

CROSSING THE GLACIER

December 2011

We cross the glacier at midnight. A row of bobbing head-torches in a sea of darkness. Ice-axe, crampons and a pipe over my shoulder for water. And more stars than I thought possible. This is outer space. We climb through the night.

The sun is up and I see where I am. I'm twenty thousand feet up a Himalayan mountain, lying on a four foot wide bridge of snow and ice that leads to the summit. We are an hour from the peak and I have never felt more tired in my life. I try to move. There is a sheer drop on both sides. I freeze. What am I doing here? And then I feel it. Immediate and sickening in my stomach. The shocking starkness of it inside me. If I fall here, I fall to my death. There is no one here to help me. I am alone. With it comes a feeling I have never felt before. I've thought about it many times but never felt it. Death. My death. It is as close to me as the drop on either side. It is all around my ears. I have to move. I start to climb.

I climb the street humped high with snow. I'm wearing boots and the snow is falling heavy and thick. I've just come from a screening of my film at the Egyptian theatre on Main street, Park City, Utah. The Sundance film festival. And I'm electrified. I decide to walk, out of the town, into the snow. There are some other shops out here and I want to buy some presents for home. I walk along the edge of a larger road, the blizzard really picking up now. I love it here. I feel like a filmmaker for the first time in all my years dreaming about film. I reach the shops at the end of town. I step under a walkway and call home. My mother answers and I listen to her voice as I watch the cars pass slowly on the road through the blizzard. I tell her my foot is hurting, that there's something wrong with my foot. But we talk about it normally, neither of us is worried. Afterwards I head back towards town.

I'm in his office and he tells me. Light leaves the room. And air. And sound. And time. I sit on the chair opposite but I am far away. Deep inside. Looking up through a tunnel of myself, as he speaks on past those words. "Three to four years to live." I don't hear him. Is this my life? Is he talking about me? I leave the room, the tunnel all around me, and stand before my wife in the waiting room. The colour leaves her face. Her father is beside her. They come into the room and he tells them the same thing. I don't hear him. Ruth starts to cry. Within ten minutes we are out on the street. Not knowing what to do, we do what we had planned to do before. We go to lunch. Ruth's Dad will meet us after. We walk through the streets like the survivors of some vast impact. Pale powdered ghosts.

We reach the restaurant. Dunne and Crescenzi on South Frederick Street. Our favourite. I stand into a doorway outside and call my parents. It is the worst phone call of my life. I tell them everything, fast, hearing the panic in my voice. Later, I'll thank them for coming when they arrive at our house and they'll look at me as if I'm insane and I'll become aware, for the first time, that nothing is the same. We enter the restaurant. Sit down like everyone else. We sit there, not knowing what to do, what to say. The waiter comes over and starts to speak to me. Ruth starts to cry. The place is underwater and I can't hear what he's saying. Ruth is pregnant with our third child.

We are orphans of the universe. Our species is defined by asking questions, out into the dark, without anyone to guide us except each other.

Time is a trick. From an outside vantage point we live a certain length of time, one that we measure in minutes, hours and seconds, birthdays and anniversaries. But we don't live at a vantage point to ourselves, we are immersed. We live in fits and starts and jumps, like dreams. And the lives we inhabit are measured in moments, irrespective of time. How we live is strange and uncertain and not written on any map.

In a movie, when a doctor tells a patient they have a certain time left to live, it sparks a voyage of discovery, a quest for authenticity and redemption. In *Joe Versus The Volcano*, one of my favourite, Joe Banks, when told he has a 'brain cloud' goes outside and hugs a large dog, then goes on to do what he's wanted to be doing for years: he lives his life.

I thought of him often in those first days after. How that moment I had always laughed at had become my life. What now? What do I do? And it came to me very quickly. I suddenly knew what was different between me and Joe Banks, between all the stories and my life. I was happy. I was exactly where I wanted to be, doing exactly what I wanted to be doing, with exactly who I wanted to be with. It's quite a realisation to discover beyond doubt that you're happy. And death had brought me there.

Death. On my shoulder. In my head. In the garden. At the door of my office. In every glance with my wife. My new companion: The end of my life.

We were living in the countryside, in a little cottage on the border of Monaghan and Louth, with our two little boys, Jack and Raife. We moved there so we could afford to live the life we wanted to live. I was working on my films, Ruth was writing her first novel, and the boys had a garden ten times the size of our previous house. We had a plan. And it was working. We were happy.

But that was before. This was after. Never before had I felt that split, but now a fault line had opened between our past and present, and there was no going back. Death, which before had lived on some distant horizon, was now in our living room. We were lost, within the familiar surroundings of our lives. Ruth and I cried a lot, at night, in bed.

Human time is not measured by clocks and watches. Time slows down, time speeds up, and the mystery of how we live is ever present, despite our will for it to be otherwise. Our lives are not the legacy we leave behind, or the value of the work that we do. Our lives happen in between the deeds and ideas that define us. Each of us feels it, the mystery, the strangeness of life on earth. Of life and death. We feel it when we travel, we feel when we stay at home. We feel it when a loved one dies or when a loved one is born. I'm sure we all crave more certainty than we have but that is not human life. That is the ticking of a clock.

When you are told you will die within a certain period, time slows down. Life becomes dominated by the last time. Is this the last time I will read a book to one of my boys? If not the last, how many more? How many? Everything is heightened. I stand outside in the darkness and watch my son playing in the window. I stand until the cold is in my bones and wonder is this the last time that I'll stand? I'm in my life and outside it, in the moment and self conscious of the significance of every moment.

It's lucky. In this heightened state experience is burned into my memory. I'm running after my son and I'm thinking is this the last time I'll be running? So I speed up. I'm running with a limp and so running full tilt it becomes a series of long hops and strides. But I'm running, across the grass, after my son, who is laughing uncontrollably, in the half fright ecstasy of pursuit. And I'm remembering it. Fear of the last time is recording every second. Which is lucky, because it was the last time. And when you lose something central in your life it's important to have a memory of it, so you don't feel insane, so the pain you feel has a corresponding shape, something that says definitively "That was real." Then, happy or sad about it, I have that forever.

I, and my family, were determined to prove the diagnosis wrong or find a treatment. So we pursued every thread. Every possible mimicking illness, every alternative blood test, every experimental trial. It was a long road, but it gave us hope, a focal point to lift our eyes from the life that lay in tatters all around us. Because that's the thing about your death, and the threat of your death, it's not just about you, it pulls in all your loved ones. Everybody's life had stopped.

I pursued treatment with everything I had. I wasn't going to die like this. This wasn't my life. I visited healers up and down the country, down bumpy side roads to mobile homes on breeze blocks, where the hopeful and the desperate sat outside in their cars looking out self-consciously into the drizzle, waiting for their turn to step into the musty blend of Catholicism and Mysticism, and the exchange of cash for hands that heal and a strange typed bit of paper with further instructions involving home remedies and prayer.

I did reiki three times a week with an accountant outside Drogheda who did part-time sessions out of her home. I had a second-hand convertible golf and I drove with the top down through the long roads of trees by the water three times a week. It was amazing. It was so good in fact that I found myself thinking that I would not be without these experiences, that I would not choose otherwise. I would come out after a session and the world was alive and green and full of hope. It was a start.

I read books about people who had cured themselves of cancers the size of basketballs, of how sickness was repressed emotion expressing itself on a cellular level. And in all the books the same refrain: you are the cause, you are the cure. I determined immediately that if I was in any way

causing this I must take it on. I started seeing a psychiatrist.

Old school Freudian, lying on my back, the psychiatrist sitting behind me in the half darkness with a notepad and pen. I went for it, gave it everything I had, determined to uncover any emotionally damaging activity. I mortified myself. Probed every private and emotionally embarrassing corner of my mind and spoke it aloud in the hope that it would do some good. Fear of death left me fearless of anything else. I raised the roof.

I went once a week but the going was slow. Too slow. I pushed myself to talk, to let it all out in the hope of a *Good Will Hunting* breakthrough. But it didn't work, it was good but I couldn't escape my voice. So I quit. My psychiatrist didn't take it very well. Apparently I was the first person to ever leave and she wasn't very happy. I told her that I felt it was moving too slowly, that I needed something that would work a bit quicker, I told her it wasn't her it was me. What I really wanted to say was that if I had ten years I'm sure it would work fine but I didn't.

I went to the house of a woman who did a course based on one of the books I'd read. It was a bungalow in the forest. I sat in her living room and she put a blanket over my lap. I closed my eyes, listening to the sound of her voice. Within a few minutes I am crying, then sobbing. Moments from my past crystallise before me, moments of hurt, of humiliation, of despair, and all the time her voice, pushing me to go on, go deeper. When I was a child I made myself walk into a pitch black field because I was so afraid. I went into the darkness and found a field full of stars. And so I sat on this woman's armchair and cried like a child and afterwards she gave me soup.

In the driveway as I got into my car, she stood in the doorway and said "You watch those doctor's faces now, when they do their tests and see." I had done it. I had freed myself of any damaging emotion. At reiki the following day my lady put her hands on me and said, "What did you do?" I was on fire.

The result of all this was that, emotionally and spiritually, I was about the healthiest person with Motor Neurone Disease you were ever likely to meet. But to the progression of the disease it did nothing. It progressed, did its own thing, worked on its own timeline.

I fell. I had made myself walk up and down the hall with a walker twice a day. I was fighting to stay on my feet. And one day I fell, badly. Our hall is tiled and I must have made quite a noise because Ruth came running. When I saw her face I knew it was bad. I never walked after that.

I hit rock bottom. We were trapped in our little house in the middle of nowhere and every day the house seemed to grow smaller as our despair grew larger. Ruth, the boys and I were trapped in this fog that seemed to permeate everything, to confound every effort. In the end, it was Ruth who saved us once again. Against my fears and the fears of my family, Ruth took us off to Australia. Ruth, the three boys, and me in the wheelchair.

We went for six weeks and stayed for six months. It was one of the best times of our lives and it changed everything. Two of our best friends were there who laid down their lives to make ours easier. We rented a house, with a swimming pool, and started writing full-time again, me for the film board, Ruth on her novel. We saw a psychotherapist once a week, a lovely woman who talked with you face to face, and we went to the cinema and ate a lot of good food. We were happy.

I realised that I had a simple choice, I could accept that I had MND or I could give up. I realised that I had been carrying around the burden of responsibility for having MND. That I was the cause, but through some failing of my own, I was not the cure. I had experienced firsthand the benefits of New Age therapy but like so many systems of belief, genuine origins can often turn to dogmatic pronouncements of panacea. They can condescend to the sick, who are desperate to believe that the power to be better is within their grasp. But it is an unfair responsibility. People get sick. I wish that all things happened for a reason and that all things are in my power to change, but I don't believe it. And it's an arrogance and a burden to tell someone who's sick that it's their fault if it's not.

I have Motor Neurone Disease. It is a part of who I am, evolving, influencing and living with all the other parts of me. I live with my beautiful wife and three boys. I have a ventilator to help me breathe, just as I have a wheelchair to help me move. It isn't easy living with MND. I cry a lot, for an Irishman. When I'm happy I'm happy, when I'm sad I'm sad. The greatest achievement of my life is that somehow I managed to be the person that Ruth fell in love with. That's it. And our boys save our lives every day.

People inspire me. My parents. My sisters. My friends. Professor Tim O'Brien who lives and works in Dublin, has MND, and has been living on a home ventilator for thirteen years. That's it. Nurses who are kind and gentle and sincere to a total stranger. The HSE, IMNDA and The Irish Film Board who support me. A friend of mine, Phil, visited me almost every day for the four months I was in hospital. That's inspiration.

It's now four years that I've had MND. The "three to four years to live" did not factor in the ventilator. It never does in this country. I'm past the four years and back out into the unknown, just where I want to be.

It's cold and autumn is turning into winter. The leaves move across the road bright with the sun. We visited my parents today. My mother lit the fire in the kitchen and we talked of Christmas. And for the first time since I've had MND I felt it. A fluttering, an anticipation, a dream of childhood Christmas. When we leave the sun is shining and my soul is shining like the winter sun.

Society is predicated on the idea that we all have the same wants and needs. But that's only when you reduce us to the same. What's different about us is just as important. The mystery of each of us. When we've read all the books our parents read, and missed a few, and read a few they never read, we still won't know what that person sitting opposite us on the train is thinking, feeling, remembering or dreaming. Never. Not for sure. Isn't it wonderful?

I'm sitting in a cafe. I have a pipe over my shoulder for air. The place is full of people sitting in twos and threes, talking over lunch. Two girls sit opposite me, leaning in across the table, deep in conversation. What are they talking about? I look around. What is anyone talking about in this sea of voices?

Truth does not endure. If it did, a great silence would hang over the earth. We take what we can from the past and make the rest up between us as we go along. It's wonderful. It means at any given moment, anything is possible. Ruth walks back towards our table, carrying our coffee. She is pregnant with our fourth child. And our fifth.