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Opening Extract from...

In the Blink of an Eye

Written by Hasso and Catherine von Bredow

Published by Orion

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In the Blink of an Eye

Hasso and Catherine von Bredow



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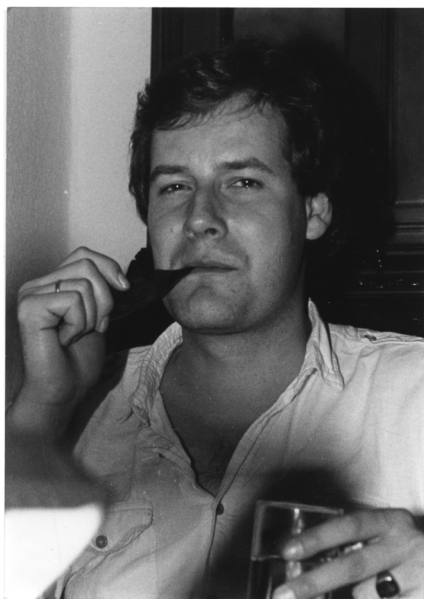
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On Hasso's behalf, I want to take this opportunity to express profound and lasting gratitude to everyone, family, friends and carers, who played their part, however great or small, in loyally supporting him through all his locked-in years, in encouraging his efforts to write and in humanising his care with so much genuine love and kindness.

Finally, I would also like to thank my mother for her enduring strength and support and, in particular, for her patient reading of the manuscript. Above all, though, thanks are due to my three wonderful children, who have so much of Hasso in them, and without whom I certainly would not have come this far.

Catherine



Angfangs wollt'ich fast verzagen,
Und ich glaubt', ich trüg' es nie;
Und ich hab' es doch getragen —
Aber fragt mich nur nicht, wie?

*At first I almost despaired,
And I thought I would never be able to bear it;
Yet even so, I have borne it —
But do not ask me how.*

'Junge Leiden', Heinrich Heine, Lieder VII
(Translation Emily Ezust)

Locked-in syndrome: a rare neurological disorder characterised by complete paralysis of voluntary muscles in all parts of the body except for those that control eye movement. Individuals with locked-in syndrome are conscious and can think and reason, but are unable to speak or move. The disorder leaves individuals completely mute and paralysed. Communication may be possible with blinking eye movements.

There is no cure.

Source: National Institute of Neurological Disorders and Stroke

Preface

I was twenty-four when I came face to face with the young man who was to change my life forever. Tall, good-looking and blessed with a natural, easy charm, he was unlike anyone I had ever known before or since.

Hasso would never have considered himself to be in any way special. But everyone who knew him tended to disagree. He was born in Hannover in 1958 into an old German family from whom he learned integrity, a strong sense of identity and courage in adversity. Hasso's heritage taught him from an early age to expect nothing but to give his all to any situation.

He was for me an irresistible jumble of seeming contradictions. Despite a vein of sometimes stern discipline running through his nature, Hasso was warm, generous-spirited and above all funny. He loved to laugh and to make others laugh. With his impeccable manners and his noble bearing, there was an old-world charm about him that set him apart and sometimes belied his easy-going, fun-loving personality. He loved rock music and heavy metal, but would kiss a lady's hand on being introduced. He wore jeans and leather but was equally at home in a traditional green hunting jacket or a tailored suit. He had no money, but carried himself with a sense of history and honour. He loved nothing more than to work in his garden and walk the woodland paths with his children, yet also had a fondness for smoke-filled bars and all-night drinking sessions with friends. Hasso embraced all these baffling opposites with equal enthusiasm and natural joy, never feeling the slightest sense of conflict or contradiction.

When I met him in Germany in September 1982, he was an infectious blend of enthusiasm and idealism.

Within hours of meeting him I knew that I could never bear to be parted from him. It was an unbelievable moment. He told me that very day that he had made up his mind that we should be together for the rest of our lives. He was calm and very sure. ‘Everything is perfectly clear,’ he said. And so it was. He remained steadfast in what he wanted. Never wavering, ever.

1 May 2000 dawned like any other day. I was not to know, however, that it was to be the last day of life as we had known it. When that day came to a close, Hasso, just forty-two years of age, had suffered a rare and massive stroke in his brainstem. Without the advanced technology of resuscitation it would certainly have killed him. There had been no sign, no warning. The picture was grim. He was totally paralysed and was being kept alive on a ventilator. Apart from his eyes, which he could still open and close, nothing else in his body would obey his brain. This vibrant, funny, charming man was now immobile and incontinent, unable to speak, eat, drink or breathe properly. Yet, as if all that were not enough, his mind, his senses, his clarity of perception remained untouched. Immured within the tomb of his otherwise perfectly healthy body, he was acutely aware of what had happened and totally conscious of the horror of it all. The medical term is ‘locked in’. He was, in effect, buried alive.

The consequences were shattering. His ‘night of the soul’ was long and dark. During the four years that followed, he travelled a spiritual and emotional path neither he, nor anyone else, could have thought possible.

Confined to a hospital bed and a wheelchair and now incapable of independent living, Hasso found himself face to face with a life as far removed from his own as it was humanly possible to imagine. After almost a year in hospital, and in spite of the fact that his condition had failed to improve significantly, we finally managed, against the odds, to get him home to live with us.

For me, the effects of Hasso's stroke had been immediately and profoundly devastating. As he struggled to define himself within the parameters of his new existence, despite all my intense desire to help, I was faced with the realisation that I could do absolutely nothing to take away his suffering. The truth was unavoidable from the beginning: nothing I could do would ever be enough. All my efforts seemed dwarfed by the immensity of his condition. There was no way on earth I could change anything, and the man who was all the world to me now remained trapped behind the impenetrable walls of this prison.

Inevitably, the effect of that first year and of his struggle to find a way forward left an indelible mark on him. With the power of speech continuing to evade him, he nevertheless burned with the desire to connect with his world, his family and his friends, as well as with a growing compulsion to tell the story of his experiences. He felt driven to express the magnitude of what had happened and also to communicate to a wider readership the realities of a life 'locked in'. Throughout the long days and nights of his confinement in hospital, he had planned and structured the ideas for this book in his head, storing up details and memories for the time when he could transform them into the first draft of a text.

He began with characteristic aplomb. To my astonishment, one evening, within days of returning home, he used eye blinks to spell out a string of words to me. Although I was accustomed to his using this method to express his needs and thoughts, I was at first baffled by their apparent irrelevance to the moment. It didn't take me long, though, to realise what he was doing. This, I saw suddenly, was the beginning of a narrative, a book. It was to become his way out of the circle of silence. His body had become his own prison, but his brain was intact and his spirit unbowed. Inside, though deeply scarred, he was still the same person and he was now

determined to use this book to prove it. It was his way of releasing the voice which had been taken from him.

Technology was to prove his ally on this front. Though almost completely paralysed, with only a tiny residue of voluntary movement in his thumb and the ability to open and close his eyes, he 'wrote' this account of his stroke and its consequences from his wheelchair; at first dictating with eye blinks, and then with the aid of a specially designed computer and ultra-sensitive switch system. Given the profound level of his disability, the process of writing in this way was complex and grindingly slow. Each day he would insist on spending hours and hours seated in his wheelchair in front of the computer, trying to articulate his thoughts and transfer them onto the screen. Letter by letter, his often unreliable, flickering thumb movement would select options from the on-screen talking keyboard until words slowly formed, multiplied and transformed themselves at a snail's pace into whole sentences. Sometimes, several hours of gruellingly tedious work would result in one short paragraph of a few sentences, produced in a massive size 72 font to the unremittingly droning voice of the scanner. On other days he achieved a little more; and then, after a short break, he would want to press on and on until, day by day, the text slowly piled up in front of him. Although he could not focus his eyes well enough or move them across the screen to actually read properly what he had written, he plodded on, depending on memory and my re-reading to help him. The painfully slow nature of the whole thing was, doubtless, intensely frustrating. But so was absolutely everything else. Here, at least, was a kind of liberation. The effort filled what had otherwise become the wretched tedium of his new life and, though he frequently found it exhausting, it gave him, finally, a very real sense of control and self-expression. He had found a way of translating himself, of revealing to anyone who might still doubt it that, below

the rigid, frozen surface of his locked-in body, there ran the same deep, fast-flowing current as ever before.

For the next 18 months or so he laboured on like this. He was genuinely moved when friends and family urged him to publish the book and was encouraged by their enthusiasm for the snippets of text he would show them in response to their curiosity. 'I'll need your help with this . . . big time,' he told me, knowing that my promise was a given. In the final stages of the writing, he began to think about presentation and about the whole process of organising and editing the text which he knew would need restructuring somewhat. Because of the constraints of the composition process, he had only been able to write in a linear fashion, with no means of going back over his text, of rereading or reworking his pages. He solved the problem by adding extra information to his first completed version and I then had to find appropriate sections in the text to slip them in. He also wrote up detailed instructions about how he wanted the text organised. Occasionally I offered some thoughts of my own. Sometimes he liked my suggestions, sometimes he didn't. And he wasn't tentative in showing his rejection or disapproval of my ideas! We often ran into disagreements about tiny details; but in the end, as I saw it, it was his book and even if he knew I wasn't always quite comfortable with the way he wanted to present some of it, he also knew that I wouldn't interfere too much with the final version. Apart from some minor changes to structure and content, it was my primary concern to preserve his account in its entirety and to retain its authenticity. Over time, his growing tendency to compress and condense his sentences (in order, I suspect, to get to the end before his strength failed him) relied on my ability to decode or interpret them. This necessitated some expansion on my behalf and I used much of the 'extra information' pieces he wrote after he had finished the text proper, to flesh out these sections, always trying to

preserve his words and fit them into the main body of the text.

Bouts of illness and discomfort frequently interrupted this process. We were often thrown off course by lack of time on my part (the demands of 24-hour care allow for few opportunities for proofreading and editing), and by exhaustion and frequently overwhelming periods of weakness or even depression on his. But he would always rally himself and focus his spirit one more time to the task in hand. Once he felt that the main part of the writing was complete, he would nevertheless frequently return to it, making new suggestions or writing additional material. Many of these were fascinating and full of interesting detail.

When I read the dedication, I understood not only how important the book itself was to him as a means of communicating the unimaginable, but how deeply he felt the compulsion to write and, by so doing, to give the children something of himself.

After his death, it took me a long, long time to find the courage to take up where he had so prematurely had to leave off. Regular enquiries about the book often left me feeling disappointed in myself and embarrassed at my inability to see it through. I felt unequal to the task and Hasso's dream of publication for a while remained just that. After almost two years, however, I finally found the resolve to return to the words he had so painstakingly created and to attempt to produce a manuscript that I could present for inspection.

Several months later, a friend recommended an agent who might be interested and, with much trepidation, I sent off the finished version for the first time. When asked to a meeting, I found the discussion about Hasso's condition and his writing really difficult and the subsequent kind but definitive refusal left me deflated. I wanted to give up. However, I decided that I would try to raise the cash myself to get the book published

privately. That way, at least family and friends would be able to read it. The chance discovery of a publisher in our local area brought me in touch with the team who oversaw this first stage of the project to fruition. I could not have been more fortunate. The understanding and support they gave me resulted in 200 bound and printed copies of Hasso's manuscript, produced to the best standards within the most affordable format. I packaged these up and sent them out across the country and throughout the world to all of Hasso's family, friends and colleagues and to those who had been touched by him. And there, I thought, it had ended.

What followed, however, was both a surprise and a spur to action. Letters came pouring in from all those who had received it and from complete strangers to whom it had been passed on. I found their words deeply moving. All were, as one friend put it, 'profoundly affected'. Some, who had known and loved him before the stroke, mentioned how 'poignant and unforgettable' they found the characteristic humour and honesty of his words and that they would treasure them, almost as a kind of parting gift from him. Others, who had only got close to him in his 'locked-in' state, mentioned his courage and warmth and the regret that they had not had the chance to get to know him before. 'It is an extraordinary story told by someone whose strength of personality, bravery and compassion shines through on every page,' wrote someone whom I had never met, but who had been moved enough to write. Each letter expressed the conviction that Hasso's account should be more widely read and that his story was far too remarkable to be forgotten. Some medical professionals even wrote asking for ways of obtaining more copies, as they wanted to be able to recommend it to their students, to nurses and fellow doctors. 'There are many lessons in your book for doctors and nurses – in fact for all of us,' wrote one specialist. Again and again, people urged me to

find a way to get it published properly so that it might, as one dear friend wrote, stand as a ‘monument to the very best that is human’, and a ‘tribute to his spirit’.

I was overwhelmed. But there was something more. An immense pride welled up in me for the effect that Hasso’s courage had had on others and how his efforts to break out of the prison of silence that engulfed him had transformed themselves into a life-changing, even a life-affirming force. He had shown unbelievable determination to make it happen. I knew that I couldn’t now give up until the book had found its way towards publication and that I would have to devote myself with renewed vigour to making that happen.

In the event, it was Hasso’s own words that pulled it off, firstly through the sensitive reception they received from the woman who would become our agent, Sheila Ableman, and then through the response and the inspired guidance of the team at Orion. Hesitatingly and, it has to be said, reluctantly, I now turned myself to the task they requested of me: that of writing about the experience from my own perspective. To this end, I was prompted and encouraged to revisit the journals I had written at the time and then to join my own voice to Hasso’s by contributing to the final text. In the end, though I found the task daunting and, at times, all too emotionally draining, eventually I managed to find some way into unlocking a past that had been so unbearable. It may even be true that, by shining a light onto my own experience of Hasso’s suffering, perhaps I discovered a path towards retrieving from the overwhelming sense of loss I felt a more complete picture of what he had gone through, of our life together and of what he meant to me. My emotions and my memories became a kind of language of their own, a way into expressing the inexpressible; a kind of journey, I suppose, both backwards and forwards. And always, at the front of my mind, stood the conviction that, if, by publishing this book, Hasso would,

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finally, really be able to tell it how it was, then that, for me, was worth the struggle. And I would have kept my promise.

In the end, this little book has become something momentous. For Hasso, it was a reassertion of his sense of self. Its voice is resolute and so recognisably his own. For all of us who loved him, it will remain a testament to his spirit and his courage.

Catherine, January 2009

—— PART ONE ——

*From the Fast to
the Slow Lane*

May 2000

I May 2000

There is a before and there is an after. There is a day, a moment when, abruptly, one life ends and another begins. When, without one even realising what is going on, life has become ‘other’. A watershed.

You don’t realise it at first. You can’t even recognise that it has come. Your connection to your own self and to your life is so strong that you cannot contemplate the split. A seismic rift that has ripped life in two. Your brain needs time to catch up with the inexorable flow of the change. When it does, your life has already drifted off beyond your reach and the doors have slammed shut on what you believed yourself to be. In the blink of an eye, you are where you never desired yourself to be, a person unrecognisable to yourself, transformed beyond your own understanding. The before and the after. With no going back.

I lay prone in an ambulance. Outside, the world flew past me. May morning sunlight, now beyond my reach, birds traversing the sky on the upward lift of warm air, blossom and tender green leaves brushing the sides of the vehicle as it sped through the country lanes. Urgency imprinted itself on the landscape and on the buildings, darkly glimpsed through the tinted windows, as the blue light and sirens urged motorists and shoppers out of the way in the streets approaching the hospital.

Unprepared and unwilling as I was, I found myself propelled headlong towards the future prepared for me in the silence of time, come like a thief in the night to strip me of myself.

‘I am only forty-two,’ I thought. ‘My God, I’m only forty-two.’

Blankness and gravity were etched on the faces around me. Outside, the world, my world, flew past with horrifying speed, past all those ordinary people who remained oblivious to the enormity of what was unfolding in my life.

‘Oh, my God, I’m only forty-two.’

The words repeated themselves in my head like a mantra.

There was no reply.

It all began with the dawn of what promised to be a perfect day. I remember feeling all the impatience and excitement of waking to the beckoning sunshine of that warm May bank holiday morning and the children’s delight at my suggestion of an early bike ride through the country lanes.

The night before, having completed many hours work on my laptop, I had gone to bed quite late. I was on my own in the house looking after the children, while my wife, Catherine, was visiting her family in Devon. We normally did everything like that together as a family, but this once had decided that Catherine should go alone for the weekend. Our eldest daughter, Lucia, was spending the night with a friend in the next village. So, taking advantage of the relative quiet, once the two younger ones had gone to bed, I had decided to give the household accounts a long-needed facelift. I had managed to amass a backlog of months of paperwork, and spent the whole evening sorting through it, recording individual notes in pencil against each item. These records were part of my own idiosyncratic system, developed over many years and by their very nature, tedious and long-winded: hence the backlog. However, I had occasion many times to

be glad of the details that I had recorded like this and knew it was probably worth making the effort. The fruits of that long evening spent alone have now disappeared into the mists of time.

In spite of the children's usual nocturnal activities, I wasn't that tired and had got up early, feeling the pull of the wonderful morning outside. The sun was flooding through the house and I was eager to get out into the magic of the May morning. I sent Sophia and Christian off to sort out breakfast and headed for the shower.

As I was leaving for a business trip abroad the following day, I was determined to get the most out of the time we had together. When at home at the weekends in my garden in Kent, I often looked up at the planes crossing in the sky above and would think of the coming week and the next trip I would be taking for the bank. I tended to think of my life in the office merely as a role I was called upon to play and, in truth, I never really relished all the travelling my job involved. In fact, travel was much more Catherine's thing, whereas I preferred the tranquillity of the fields and the woods near home. With the windows wide open that morning and the sound of birds floating on the air, I couldn't wait to get outside.

I turned on the water. Halfway through, I suddenly heard a buzzing in my ears and realised I was starting to feel very strange. Just like that. No prior warning, no other symptoms. Absolutely fine, and then suddenly it felt as if the life blood was seeping out of me, which on reflection it probably was. I sank down and tried to steady myself but whatever was going on didn't feel as if it was going to go away. In fact, I rapidly began to feel worse and worse. With trembling hands, I pulled down a towel and, willing my wobbly feet forward, I stumbled back to bed. I was beginning to worry. This didn't feel like anything I had ever experienced before. My thoughts rushed

ahead to the following day, the day after the bank holiday, when I was supposed to leave for Germany on a business trip. I began to wonder what my colleagues at work would think when I didn't turn up. Already I had a suspicion that something pretty serious was happening.

Lying there, wrapped in a towel and unable to conquer the creeping weakness that was invading my body, I began to feel the possible seriousness of my predicament. Catherine was due to return later that day, but for the moment, I was in the house alone with Sophia and Christian and would need to think about what to do with them if this sensation didn't pass. As I lay there trying to recover myself, I had to admit that I was feeling very strange and unwell and decided there and then that I would have to do something to make sure that they would be OK, as I was feeling more and more unable to function properly. Christian's classmate and his brother were due to come that morning to play with him. I told him to call the boys' parents and ask them to change the arrangements, as I obviously didn't feel in a fit state to be able to manage such a lively gang. Fortunately, the boys' parents suggested that it would be better to come and collect Christian and keep him with them until I felt better, and that they would soon be on their way.

Sophia very sweetly brought me breakfast in bed, but I couldn't eat anything. The two of them sat on the bed next to me and did their best to make me feel better. They had never seen me ill in their whole lives and I knew that this was a shock for them.

I felt dreadfully nauseous and the noise in my ears hadn't stopped. Suddenly I was very sick. I knew I couldn't stand up or try to make it to the bathroom. Sophia gave me the bin beside the bed, and when I had finished she calmly cleaned me up. I remember thinking that she should have been spending the day laughing and hanging out with her friends

like a normal thirteen-year-old, instead of having to take the responsibility of her disintegrating father on her young shoulders. But she did, and she was amazing. In their turn, Lucia, sixteen, and Christian, only eight, would also rise to the occasion and show a love and maturity well beyond their years. It is not what a man dreams of for his children. But their response that day and each day since has certainly made me hugely proud and full of love for them.

Shocked to feel my strength ebbing away so rapidly, I tried to write down the time on a piece of paper, but, while doing so, I noticed that my handwriting was looking worse than ever. Sensing that I might have to see a doctor, and in a last-ditch attempt to keep up appearances, I managed to put on my jeans and removed all my credit cards but one from my wallet. Since I was due to leave for Germany the following day, I had already prepared my documents for the journey and had left them beside the bed. Reaching for them now, I grabbed my passport and German ID card. I found my donor card and put it in the wallet.

Quite alarmingly, I suddenly began to notice that I couldn't move my left side and, when I tried to speak, I knew I was sounding strange. I reached for the phone and called Catherine. My mother-in-law answered, and she must have been concerned, because I could hear the anxiety in her voice as she asked if I was all right. I said I wasn't and when Catherine came on the line I tried to tell her what had happened, but I was aware that my speech was really slurred. I knew I sounded drunk. As my words blurred into a mumble, Sophia took the phone and I tried to explain to her that I thought I had had a stroke. She repeated the words to Catherine in a slow and hesitating voice filled with incredulity and shock. Although I had not articulated the thought until this moment, I realised at that point that I was sure that this was indeed what was happening. Catherine immediately asked if I had called the

doctor and, when I told her that I hadn't, she said that she would immediately do so. Sophia replaced the phone for me and the strange unrecognisable sound of my own voice reverberated on in my brain.

That would be the last time we spoke to each other. That hurried moment of panic and disbelief when I felt us stretching out to each other across the distance. From that moment on, speech and all capacity to make the slightest voluntary sound faded from me, the deafening silence enveloping me like an extra large coat, muffling out all sound and exiling me from any true expression of my self.

Beyond words, beyond touch, beyond life. The before now irrevocably divorced from the after.

After putting the phone down, I must have fainted. I don't know how long I was out of it, but I temporarily lost consciousness. When I came to, an ambulance team was there and Lucia had returned home with her friend's mother, Lena, who mercifully now stayed and took control of the situation. She promised to follow the ambulance to the hospital with Lucia and Sophia and to make sure that Christian was safely collected and looked after for the day. She assured me she would stay with them and take care of them till Catherine arrived and this was obviously a huge relief to me. The ambulance men then carried me downstairs to the waiting ambulance.

On arrival at the local accident and emergency department, I tried to explain to various doctors what had happened. One of them even asked me in German to try and tell him my version of events, but I couldn't manage to put two words together. The girls were kept away from me most of the time, and I later discovered that they were waiting in a side room and were not allowed to come close to me. Each time they tried to get near me they were sent away. As this phase went on for most of the day, they were very distressed at this,

especially as no one explained to them or to Lena much of what was going on. In fact, I hardly saw anything of them all through that day until Catherine arrived. In spite of this, they had the courage to keep returning and to try to talk to me, only to be sent away each time. I had the distinct impression, as the day wore on, that no one was really sure what to do anyway and this added to my anxiety.

It was during the process of the first brain scan that I noticed my body becoming stiffer by the minute. After the scan I returned to A&E, and as by then I couldn't speak at all, I was pleased that the staff had given me a catheter. I knew from my father, who had had a stroke, that the bladder was going to be a problem. To compound the horror, I realised that now I couldn't move a single muscle any more. I seemed to have become entirely paralysed. My brain was spiralling into shock and panic. I couldn't grasp the objective reality of what was happening. Catherine was still hundreds of miles away and I desperately wanted her to be there with me. Moreover, since it was bank holiday Monday, the A&E department had a skeleton staff on duty, mainly junior doctors, and I was left alone for long periods of time. My thoughts raced and I fought hard to keep the terror down.

Then, with sudden clarity, I began to realise that the journey I had made to the hospital, via the old familiar country lanes, was a journey towards this moment. I saw the man I had left behind waking full of life to that wonderful May morning and asked myself how I would ever be able to find my way back to him.

In truth, it is someone I have longed to be, but whom I have never been able to find again.