

# Preface

**M**any thousands, perhaps millions, around the world suffer silently with chronic fatigue syndrome. They suffer terribly from the illness itself—there is much physical pain. They also suffer great loss, forced to endure shattered hopes, plans and relationships.

Most of the time, though, they will tell you that the worst suffering, beyond all the physical hurt, comes from widespread misunderstanding of the illness and from the suspicion people have about its reality and therefore about the validity of the sufferer.

Those of us with chronic fatigue syndrome—or CFS as it is often known—hate the fact that it's 'just' a syndrome. Too often it is written off as being 'all in the mind' or 'just being tired'. Sometimes it's even judged to be a kind of lifestyle choice. If only it were that simple! CFS sufferers try to find other names for the illness, other categories, but in the end it remains 'just' a syndrome. Yet so is SIDS (Sudden Infant Death Syndrome), and so is SARS (Severe Acute Respiratory Syndrome). No one misunderstands either the tangible reality and validity of those syndromes or their devastating consequences.

In the end, CFS sufferers can seldom win out over all the misunderstandings and misguided judgments. They are forced into retreat and often into deep hurt. They are just too ill to keep beating

their heads against a brick wall. They are driven into silence, resentment, anger and sometimes depression.

All of this drives my passionate hope for this book—that in some small way it can give CFS sufferers both a voice and validity. I want to show them that they are not alone in their struggles. If my story is able to contribute anything, I hope it can be a voice of acceptance and comfort—a voice of someone who knows the reality of this illness and can communicate that reality on behalf of those whose own voices have been crushed or humiliated into silence by too many suspicions and misjudgments.

I also want to provide CFS sufferers with a resource they can pass on to doubting or puzzled family, friends, neighbours and work colleagues. All these people need to know that the suffering of CFS is more than enough on its own without other people's unsympathetic scepticism. This book is a voice urging acceptance and love, probably over the long haul. It is a voice that rages against the simplistic notion that CFS is 'all in the mind', a cop-out from life or, worst of all, a fraud.

I have two primary desires for the book. First, I want it to be of help to anyone battling CFS—or indeed, any kind of serious, long-term illness or upheaval. I confess to being a pragmatist. My aim is to provide practical insights through real-life experiences that can help make the long haul bearable.

For family and friends of those doing it tough, I offer practical suggestions, often born out of much pain and hurt, about how they can best be alongside those who suffer.

Second, I want to point to the fact that though CFS has been truly a 'wilderness experience' for me, it has never been totally dark—never without hope. Primarily, this hope has come from the way I have been resourced, encouraged and uplifted by an unshakeable faith in God. This part of my experience will not be shared by everyone who has CFS, but for me it is simply impossible to leave it out and still write a true account of all I have been through.

My journey through CFS raises honest questions, not only about why we suffer, but also about how there can be help and hope, even meaning, in the darkest days. It is a reporter's story written in the style I know best, a factual narrative based on 500,000 words of diaries I recorded through my illness. I hope you find it an honest, accessible and authentic read.

Of course, no two CFS stories will ever be the same. I don't imagine that my story or my way out of this illness is typical. There is no typical story. However, the syndrome is very real—and if my story can affirm, empower and encourage other sufferers, it will be worth the battles I have been through with this terrible illness.

*Leigh Hatcher*

# 1 CHAPTER

## Into the Wilderness

*Monday, 19 January 1998, 3.00 p.m.*

I can pinpoint the exact instant my life turned upside down. I was in the middle of a two-week holiday at one of the golden beaches that line the east coast of Australia. I have been to lots of impressive places around the world, but for me few can match the simple beauty and serenity of MacMasters Beach on the central coast of New South Wales. We were staying with my mother, who had retired there with my late father in the early '90s.

I am a man of simple needs when it comes to a holiday—surf, sun, sleep and good food. My daily routine on our beach holidays went like this: up at 6.00 a.m. for fifty laps of the tidal pool, back to the house for breakfast, back down to the beach with the family for the morning, lunch, a ten-minute nap, back to the beach for the afternoon, then dinner and more sleep. Bliss!

On this particular day, though, I woke from my ten-minute nap two hours later, feeling as if I'd been run over by a truck. I felt all the aches of a typical flu.

We pressed on with the rest of the day. That night we drove to Sydney for a friend's sixtieth birthday party and then returned to the coast. For the rest of that week I felt below par, slightly smashed

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though not ill enough to immediately rush off to the doctor. I remember starkly feeling a strong and sudden reluctance to press on with my laps of the pool or take the plunge into the clear, sparkling surf. For years I had had a love affair with lap swimming and the surf, but now the thought of any extra exertion—and especially of the cold water—seemed more than my body could handle.

I have since become convinced that your body tells you what it needs. My body was going into self-preservation mode.

We returned home from our holiday at the end of the week with me still feeling below par. It did not seem that serious, but I was clearly not well. I was surprisingly tired, achy and slightly nauseous. Facing a long weekend when medical help would be hard to get, I thought it best to see the doctor. He sent me off for some routine blood tests, saying it was probably a virus which time would simply heal.

The next morning I took a couple of our kids to a Sydney beach, though again I did not feel able to take the plunge into the surf. As I sat on the sand, my mobile phone went off. It was my doctor, rather alarmed. He said one of the blood tests had shown abnormal liver function levels and concluded that I must have come down with hepatitis. I was to rest and be very careful of any close contact with other people, especially kissing. He would order some new tests and I should not go back to work as planned the following Monday.

The further tests showed it was not hepatitis A, B or C. I seemed to have somehow come across a virus that had simply gone to my liver. The doctor ordered me to take two weeks off work and rest.



The fortnight passed quickly. By that time I was becoming a bit agitated to get on with my life again, especially my swimming.

But my body had other plans. I was still not at all well. The flu-like aches and fatigue continued, and there were often times of the day when I would become inexplicably worse. I had lived a highly

active life and loved exercise, with fifteen minutes of weight training every morning and swimming up to five kilometres each week. Now suddenly the simplest trip to the shops left me debilitated.

There was nowhere to go but back to bed. The doctor gave me another week off.

At the end of that week, our family went away for the weekend to the beach with six other families from our neighbourhood. Our four kids are Tristan, Amy, Johanna and Sophie. At the time they were sixteen, fourteen, eleven and eight. My wife Meredith and I were in the midst of a busy, demanding yet delightful time with our family. Our neighbourhood was like a big community, so the weekend was to be a great getaway for us all.

By this stage I was beginning to be optimistic that my health was starting to turn the corner. I had been tentatively trying to take on more and more activity and getting away with it—at least some of the time. We drove up on the Friday night, and I thought it was safe enough to start lifting the dietary restrictions I'd been advised to follow. Like everyone else, we stopped for a dinner of takeaway burgers on the way. Next day we had a leisurely morning down at the beach. So far so good.

Then we had a BBQ lunch—and without warning I started feeling very unwell again. Aches and fatigue began to overwhelm me. I went to bed and spent the afternoon in more physical trouble than ever. I slept and then woke with the now-familiar feeling of being run over by a truck. I slept some more and woke again feeling terrible. I spent the rest of the day like that, despairing that I had missed an enjoyable afternoon at the beach. I wasn't much fun that night either, and we ended up returning home the next day more and more frustrated that this 'thing' was not going away.

It was now one month since the original viral illness hit and two weeks since the doctor said I should be able to return to work. I was one of the front line news reporters for the Seven Television Network in Australia, and my enforced absence from my job was a

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growing frustration. I had been at Channel Seven as a reporter and newsreader for just on ten years and I loved my work. It was challenging, stimulating and varied—rewarding both personally and financially. I was highly regarded, being, among many other things, the Seven Network's Olympic correspondent right from the very early days of Sydney's bid for the 2000 Olympic Games. We were now two-and-a-half years away from the big event. It was all set to be a career highlight.

I had always prided myself on being a committed, resourceful and effective journalist. I would rather spend a day out on the road, facing the many demanding challenges of TV journalism, than sit around all day waiting for the 'big story' to hit and end up doing nothing. So after one month of being ill, I began to get the guilts. My bosses were most understanding, and since they knew my work ethic well, there was no pressure to return until I was fully well again.

I deeply appreciated their support and care, yet I became more and more agitated that I couldn't shake this 'thing' and jump back on the bandwagon of life and work.



Over the next week or so I went back to my GP a couple of times. I reported to him the symptoms I was continuing to suffer. There were aches all over my body like a bad dose of the flu (though it was clearly not the flu). Accompanying the aches were what I described as large 'crashes' at various parts of the day. They were like blood sugar crashes, as if I had done a hard day's work on little food then had to do another eight hours before eating again. When these crashes hit, there was nowhere for me to be except in bed. I was unable to pinpoint why they happened or predict when they would strike.

I noted other bewildering things about my body. One was how awful I felt when I woke in the morning. I had always been a morning person, bounding out of bed at 5.30 or 6.00 a.m., frequently

down to the pool for a two-kilometre swim. Now, most mornings I woke up feeling as if an elephant was sitting on me.

I also found that for most of the day I was growlingly hungry. This was a marked and consistent difference in the way my body had always operated. Yet although I was exercising less and eating more, I was quite dramatically losing weight. I'd always had to work hard to keep my weight down; now it was falling off.

In addition, for some reason I was really struggling to handle stressful situations as well as I used to. It was only the usual argy-bargy of family life. But after a career of facing down impossibly stressful, sometimes life-threatening situations, I would blow up at my family as never before.

All of this I faithfully reported to my increasingly puzzled doctor. I explained that despite these baffling and draining symptoms, each morning I determinedly got out of bed, went for a walk (more like a shuffle) around the block, and tried to get on with the day. He sent me off for new tests.

They all came back 'normal', but normal was the last thing I was feeling.

Unable to take it any further, my GP referred me to a liver specialist, who ordered still more tests. They too came back normal. He ended up labelling me 'mystery man' and became clearly frustrated with my lack of progress. In one phone call he expressed a surprising level of agitation. 'Well, I've done everything I can for you and have sent you off for every test I can think of,' he said. 'The only other test I could order is an AIDS test.'

I felt sharply accused of being less than frank with him, to the extent I could be hiding AIDS. I was shocked at his accusatory tone, as if it were up to me to get better myself.



By now I had been off work for two months. I had never experienced anything like this. I continued to feel acutely guilty, though



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still my news director extended to me the most generous and gracious consideration. Fortunately, a good and long-standing friend, Dr John D'Arcy, a general practitioner and the medical reporter on our news team, began to visit me at home. He could clearly see how ill I was and urged me only to return to work when I could.

Notwithstanding all this, I decided that my best way forward was to see if I could push my body back into real life again. Perhaps it needed a kick-start. After eight weeks away I negotiated a partial return to the newsroom on half days.

It was great to be back among colleagues and good to be seen on the television again, though I still looked pretty ill. Initially I was frustrated that more often than not I was assigned to be 'on the bench', waiting for the big story that frequently did not eventuate. I felt they were being too protective. I'm sure our medical reporter had a lot to do with that.

My wife's birthday, 10 April, raised new alarm bells. We had her family over to lunch and didn't eat until 2.00 p.m. As we waited and waited, I started to spiral into one of my crashes. But it was unlike any I had experienced before. Accompanying the crash was a mounting rage about the lateness of lunch. This was all too much and something entirely outside my experience and control.

When I finally gobbled down the meal, the spiral continued. I had to excuse myself and head to bed, where I wasted the rest of the afternoon in a great deal of physical trouble. My whole body felt toxic. Each time I woke I seemed to emerge into a half-conscious daze only to sink back into sleep again. Sadly for Meredith, it was not a very happy birthday.

After attempting a number of half days at work, I decided to try a full day. It was an enjoyable shoot at a lakeside resort for a leisure and lifestyle show put together by the newsroom. Blessedly, I had a producer working with me organising all the logistics and components of the story, because for much of the shoot I lay in the car

feeling like I was dying. Such pain all over my body. I would sleep, do an interview, sleep some more, do some on-camera work and then go back for more sleep.

This was an all-too-familiar scenario from my days at home, but now I was frustrated and angry that it was on show before my work colleagues. It seemed as if my time-honoured work ethic had been completely overrun by this lingering illness that kept on throwing up 'normal' test results. I returned home that day physically devastated, and yet again went straight to bed.



Part of my daily routine for nearly a decade had been a brisk walk to work. We lived just two kilometres from Channel Seven Sydney. The day after our leisure shoot, I decided to resume my walks to work. I was fiercely determined that this 'thing' would not get the better of me.

Again I woke feeling awful but pressed on to work regardless. I lasted one hour. Once again I felt that dreadful toxic feeling, as if something poisonous was running through my blood stream. I thought I had become good at hiding it but it must have been evident in my physical appearance. The news director took one look at me and ordered me into a camera crew car to be taken straight home.

At last I was forced to run up the white flag and accept that still, some three months after contracting my original virus, I was not well. Despite the best will in the world, I kept on crashing, so debilitated. And I had no idea why.

Neither did I know that all this was just the beginning, and that stretching out in front of me was the hardest journey I had ever had to undertake. In fact, I had entered a wilderness. It would be a long time before I would be able to emerge again.