in one of my cerebral arteries, cutting off the blood supply to part of the one organ in the body that, next to the heart, is most greedy for blood. Eventually, perhaps some hours later, like a breaking dam, the clot burst into the right side of my brain, causing an uncontrolled 'bleed' that would result in irreversible destruction of the brain tissue deep inside my head.

I was oblivious to this cerebral drama; all I knew was that I had a raging headache, and then, the next morning, that I could hardly move. Overnight, I had suffered what the specialist would call a 'right hemisphere

infarct', and what the world knows as 'a stroke', a word whose Old English origin connotes 'a blow' and 'a calamity'.

Actually, it's a calamity that will befall some 450,000 individuals in North America (including Canada), and 150,000 in Britain each year, but when it happened I was completely ignorant of the affliction that Sherwin B. Nuland, author of *How We Die*, calls the third most common cause of death in the developed countries of the world.

It was just another bright summer Saturday morning, and here I was in bed, unable to get up – alone at home, a four-storey town house in Islington, North London. My wife, Sarah Lyall, a journalist with the *New York Times*, was away in San Francisco. We had been married scarcely two months, and it was odd to be on my own again. It was odder still to be so helpless, but I was in no pain, and, in retrospect, I realize that I was barely conscious. Downstairs, the grandfather clock was chiming the hour: eight o'clock. I could see that beyond the heavy maroon curtains it was a lovely day. Through the open window, the sounds of the street filtered in, sharp and echoey in the stillness of the weekend.

I was supposed to drive to Cambridge that morning to visit my parents. So, time to get up. But there it was – I could not move. More accurately, I could not move my left side. Overnight, my body had become a dead weight of nearly fifteen stone. I thrashed about in bed trying, and failing, to sit upright, and wishing Sarah were with me. For some unknown reason, I experienced no anxiety about my condition, just irritation and puzzlement. Why should I, who had recently sailed through a full medical examination, be unable to do as I pleased?

It was my dentist, Mr Glynn, who, a year earlier, had

first questioned my immortality. 'Teeth,' he observed, studying the X-rays of root-canal work to my upper-right quadrant, 'were not designed to last more than forty years.' He snapped off the light. 'And, frankly, nor were we.'

I was forty-one then, and whenever I was reminded of Mr Glynn's wisdom by some ache or twinge, I would wonder when some other body part would follow the example set by my teeth and protest, 'Enough!'

As my forty-second birthday approached, Sarah, a New York doctor's daughter, was anxious for independent verification that she was not marrying a crock. She'd witnessed enough of my candle-at-both-ends lifestyle to believe that this was a desirable prenuptial precaution. My assurances that McCrums lived for ever (all my grandparents died in their eighties) cut no ice. So, at her insistence, I made an appointment with Dr Guy O'Keeffe, who has a pretty little surgery near Eaton Place. From Dr O'Keeffe's examination room, the world seems secure, a place for healthy young women to bring up big bouncy babies: the air is flavoured with Johnson's baby powder, and highbrow Muzak tinkles in the background.

Dr O'Keeffe himself – sandy-haired, trim and boyish – seemed a promising recipient for intimate disclosures. Good health, his manner says, is our birthright; everything can be diagnosed, treated and cured. So he poked and prodded and pricked. He took blood and urine. He weighed and measured. He eavesdropped on the secret colloquy of my vital organs. In half an hour or so, he was asking me to put my clothes on again. The tests would be sent for analysis but, according to all the visible signs, I was fit. 'For a tall guy you're okay, but keep an

eye on your cholesterol,' he said. It was good that I didn't smoke, but I'd be wise to watch the drink.

Of course. We chatted about 'units': I am a lifelong subscriber to the British media maxim that 'White wine is not a drink'. Dr O'Keeffe nodded competently and made another little note. A daily half-bottle of wine was okay with him.

I returned to the street, ready for anything. Jungle warfare? I could hack it. Cross-country skiing? I blessed my hardy, long-lived ancestors. No question, mine were a better class of gene.

That was in June. In the meantime, Sarah and I had come back to London from our wedding, in Philadelphia, to begin our new life together. Our honeymoon seemed to segue into a month of dinner parties at which my new American wife was introduced to some part of my circle for the first time. Clearly, we were going to live for ever and then happily ever after.

In July, Sarah flew to San Francisco to interview the novelist Amy Tan about her new book *The Hundred Secret Senses*. We were to be apart for eight days. I remember taking her to the airport and praying, as I watched her in the rear-view mirror – a small blonde figure with an oversize red suitcase waving goodbye on the pavement – that no harm should befall her.

Now here I was, a week later, unable to get out of bed. I have relived this moment a thousand times in a fruitless quest for some explanation – the moment my life divided into 'old' and 'new'.

Strangely, I had felt ready for a change, though I could not say what kind. At that time, I earned my living as the editor-in-chief of the publishers Faber and Faber, working with a variety of writers from Kazuo Ishiguro

and Peter Carey to Paul Auster and Milan Kundera. I also wrote fiction and had, for several years, combined this with occasional freelance journalism in troubled parts of the world: Peru during Mario Vargas Llosa's presidential campaign, Cambodia during the UNTAC (UN Transitional Authority in Cambodia) election, and, most recently, East Timor. Like many of my generation, I'd envied those, like my parents, who have lived through wars and revolutions. Consciously or not, I'd always hoped my trips would yield a frisson – a moment of danger from which none the less I'd emerge unscathed. Mentally, I wore a flak jacket and jeans under my yuppie suit and I liked to think I was more at home on the road than in the chic, heartless salons of Thatcher's London, though in truth I had begun confiding to Sarah a vague dissatisfaction with my working life.

Indeed, on the very evening of my collapse, I'd done something I now think of as typical of my 'old' life. I'd gone out for dinner at the Ivy restaurant in Covent Garden with my friend the literary agent Kathy Robbins, specifically to discuss Life (mine and hers). Before taking the taxi to the West End, I'd swallowed a couple of Nurofen tablets for the headache that had been troubling me all day, and at the Ivy I ordered a glass of champagne while I waited for Kathy to arrive. In that life, a glass of champagne would dispel most troubles. How often, as editor-in-chief, had I downed champagne with Faber authors in the Ivy's upstairs dining room. So I gave no thought to the headache: I'd had this problem, on and off, for years. Indeed, there had been a time in my twenties when I was sufficiently worried to seek medical advice, after which the complaint had vanished as miraculously as it had first appeared.

By the time Kathy and I were sitting with our coffee,

kvetching about the world in the restaurant's restful half-light, I was conscious that my headache was still nagging. I remember yawning with unaccountable weariness, wondering why, after only two glasses of champagne, my speech was so muddy and indistinct. My American Express receipt shows that I paid for our meal at 22.38. My signature is steady. Then we rose from the table and made our way to the street. But something was not quite right. My legs felt spongy, as though I was walking through treacle, every step effortful and uncertain. But I said nothing. I believed in my body. Whatever it was would pass.

Opposite the Ivy, in the St Martin's Theatre, *The Mousetrap* was playing – 'the world's longest-ever run', now in its forty-third year. I had occasionally observed that Agatha Christie's thriller and I had aged well together, but tonight I was ready to call in the understudies. We reached St Martin's Lane, a walk of perhaps a hundred yards, during which every step had become more difficult for me. Here, I said goodnight to Kathy and, desperate to be home, hailed a taxi, articulating the address with some effort. The driver repeated it contemptuously, as if picking up a drunk. I climbed heavily on board and sank into the back seat.

When we reached Islington, my legs felt like lead and I was walking like a deep-sea diver, but I made the front door without falling over and let myself in. I was plainly unwell, but my symptoms were unfamiliar. So I turned to that sovereign English remedy: I decided to make myself a cup of tea.

Downstairs in the kitchen, I listened to a cheery message from Sarah on our answering machine. It included a San Francisco hotel number to call but, feeling quite extraordinarily tired, and calculating that

the time difference was not in my favour, I decided to wait until morning. Then, clutching my comforting mug of herb tea, I went upstairs to bed. I remember resolving, as I drifted off to sleep, to rise early to beat the weekend traffic on the Cambridge road.

When a stroke occurs and the brain suffers 'a haemorrhagic infarct', the body experiences a colossal disturbance of its innate sensory equilibrium. Literally overnight, I was changed from being someone who could order an expensive meal in a fashionable restaurant to being an incontinent carcass, quite unable to make any sense of his body. I was conscious and alert (I thought) but my limbs were not responding.

My recollection of the first phase of the morning is disconnected and hallucinatory. Perhaps I passed out, or fell asleep, because the next thing I remember is the clock in the hall chiming ten. Ten o'clock! I would never get to Cambridge! Time to get going! I rolled with difficulty to the edge of our big brass bed.

Then I was falling heavily to the floor, dragged over the edge of the bed by the dead weight of my left side. I was shocked and dismayed, and my first thought was to telephone for help. There was a phone on the bedside table, but of course it was now out of reach and anyway I'd left Sarah's hotel number downstairs in the kitchen. So there I was: cut off. In extremis, the body is merciful. My feelings were ones of mild frustration, 'Oh no!' rather than 'Jesus Christ!' At worst, I felt like Alice under the glass table trying to reach the key that would open the door to the magic garden. I tried in vain to remember the name of Sarah's hotel. Wentworth? Grand Western? Nothing came. Even if I could reach the phone what help would it be?

A new anxiety was distracting me. I was desperate to

pee. Suddenly there was a hot cascade of urine on my chest (I was lying on my back, naked). Afterwards, I suppose I became unconscious because when I came to again it was much later. The street was noisier and busier and I sensed from the light on the ceiling that the sun was high. When the telephone rang briefly, maddeningly, and stopped, I knew that downstairs in the kitchen the answering-machine would be clicking into action. Up here in the bedroom it was out of earshot.

Time blurred. When the clock chimed again, it was three. If this was a nightmare, it was time to get back to the waking world. But it was not a nightmare, and the fact that I could neither sit nor stand was all too real. As the afternoon wore on, the bedside phone rang briefly several times. We had set the machine to respond after two rings and in that other life that now seems so distant I had often, to Sarah's amusement, hurled myself across our bed to pick up and answer before the machine clicked on. Today, the scoreline was: British Telecom 7; McCrum 0.

What did I think about, lying there on the floor? Oddly enough, it was my missed rendezvous with my parents that became my obsession and I entertained all sorts of explanations to the conundrum of my immobility. Perhaps, like Stephen Hawking, I was suffering from motor-neurone disease. Perhaps I had a brain tumour. My cousin Jane had died of a brain tumour. At times, bizarrely persuaded by the remaining strength in my right side, I imagined hobbling across the street to my car, somehow driving with one arm. I was like a rat on a wheel, revolving desperate escape plans. I had no inkling of how ruthlessly I had been disconnected from the world of appointments and obligations, or how long it would be before I returned to it. Suffer a stroke and you

find that the complex wiring we call 'the individual in society' is peremptorily ripped from the fusebox of everyday life. I had blown a connection in Nerve Central and all my circuits were down.

Then the phone rang again, and stopped, as before. I felt I had to do something decisive. I knew there was a phone on the floor in the living room downstairs. Somehow I had to get there. With what I now see must have been an extraordinary effort, I dragged myself under the frame of our big brass bedstead with my 'good' right arm, noticing with interest the little flergs of dust and the strange debris that collects in such places – forgotten paperbacks, discarded Kleenex, a pair of Sarah's tights – and then squirmed, commando-style, over the carpet to the head of the stairs.

Here, reaching out to the banister, which fortunately was on my right side, I pulled myself over the top step. Again my dead weight took control, and I found I was sliding helplessly and painfully head first down the stair-carpet to the mezzanine landing where I had a borrower's-eye view of my library of modern first editions: Kazuo Ishiguro's *A Pale View of Hills*; *The Rachel Papers* by Martin Amis; *A Good Man In Africa* by William Boyd; and Raymond Carver's *Will You Please Be Quiet Please?*

I vividly remember – indeed, I will never forget – this part of the day on the landing at the angle of the stairs. For some hours, I lay on my back staring up at a framed brown-green school map of French colonial Indo-China, a souvenir of that trip to Phnom Penh in 1993. Then I had been looking for an adventure. Now I seemed to be caught up in one. I had crossed by night from what Susan Sontag (in *Illness As Metaphor*) calls 'the kingdom of the well' to 'the kingdom of the sick' and, though I