EVERYTHING
BEAUTIFUL IN ITS TIME

Catherine Ashenfelter

Published in paperback form in 2013 by YouByYou Books.

Front cover picture*: New Life* (detail)
© Catherine Ashenfelter

Back cover photograph taken on New Year's Eve, 1997
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Photomontage of three wheelchair pictures in Hyde Park
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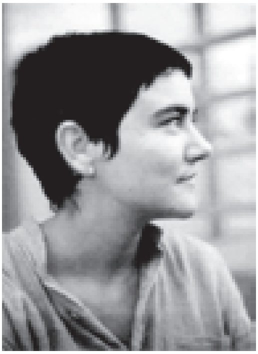
THIS BOOK IS DEDICATED TO ALL THOSE WHO HAVE DIED FROM M.E. AND TO THOSE FOR WHOM THE ILLNESS FEELS LIKE A LIVING DEATH.

MAY THEIR SUFFERING NEVER BE IN VAIN BUT ALWAYS A REMINDER TO STRIVE FOR THE TRUTH OF THIS DEVASTATING ILLNESS.



Sophia Mirza
1973-2005

Lynn Gilderdale
1977-2008

Although I never met either of these young women, both from East Sussex, they (along with other sufferers) were often in my heart and mind as I wrote this book.

Acknowledgements

There are many people I'd like to acknowledge for helping me over the years, but I wish to acknowledge the following in particular:

MY PARENTS AND FAMILY
For believing that I suffered from
a genuine physical disease

MY GP
For her care and support during my years of severe M.E.

THE WYE AND BROOK
HEALING PRAYER GROUP
A local group who prayed for my healing
for 20 years

But above all, I wish to acknowledge
MY HUSBAND, JOHN
For his admirable loyalty and commitment
through many difficult times.

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Introduction

‘All truth passes through three stages.
First, it is ridiculed.
Second, it is violently opposed.
Third, it is accepted as being self-evident.’ (1)

In July 2003, the door of Sophia Mirza’s Brighton flat was smashed down by East Sussex Police, followed by her being forcibly removed from her bed and taken to a locked room within a secure ward of a mental hospital. Sophia suffered from severe M.E. (Myalgic Encephalomyelitis) and the horrific occurrence took place in front of Sophia’s devoted mother, a former nurse, who’d moved in with her daughter to offer twenty-four hour care. The sectioning had been ordered by a psychiatrist (who was recommended by Sophia’s GP) and a Social Worker.

Following a lengthy tribunal, Sophia was released from the mental hospital after two weeks, during which time her health had deteriorated even further. Tragically, in November 2005, Sophia died from M.E. The cause of death at a subsequent Inquest was attributed to C.F.S. (Chronic Fatigue Syndrome) (2), where it came to light that her spine had been 75% inflamed (3). Sophia did not have a mental illness.

This is one of many heart-rendering, woefully unjust events which have happened to those who’ve fallen victim to the illness of M.E; events which are nothing less than crimes to humanity.

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1. Arthur Schopenhauer, German philosopher (1788-1860).
2. Chronic Fatigue Syndrome, in this case, meant the same illness as M.E. This is not always the case, though.
3. *www.sophiaandme.org.uk*

Why are M.E. sufferers often victimised?

Despite over 2,000 medical papers since the 1950s (4) showing that M.E. is an organic, not a psychiatric disorder, there are still medical text books placing M.E. wrongly in the psychology section. This is often done on purpose by the books' medical advisors, rarely due to any ignorance. Medical students are being brainwashed into believing that M.E. is a behavioural disorder: that if only the patients could change their way of thinking then their symptoms would just disappear.

At the time of writing this introduction in 2010, I feel we've got onto the second line of Schopenhauer's quote, of M.E. being 'violently opposed'. This is because those who are gaining from the lies are getting scared. More and more physical abnormalities are being discovered all the time and things are getting closer towards a diagnostic test for M.E., when a test will show indisputably if someone has M.E. or not. Meanwhile, the 'enemy camp' are now infiltrating the general public by placing misinformation about M.E., for example in the guise of glossy paperback books, alongside birthday cards and Harry Potter stickers in mainstream shops.

Who is this enemy camp? Are they some kind of sadistic medical student with extra hair growth on their claw-like hands, howling by the light of a full moon as each book of lies gets printed?

Well, who knows what they might get up to in their spare time but the enemy camp are more likely to be a picture of success, dressed in a suit and tie if male and a tweed Laura Clement suit with sensible shoes if female.

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4. Quote from Professor Anthony Komaroff, Professor of Medicine, Harvard University, USA, regarding international papers on M.E. from 1955-2005. See the paper *The Group On Scientific Research Into Myalgic Encephalomyelitis (The Gibson Parliamentary Inquiry)* Hooper/Marshall/Williams Dec.2005, p6. *www.meactionuk.org.uk*

They are the kind your parents would be delighted for you to marry, with such a long string of letters after their names that you'd be in danger of tripping over them.

The enemy camp consists of elements of corporate industry, e.g. certain people working for chemical, pharmaceutical and medical insurance companies; their pushers consist of certain doctors, nurses and members of government.

What is it they're after? Most likely, they're after money, dosh, filthy lucre, either to make it or to save it. Money can be saved by not handing out insurance claims and state benefits; also, by avoiding being sued if you're a chemical company by denying a link with chemically-induced M.E. (such a link has been proven scientifically). (5)

Drug companies can make money from over-emphasising the word 'fatigue', whilst neglecting other M.E. symptoms; consequently, anti-depressants for fatigue can be prescribed inappropriately.

What is M.E? What is C.F.S.?

M.E. is a neurological disease and stands for Myalgic Encephalomyelitis. It is an injury to the Central Nervous System, usually triggered by an infectious disease, e.g. a virus, or by chemicals overstimulating the immune system. It is a multi-system disease (6), affecting not only the neurological system but also the immune, endocrine, musculo-skeletal and cardiovascular systems.

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5. Vojdani A, Lapp CW. *Immunopharmacol Immunotoxicol* 1999:21: (2): 175-202.

6. *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document* by Bruce M. Carruthers and Marjorie Van de Sande, p2, published by Carruthers and van de Sande ISBN: 0-9739334-0-X Copyright © 2005.

C.F.S. was a name created in the 1980s with almost exclusive emphasis on the word ‘fatigue’, leaving out much pathology and previous physical M.E. research findings.

C.F.S. may or may not mean the same disease as M.E. This is because there are currently at least 10 different interpretative criteria for C.F.S., some with an immune and others with a psychiatric specification. If the criteria used for C.F.S. involves damage to the Central Nervous System, then it could well be M.E. If the criteria used focuses mainly on psychiatric fatigue, then this is not M.E.

Are there any treatments for M.E?

There is no medical ‘cure’ as of yet for M.E. but there are tried and tested treatments that may be useful, certainly at the beginning of the illness. Various types of Essential Fatty Acids (especially VegEPA), magnesium, Co-Enzyme Q10 may be of some help. Antiviral treatment is probably the way ahead, medically, for M.E. Some useful further reading for medical treatments is at the end of the introduction.

A Diagnostic Test for M.E.

The obvious answer to help sufferers is by developing a diagnostic test for M.E. (proving if someone has the illness or not). We are close to diagnostic tests (Kerr’s work with gene expression, Myhill’s work with mitochondria, i.e. energy supply to muscles, urine tests in De Meirleir’s work to measure abnormalities in the immune system). Indeed, some may say that diagnostic tests for M.E. have been around for a long time. Canadian doctor Byron Hyde is convinced that SPECT scans give a strong indication if a person has M.E. or not. This work has been confirmed by both Schwartz and by De Costa. All these tests have been funded privately, not by the State.

The Government's research body, the Medical Research Council, has a custom of ignoring biomedical projects presented to them by researchers, favouring lifestyle management and psychosocial research for M.E. instead (which isn't proper science).

The National Institute for Clinical Excellence (NICE) is the Government's Drug Advisory Board. Currently, it mainly recommends C.B.T. and Graded Exercise for M.E. sufferers; these are therapies which can make sufferers much worse. It's difficult at the moment to get any other M.E. treatment on the NHS, unless your doctor is brave enough to battle with NICE.

Many interest groups don't want a diagnostic test for M.E. because then the illness will exist big-time and cause their monetary dominions to tumble down.

The International Scene

The attitude to M.E. seems to be pretty similar throughout the world, unfortunately. Wherever there are medical insurance companies or a National Health Service, the scientific evidence seems to be ignored. Canada appears to be more open than most other countries to the illness, possibly because doctors have more freedom to practise there. In the States, a centre for Neuro-Immune disorders which includes M.E., opened in Nevada (the Whittemore Peterson Centre) in 2010. There is much hope in this centre, whose researchers have helped to discover the XMRV virus link with M.E. A similar biomedical centre for M.E. is hoping to be built in Norfolk, UK, from funding raised by Invest in M.E. (Sadly, the XMRV virus link has received very bad medical press since the writing of this introduction.

Medical ‘opinion’ has now largely dismissed a link of XMRV with M.E.)

How an M.E. sufferer and their carer feels

Just imagine the following scene: a terrible illness, which can potentially affect any system of the body, where each second is a battle to survive; where life is stiflingly lonely from inability to work or socialise properly; where you’re lucky if your GP even believes in your illness and if they do, his/her hands will be tied as to what to prescribe on the NHS. (Some GPs won’t support a sufferer’s entitlement to benefits unless they take part in the ‘recommended’ Graded Exercise and C.B.T. which make many M.E. sufferers worse.) (7)

A patient can despair, not just from the illness but also from the sarcasm and mockery about M.E. which pops up on the radio, TV and in general reading material, let alone in medical lectures. Families are under unimaginable strain, relationships crack up and break down, all fuelled by the misinformation machine.

Meanwhile, the sufferer wonders how they can even survive each day whilst racked with pain, paralysis, difficulties speaking, all in a quiet, darkened room away from noise and light. Hope in human nature may be lost. The sufferer will wonder if their carer will leave them and the carer will wonder how on earth they themselves can keep going.

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7. It is illegal for the Benefits Agency to stop financial benefits when an M.E. sufferer refuses to participate in Graded Exercise or CBT. See the Grace Charity for M.E.’s document, *Saying No Can Be Positive, www.thegracecharityforme.org,* under Documents.

The Hope

In order to breathe, one must have oxygen; similarly, in order to survive, one must have hope. What real hope is there for the desperate sufferer and overwhelmed carer?

Scientifically, there is much hope. Research has shown M.E. to be indisputably a physical disease with real pathology; these findings have been around for decades with more and more physical discoveries all the time. The challenge remains to get this research out to all concerned.

Legally, hope lies with those willing to make just judgements for the oppressed.

Politically, hope lies with those willing to highlight the injustice faced by M.E. sufferers.

Hope also lies in M.E. being accepted as a neurological disease (8), in the same way as Multiple Sclerosis was eventually accepted as neurological. Previously, Multiple Sclerosis had been viewed as hysteria in medical circles – wrongly, of course.

Spiritually and perhaps ultimately, hope lies in God. He is described as a **God of hope** (9). Personally I've learnt over the years to ask Him to give me His hope, a quality which is intrinsic to His character, when no other hope can be found. He has always done this without fail because He is true to His promises.

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8. Lord Brain included M.E. as a neurological disease in his book *Diseases of the Nervous System*, Sixth Edition, Oxford University Press, 1962. His book appears to have been ignored in medical education. The World Health Organisation has listed M.E. as a neurological disease since 1969.

9. Romans 15 v.13.

Sophia Mirza, the young lady mentioned at the start of this introduction, whispered to her mother that she didn't want her life to be in vain, requesting that her mother made her story publicly known.

"Years ago I had nursed patients with all sorts of disease; never had I seen anyone so profoundly ill, in so many diverse ways as Sophia," said Criona, Sophia's mother (10).

Sophia, Lynn (11) and all those affected, we will do what we can for the truth of M.E., with the help of God.

Further Reading

The Political Scene for M.E.

Various papers regarding how M.E. is influenced by politics of Government, psychiatrists, pharmaceutical companies and private medical insurance can be found at *www.meactionuk.org.uk* Papers such as:

Denigration by Design by Margaret Williams. This is an evaluation of the work by psychiatrist Professor Simon Wessely and the 'Wessely School', who have written inaccuracies about M.E. (to put it mildly) by disregarding much of the biomedical evidence. Instead they promote a 'somatoform disorder theory' (when physical symptoms are caused by a mental disorder). The views of the 'Wessely School' have a tendency to both trivialise and patronise M.E. patients.

Corporate Collusion by Hooper, Marshall and Williams

Magical Medicine: how to make a disease disappear by Professor Malcolm Hooper.

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10. See Footnote 3, p7.

11. The story of Lynn Gilderdale (whose photo is at the front on the dedications page) can be read from the book *One Last Goodbye* published by Ebury Press 2011. It is written by Lynn's mother, Kay Gilderdale.

What is ME? What is CFS? by Hooper, Marshall and Williams.
Skewed by Martin Walker, published by Slingshot Publications, 2003.

M.E. Research

Here is a selection of research contacts:

1) The Nightingale Research Foundation based in Ontario, Canada. This was founded by Dr. Byron Hyde.
www.nightingale.ca
121 Iona Street, Ottawa, Ontario, Canada K1Y 3M1.
There are several M.E. related research papers here; also, a wonderful book (724 pages long), entitled *The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*, by Dr. Byron Hyde, ISBN 0-9695662-0-4, is sold from here and is a real gem to have.

2) M.E. Research UK (MERUK) funds biomedical research into M.E.
www.meresearch.org.uk
The Gateway, North Methven Street, Perth PH1 5PP.

3) A Hummingbirds Guide to Myalgic Encephalomyelitis.
www.ahummingbirdsguide.com
This highly informative website is vital for all M.E. sufferers to access. Set up by severe M.E. sufferer Jodie Bassett in Australia, it has research papers as well as other important information.

Medical Treatments

My personal belief is that firstly, all sickness should be prayed for. Sometimes God can also lead us to other methods.

The Grace Charity for M.E. has some treatment advice from a survey which was carried out (*www.thegracecharityforme.org*). Look under survey. In addition, a Hummingbirds Guide to M.E. (*www.ahummingbirdsguide.com*) has much information about possible treatment.

Some tried and tested M.E. treatments are Essential Fatty Acids (especially VegEPA), Co-Enzyme Q10 (an enzyme for cognitive function) and Acetyl L-Carnitine (an amino acid for muscle function). Some sufferers find magnesium and Vitamin B12 helpful. (Too much magnesium can cause diarrhoea.) Please be aware that these treatments might not help every sufferer.

Most of these treatments can be found in Health Food shops or online. Your GP might be willing to prescribe one or two of them.

VegEPA can be purchased via emailing: *home@thevegepaformescheme.com*.

‘I will remember the deeds of the LORD;

Yes, I will remember your miracles of long ago.

I will meditate on all your works

And consider all your mighty deeds.’

Psalm 77 v11-12

PART ONE: THE ONSET

1. *Wuthering Heights*

It was Thursday, on a mild, wet November evening. Our usual coal fire with its soporific effect wasn't even lit, making the brass fireguard nearby superfluous.

For teenagers who loved pop music, Thursday night meant only one thing – *Top of the Pops*. Within moments, our cosy sitting room transformed into a stage of lip-synching and dance routines, encircled by jeers or cheers which greeted the oncoming bands. The panel of judges consisted of me, my two brothers and sister whose long, chestnut hair shaped her artistic face just like the '70s chick who appeared next on the TV screen.

None of us were sure whether to jeer or cheer at this new solo act. It was both avant-garde and impressive but it was also plain weird.

My mother though, had already cast her judgement from the kitchen whilst stirring a mixture of the Christmas cake in a Victorian china bowl, a Yorkshire family heirloom.

"Will you please turn that shrieking woman off the television?" she halloed in disdain.

But I was transfixed by the woman in white, the swirling, tiny figure of Kate Bush. Perhaps the name Cathy caught my attention, a diminutive of my own, although I only like my name in full. Or perhaps it was the Yorkshire connection as she sang about the whining, windy moors where we'd spent holidays driving through the deep purple heather. Whatever the reason for my fascination, I will always associate *Wuthering Heights* with the good health I experienced just before that Christmas.

"Anyone want to make a wish?" Mum called out again, breaking my dream-like state.

Tradition was strong in my family, including the custom for us to make a wish as we took turns stirring the Christmas cake. But we were all getting a bit old by then. Only two of us were still teenagers. My brother Paul was 17 and I'd recently celebrated my 14th birthday. My older brother Graham was 21 and my sister Rosemary had just turned 24.

"Mum, aren't we a bit old to make a wish?" I called.

But the heavenly aroma of mixed spice, cinnamon and lemon juice from the kitchen persuaded me to keep up with tradition after all. Looking into the green and white bowl, cracked from overtime and overuse, I contemplated on how the ingredients would taste horrible on their own yet when blended together would taste delicious.

As I held the wooden spoon in my hands, forming large circles with it in the mixture, I couldn't think of a single wish to make.

"I'm so happy," I remember thinking, "there's nothing I want." (Although the thought of going out with the paperboy in our village flashed through my mind as possibly something to wish for.)

An altruistic conviction got the better of me with a wish that all the starving children in the world would be fed and all the wars would end. Then I turned away eagerly to finish my Kate Bush imitation.

A couple of weeks after my wish, 'it' entered my life. 'It' was an unnamed curse that forcefully destroyed my halcyon youth out of the blue. To describe its entrance as an unwelcome guest would be too kind: a destructive thief would be a better portrayal. But it didn't steal objects such as silver and gold, rather it stole my vitality and hopes for the future.

As I opened my eyes one frosty December morning, things appeared differently to look at or even to listen to. Everything seemed distant, even my mother's voice as she called into my bedroom because I was late for school.

"Catherine, it's quarter past eight – you'll miss the bus!"

She might as well have said, "We're moving to Australia today!" because words suddenly didn't make much sense to me.

I continued lying on my bed, paralysed by deep exhaustion. Each time I moved my limbs they felt heavy and painful. The glorious light that winter morning poured through my bedroom window, but hurt my eyes so much that Mum pulled the curtains.

"What on earth is wrong with me?" I fretted. "This is worse than flu!"

The suddenness of it all was the shocking thing: I'd been off my food a bit that week and cancelled my piano lesson, but essentially I'd been fine until that day, 2nd December 1977.

The days soon blurred into weeks, then into months. Girls from my school sent me a huge 'Get Well' card but I couldn't put faces to their names. My memory had been affected. All my body wanted to do was sleep.

"Maybe she's got sleeping sickness," neighbours joked with my parents, trying to lighten the strain.

They could have been right, although there was no sign of tsetse flies hovering over my head.

"If you don't mind, I really must go to sleep," I yawned to well-meaning visitors.

So I did. In the stillness of my bedroom, surrounded by the stillness of my beloved hills and fields, I slept almost solidly for three months. Even Kate Bush's shrill voice would have drifted over me like a lullaby.

2. *Fields of Gold*

The fields surrounding my bedroom weren’t the fields of Yorkshire but of east Kent. We’d moved there before I was born, making me the only family member never to have lived in the North. My mother often wondered why she’d left her cherished homeland of dales and moors.

“No-one down here has a good laugh like we do up North,” she often repeated in her articulate voice, which seemed out of place from the stronger Yorkshire accents of her relatives.

But as she surveyed the Kentish countryside it didn’t take long for her doubts to be dispersed. The view around our house was breathtaking. The towering hills enclosed us like a protection, guarding our tiny village of Brook that fitted snugly inside a valley. It was named after a brook which trickled through the length of the village, flowing right outside our house. The fields were fallow now, but at the height of summer they’d be a long, golden carpet of wheat and barley.

The countryside was an extension of home, as important as the roof over our heads. Summer bike rides were the norm as we’d line up one after the other along the leafy roads. Dad spent hours each weekend working in the garden, making it look like a National Trust landscape. On one occasion though, he was upset when some shrubs he’d planted were all shrivelled up from sprays blown in from the neighbouring field. Environmental chemicals were often lurking around us from sheep dipping and crop spraying. Perhaps these were the causes of mysterious illnesses that hit several people from our village? (12)

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12. There have been many anecdotal reports linking environmental chemicals with the onset of M.E. Scientifically, links have been made with organophosphate chemicals and M.E. symptoms. See *Perspectives* magazine, Autumn 1992, p17, The M.E. Association.

Besides the chocolate box picture, there was also a spiritual side to our surroundings. You could easily get lost in the wooded hills, so it was advantageous to get to know the windy footpaths like a native Sioux at one with Nature. The Tolkienesque feel continued at night when vixens screeched their harrowing cries and bats swooped down low. A couple of wild cat sightings were reported, once in the fields and another in the chalk-face hilltops, although no-one reported seeing the devil, said to dance at night around a nearby prickly bush.

It was easy to believe in God as I was surrounded by His creation. The sunset was His way of saying ‘Good-night’ and the sunrise His greeting for a new day. God was almost tangible for me and I felt His presence very strongly from the natural beauty. My parents felt the same, with Mum saying her prayers whilst walking up the fields and Dad saying his whilst digging the garden (or sitting on the toilet, as he once told my friends).

The village church, like the countryside, also had an edifying appeal. The Norman structure housed a collection of medieval wall paintings, their sepia-stained silhouettes clearly telling the Gospel story afresh over the centuries. My family had so much to do with the church that I thought wrongly as a child that my father was the vicar, and couldn’t weigh that up with his full-time job in London. He sang in the choir and led the Sunday School along with my sister; she was also the church organist. Mum polished the pews and floor tiles devotedly.

My father always struck me as being enigmatic, his sensitive and philosophical outlook at odds with his hectic financial career. He rarely seemed to enjoy his work, seeking tranquillity from the garden, church music and marathon running. But his greatest fulfilment came from working with Mother Teresa’s order, The Missionaries of Charity. We weren’t Catholic, but Dad’s link with Calcutta stemmed back to when he was 19 and led a Yorkshire platoon into the bloody Calcutta riots, Muslim versus Hindu. Perhaps the later charity work helped to heal that traumatic time in his life. It seemed incongruous to me that Dad was ever in the army when he was a tender-hearted man.

Mum's world revolved around her children as taxi-driver, counsellor and chef. Her enjoyment of meeting people made many a lonely soul feel wanted from her genuine hospitality, as Asian, African and Oriental passed through our door. We often joked that our sitting room became the centre for United Nations as we welcomed in foreign students from nearby Wye College.

She was frequently burdened with worry about things generally though, but this was probably out of love for those dearest to her. There's a fine line between worry and care. "Stop worrying, love," my Dad often told her. But her concern for me was now justified as I lay like a zombie in bed.

It's true that it takes love to make a home. And now at 14, being struck down violently by illness, my mother's love was evident with her gentle bedside manner which hardly left my side. She and my sister attempted to rouse me from my near comatose state, bringing me meals that I ate laboriously.

Would life ever be normal for me again? Would I walk up the fields of gold when summer rolled around? Would I play my coveted Wing Attack position again in hockey or netball? But it hurt too much to think: even following the plot of a Tom and Jerry cartoon hurt my head.

My energy was sapped just from staggering to the toilet, which was positioned only next door to my bedroom. This was followed by collapsing on the bed to recover from the short walk. Occasionally I'd endeavour to come downstairs where everyone had to clear off the sofa for me to lie down, but moving around made my headaches worse which made things more difficult for the family to endure.

“Spring will make all the difference!” a neighbour commented misguidedly.

It didn’t make all the difference, but as the daffodils and primrose clusters dotted the banks of the brook, Spring did correspond with some improvement for me. Essentially, though, my body was now in the aftermath of a storm.

My maternal grandmother, out of fun, once taught me to read the future from hand palms. I’m relieved that my clairvoyant talents were limited, as my biological aftermath from the storm was to last nearly 20 years.

3. *Identity Crisis*

As teenagers evolve from cuddly puppies into whinging whippets, their identity swings between adult surges and childlike urges. Tough decisions need to be made, such as choosing to love or hate Punk Rock and wearing either baggy trousers or straight cords. I knew quickly the kinds of things I liked: the New Wave music of Blondie won hands down over the sugary tones of Abba and I wouldn't be seen dead in a pair of baggies. The Sex Pistols though, were too radical for even a girl like me. Calling the Sex Pistols musicians in the first place ignited a similar social debate from decades before about whether Duchamp's 'Urinal' was really art or not.

It was my brother Paul who first introduced me to Blondie, their LPs spread out proudly across his bedroom. My older brother Graham was more into rock, such as Status Quo. Normally I didn't mind the clash of music drifting from their rooms but as I emerged from my three-month stupor, my brothers had to turn down their music for me and even turn it off altogether. I couldn't cope with loud sounds.

Three months of illness rolled into eight months since first watching Kate Bush scream on television. Spring turned into Summer, with fields of golden wheat and barley encircling our home. Then one afternoon my mother ran over to me on the sofa, full of excitement.

"They've found out what's wrong with you! You've a virus called ECHO 2. The GP's just phoned – he's elated!"

The news was meaningless to me, especially as none of us had heard of ECHO 2 before and thought it sounded more like a brand of cooking margarine. (Mum and I had spent months at the doctor's surgery, my head on her shoulder from tiredness, whilst enough blood tests were taken to satisfy Dracula's quench forever. It had paid off. The Royal Free Hospital in London had found the virus in one of the samples.)

Any elation plummeted though on being informed that viruses are untreatable. So I was packed off again to more waiting rooms, with Mum literally propping me up, this time to the local hospital in the hope that something could be done to help.

Here I was seen by a podgy-faced registrar who droned on and on about my weight. (I had put on a stone since being ill because I was no longer rushing around playing hockey and netball.)

“Do you just eat and eat all day long?” he jeered.

His comment was a bit of a cheek as he was hardly Twiggy himself. Something else was also scribbled down about me possibly being school-phobic.

My GP, who had initially been supportive, was growing impatient over my lack of recovery.

“Catherine really should have got over this virus by now,” he commented one day to Mum. Then he started approaching it from a different angle. “Do you argue a lot as a family? Or perhaps Catherine’s in some kind of meditative trance?”

School phobia, weight problems, family arguments and trances – these were all guesses without scientific causes. Guesses to disguise the honest answer of, “We don’t know”.

Meanwhile, the golden fields turned fallow; another Christmas came and went and the cheery daffodils bravely raised their heads in the cold March winds.

“I’m not having this!” bellowed Dad’s deep voice one Spring weekend, after he’d watched me lie down from attempts to whisk an egg white into a meringue mix. The effort of doing so meant that strength had gone out from my right arm and had left me so exhausted that I couldn’t talk.

“We’ll get Catherine seen privately by a top man in

London,” he concluded with Mum as he made himself a jam sandwich, his favourite snack.

So, not long afterwards we were off to see The Top Man. High hopes were with us as my parents and I piled into a London taxi, dropping us off somewhere near Harley Street. We entered an elegant terraced building where the three of us sat nervously in a line, silenced by the loud ticktock of a creaky grandfather clock. The Top Man called me into his room where I sat all alone, just him and me. The room wasn’t huge but it seemed vast as my vulnerability was accentuated by his authority. After a few moments he asked me to undress, taking off everything except for my pants. There was no nurse present. At 15, this was the most I’d ever shown a man of my pubescent body. I closed my eyes when he pulled back the screen and gazed lewdly at me.

The examination proceeded uneventfully. Once re-dressed, he asked me a string of questions. Although he was a neurologist, the questions were aimed at my personality. “Do you ever think you’re somebody else, like Napoleon Bonaparte or the Pope?”

The strangeness of the question triggered my sense of humour but I resisted the temptation to respond jokingly, “Yes, bless you my son!” or sing the French National Anthem.

His verdict was that more tests needed to be done at Maida Vale Hospital for Nervous Diseases. Nervous diseases? Would that mean row after row of patients twitching nervously in their hospital beds?

My parents and I had a few days in which to go back home, pack a suitcase and return to London. On the next trip all my family came up and I was stretched out on the back seat of the car, lying like a corpse over the laps of my Mum, Rosemary and Paul.

Surely the hospital would be able to help me with such a lengthy stay in store?

To my relief, the patients seemed normal when I was led to an all female ward, their ages varying greatly. In the bed to my right was Sudha, a young Nepalese girl and to my left was Margaret in her forties.

“You look disgustingly healthy to be in hospital – just look at your red cheeks!” Margaret teased me.

“That’s all I need,” I thought, “for the patients to not even believe I’m ill!”

Unfortunately, the ward atmosphere was generally strained with patients having little to say to one another. I soon found out why – most had some kind of chronic illness. Margaret was diagnosed with Multiple Sclerosis a few days after my arrival and her sobs floated through the drawn curtains on telling her relatives.

One highlight of my stay was Sudha – she was so inspirational. Sudha would sit in her wheelchair at the top of the ward, staring down its entire length towards the door, waiting for a visit from her husband who ran a Nepalese restaurant. His daily visits fed her hope. Her long, silky black hair which was often in a plait, made her a good portrait study and when I felt up to it I liked drawing her. Art was something I could still do, whereas reading and writing were difficult. One day, Sudha took out a treasured photo from her handbag: it was a picture of her wedding day, but in the photo she was standing up. Some kind of illness had struck her not long after the wedding, leaving her legs paralysed.

A second highlight was the registrar. He wasn’t sarcastic and podgy-faced like the one I had before, but charming and handsome. He often sat on my bed flicking through my art sketch pad, always declining my offer of fruit. “You’re very sweet, dearie,” he’d respond over the grapes and bananas.

I was quick to trust him, not just personally but also professionally, because he seemed to believe my illness was genuine.

But after 10 days of tests, nothing conclusive was found.

One morning, The Top Man strode over to my bed, surrounded by nervous medical students and proceeded to tell me in complex terms that all my tests were normal. “We can’t find anything wrong with you,” he said, raising his voice as if I’d wasted his time. “Although there is one avenue we haven’t explored yet – psychiatry!”

My heart sank.

“I’m not loony you know,” I found myself responding in self-defence, turning to my nice registrar in the hope that he would back me up. But he didn’t.

“Just think of it as another test,” he said, his manner unusually cold.

There was no mention of the virus which had started all my problems in the first place. They seemed to think the virus was past history and my current symptoms were something new.

That night I didn’t sleep well, feeling let down by my registrar.

“So long as the psychiatrist doesn’t ask me if I’m someone else again, like Idi Amin or Mahatma Gandhi!” I sighed apprehensively.

* * *

“Catherine Turner, come this way!” a woman’s voice boomed down the waiting room of another North London hospital the following day.

“A woman psychiatrist? Brilliant!” I muttered under my breath. “Perhaps she’ll be extra nice to me!”

My parents sat outside her office, waiting to drive me back home to Kent. They watched over my suitcase which had a teddy bear sitting on top. It looked rather comical in the stark surroundings.

The psychiatrist barely looked up as I took my place opposite her, firing question after question at me in rapid succession.

"Are you worried about anything in life?" she started, her head buried in paperwork.

Nothing of significance did worry me back then, but I still searched long and hard for an impressive answer.

"Well, I suppose I'm rather concerned about the Revolution in Iran right now," came my reply, anxious if that was the 'right' answer or not.

Then I cringed, wondering if she'd ask me if I was the Ayatollah Khomeini! The look on her face showed it wasn't the 'right' answer after all.

"I was envisaging something closer to home, like your family or school. Anything there?"

"No, not really."

"And a career… What do you want to do?" she continued, drawing no breath.

"Well, if I get better, I'd like to be a missionary."

"A *missionary*?" she roared, snarling at my suggestion. "What an odd career choice for a 15-year-old!" and she proceeded to write reems of notes with such enthusiasm, the likes of which I'd never seen before, her head bobbing up and down furiously like a moorhen. (My family had contacts with missionaries from Dad's time in Nigeria. He'd worked out there when it had been a British colony, taking the family with him, except for me as I hadn't been born then. The missionaries they met seemed focused on a worthwhile job and the idea appealed to me.)

"This interview isn't going very well," I thought.

That was an understatement, especially as it proceeded from bad to worse.

"In the waiting room I noticed you had a teddy bear," she continued. "Aren't you a bit old for cuddly toys?"

This question, like others, baffled me and I was unsure how to answer. “Well, my Mum still keeps her fluffy lamb from when she was little – it sits on top of her wardrobe. Dad still has his toy chicken from when he was a boy, although it’s only got one eye.”

Next, my parents were summoned in. I thought she was going to put the lot of us into group family therapy.

“Catherine has acute anxiety problems which are manifested by her physical symptoms – conversion hysteria, we call it. I want her here for treatment, an extensive stay, where she’ll do lots of swimming.”

“But she can barely walk,” interjected my worried parents.

“She’ll swim each day, with the lengths gradually increased – graded exercise. Believe me, it’s the only way to get this anxiety out of her system!”

But the only thing making me anxious was the psychiatrist! On leaving the hospital, I half expected to see men in white coats admitting me to the nearest lunatic asylum, handcuffing my teddy bear and locking it in a cell next to me.

The medical truth was that I had M.E., Myalgic Encephalomyelitis, a neurological disease mainly affecting the Central Nervous System. It’s a condition frequently triggered by viruses and has been scientifically documented since the 1930s. Unfortunately for the sufferers, doctors tend to be woefully uneducated about the condition, with virtually no tests available on the NHS to confirm its presence.

But I wasn’t diagnosed with M.E. for a further decade, causing a cloud of uncertainty to rain on us.

We, as a family, decided not to do the psychiatrist’s treatment, making the journey back to Kent more strained than the one when we left home. We felt shocked and angry. Dad had spent tons of money just to be told that his youngest daughter was a complete nutter. Is that the best doctors could come up with?

From the car window the North Downs welcomed me back home, their solid stature a security in contrast to my fragile time away. Blackbirds were nesting and woodpeckers were head-banging. Yet despite the sky being cloudless, the cloud of no real diagnosis wouldn’t leave me.

What did leave, though, was any respect I’d previously had for someone with a stethoscope round their neck. Doctors began to scare me and I wanted nothing to do with them – even the good-looking ones.

4. Sink or Swim

Although it was the 20th century, it might as well have been the 17th because the same criteria for witches was being applied to me. Those thought to be witches used to endure the sink or float test. If you floated on water, then you were a witch and subsequently burnt, whereas if you sank you weren’t a witch but could nevertheless drown in the process. I was diagnosed with ‘conversion hysteria’ and told to swim. If I got better from swimming then that would give credence to her wrong diagnosis, but if I didn’t improve and sank in the pool my illness would worsen from the effort. Her diagnosis couldn’t be tested as it was unscientific. Where was the litmus test or brain scan to prove I had conversion hysteria? It was entirely her own opinion – not science.

The witch test didn’t lie before me (my nose was too small) but a sink or swim one did on my return to school. Highworth School for Girls, the local grammar, swarmed with teenagers in chequered gingham frocks, their summer uniform 30 years out of date. Their outlook though was forward-thinking and led the way to women taking up influential roles in society. There was an air of ambition in the school corridors as well as an air of sweaty rubber from the plimsoll bags. We were encouraged to think for ourselves, question and debate by a mostly female staff of the Miss not Ms. calibre.

The Victorian box-shaped building let in plenty of light through its large windows, making it a pleasant place to study. But on my return, the school loomed before me like a prison.

News of my comeback travelled fast and girls crowded round me, eager to glean information.

“What’s been the matter with you, then?”

“Did you get bored being away?”

“Why aren’t you staying after lunch?”

Their enquiries set my head spinning. My brain had turned muzzy since the virus and I couldn’t cope with all their questions.

My long absence from school made me forget how noisy it could all be. Every shriek and door-slam made me tremble at my desk. I thought that I’d made some progress but being surrounded by healthy people only showed up my weakness.

The most obvious difference was that everyone else walked more quickly than me. When it was time to change lessons, I had to wait for others to go first. Only then, when the corridors were empty and settled from commotion, did I feel safe to appear and walk at my own snail’s pace. Everything about me was slow – the way I spoke, the way I moved and my response in the classroom.

“Catherine, can you give an example of personification?” my English teacher asked in an encouraging tone.

My mind went completely blank. Not only could I not think of an example but couldn’t even respond intelligently with a guess.

What had happened to my brain since the virus? It seemed injured, damaged in some way, as if I’d emerged from a car wreck. School had previously been a place where I’d thrived, enjoying it so much that I kept my uniform on in the evenings no matter how dated it looked. The school phobia label suggested by doctors was nonsense. But school had now become a confusing jumble of crowds’ faces blurring into an indistinct mass.

My favourite teacher taught Spanish although I believe she was Scandinavian, a thought confirmed by her tall, slender figure and model looks. I liked her for how she dressed as much as anything, often wearing black velvet. Everything about her communicated a modern-day woman, a breath of fresh air in the retro surroundings. Although pleased to see me back, she was angry that a number of us hadn’t shown up to a Spanish oral. “What’s your excuse, Catherine?” she jumped on me in front of the class.

“I didn’t know anything about it,” I replied, embarrassed by my memory problems.

It was true. No-one had been assigned to help organise my school day or even inquire as to how I was coping! Special needs teachers didn’t exist back then, not for grammar schools where weakness was easily overlooked. There was little surprise when I was told to repeat a whole academic year again, making me almost two years older than some of my new classmates.

But each cloud really does have a silver lining, although the clouds might need a bit of polishing to see them. Being excused from sport allowed a valued friendship to develop with another pupil, Anna-Liza Kozma, who was as poetic as her name suggested. She was nursing a broken arm at the time. In the hazy autumnal weather, we’d watch our school pals dash around during P.E., giving us plenty of time to chat on the sidelines of the netball courts. Anna-Liza always had a story to tell, which destined her for a career in journalism. One day, as I searched my blazer pocket for a pen to sign her plastered arm, she relayed a story of how she once kept a gun under her pillow at night whilst growing up in Zimbabwe. She was only 12 at the time but had to protect herself against intruders. The only things I kept under my pillow were a pair of Tesco’s pyjamas. Hearing Anna-Liza’s stories were a small consolation from no longer playing my coveted position of Wing Attack.

One subject I’m sure my parents hoped that I wouldn’t be absent for was sex education. I did manage to attend a few classes where I learnt more about STDs than the joys of being in love, so much so that the consequences of sex seemed terrifying, with every young man being a walking home to bacteria. My absence from many sex ed. lessons became obvious one day when I thought the word ‘orgasm’, scrawled on the door of a school toilet, was a misspelling of ‘organism’. Acknowledging my ignorance, I bought a book, *The Body Machine* by Dr Christiaan Barnard which included a couple of clinical chapters on ‘The Reproductive System’. It was hardly racy material but I nevertheless got the gist of things.

Conquests of the opposite sex, however, remained firmly in my head, not a reality. The illness had eroded all my self-confidence to the point where I never came close to a handshake with a gorgeous boy, let alone a snog. No teenage boy wanted a sick girlfriend, especially one who kept falling asleep on his shoulder.

Meanwhile, spring blossom flourished romantically outside the school gates. Sports days came and went as did Christmas pantomimes when Sixth Formers mercilessly imitated the staff. Trees around the tennis courts changed from viridian to reddish-brown as the sport changed to netball then back to tennis again.

Before long, I found myself sitting in the hot, stuffy gymnasium about to sit my GCEs. As we all lined up row upon row like cogs in a wheel, I wondered where the previous years of nurturing our individualism had gone? I was convinced that I’d fail all my exams. My attendance had been irregular and when I did make it to school I’d often sleep with my head on the desk during lesson time, exhausted from climbing mountains of stairs to get there.

That August, the fields at home turned loyally to carpets of gold, the wheat and barley glinting in the harvest sunshine. One morning, the postman came up our garden path with my exam results. On opening the envelope I thought a mistake had been made as it said that I’d passed eight GCEs. The grades weren’t great; nevertheless my parents yelped with delight and relief.

Once the elation died down, it was back to the hard slog of ‘A’ Levels. But pushing myself earlier had resulted in a worsening of health. The back of my neck became painful and it hurt my eyes to look up at anything above eye level. Mum remembers taking me round a bookshop where I couldn’t raise my head to look up at the books. School was also becoming burdensome again, with the depth of study at ‘A’ Level sapping the life out of any remaining brain cells. A few unfeeling Sixth Formers sensed my downturn and taunted me like birds of prey, swooping down to pull apart a sickly creature. When the careers adviser suggested I joined The Wrens (a military career) that was the last straw! School simply was not the right environment for me to progress in.

So I stopped going, not out of phobia but out of survival. Another curse though was creeping upon me, its tendrils strangling any enjoyment that was left.

This was the curse of depression. Home became simultaneously a place of refuge and confinement. Another harvest came and went with the gigantic combine harvesters hogging the little lanes around Brook. Then one boiling hot morning the phone rang, with Mum’s voice giving way to the occasional tremble. “Oh my heaven!” she said, putting down the phone. “That was the Headmistress! She wants to see you about your absence!”

The dreaded day came, with Mum looking whiter than me. She confided later how scared she was sitting outside the Headmistress’ office because it brought back memories of her own unhappy school days. As I was summoned into the dark room, it felt similar to the episode with the psychiatrist a few years earlier. The whole room seemed black, in stark contrast to the dazzling light outside. Curtains were pulled half way, emphasising the headmistress' silhouette, sombre mood and dark eyes.

She criticised me until there was no stone left unturned. My grades weren't good enough and surely I could pull myself together?

"There's a girl in the school whose mother is dying from cancer. Now there is someone with real problems. Just think of her, Catherine!"

I felt sorry for the girl but didn't see what that comparison had to do with me. There was no mention of the ECHO 2 virus which had started my problems, although the school had been notified of this long ago. Once again, the link between the virus and my current condition was missed, just as the doctors had missed it too. Instead, she recommended a visit to the school psychologist. I went but only because it was free, so Dad wouldn't have to pay. The psychologist was gentle with me but flummoxed by my physical symptoms.

With little help on offer, the only prospect was leaving school altogether. Mum braved the shame with me, helping to empty my locker and return my text books to the secretary. Mum was such a stalwart: this was all tough for her too.

As I walked down the empty corridor for the last time, the faces of self-assured Sixth Formers caught my eye through the library window. Their careers were all set... doctors, lawyers, journalists. What was I meant to do? Stay at home feeling ill for the rest of my days? On heading towards the double doors, I reflected on how five years earlier I'd entered this same building as a bright, energetic girl with a promising future, bowing from the stage to applause in leading play roles. Now I was leaving for good to no rounds of applause, nor carrying a sparkling trophy but sneaking out as an embarrassment with an illness no-one understood.

5. A Rooted Sorrow

‘Cans’t thou not minister to a mind diseas’d,
Pluck from the memory a rooted sorrow,
Raze out the written troubles of the brain,
And with some sweet oblivious antidote
Cleanse the stuff’d bosom of that perilous stuff
Which weighs upon the heart?’ (13)

‘That perilous stuff’, ‘a rooted sorrow’, refers to the depression suffered by Lady Macbeth. Spoken by Macbeth to a doctor, he begs him to help his unfortunate wife. The doctor’s reply was, ‘Therin the patient must minister to himself.’ Shakespeare, like me, seemed to have problems with doctors. I was in good company.

Depression had been a foreign concept in my past; my English teacher at school had praised me for my cheerfulness in the face of adversity. Coming from Yorkshire stock meant that my family’s foundations were built on laughter because Northerners definitely laugh more than their Southern neighbours. Our family holidays to Yorkshire used to be one fortnight of hilarity, as we joked and cackled with relatives over fish and chips and mushy peas.

Apparently there are different types of depression: one is when you’re depressed due to your circumstances; another is when you’re depressed no matter what your circumstances are.

My depression was the first one, entirely due to my circumstances. If only a doctor had said to me, “Catherine, you have M.E. brought on by the virus ECHO 2. You can’t help feeling ill. It’s not your fault,” then I’m sure the numbing fog of melancholy would have passed me by.

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13. *Macbeth* by William Shakespeare, Act V. iii.

Instead, the beautiful hills no longer lifted my spirits; a phone call from a friend became a strain, not a morale booster and I didn’t smile once through an episode of *Fawlty Towers*. Enjoyment had been sucked out from me like leeches supping on blood.

One morning, Mum was cleaning the house as usual, when she got out a tiny, silver trophy from the china cabinet to polish. The trophy had been presented to my father by an ambassador for Queen Elizabeth II when he had served in Nigeria. It commemorated his bravery from talking to rival tribes in person, thereby initiating peace and preventing bloodshed. The trophy sat very humbly at the back of the cabinet and was rarely talked about. I was immensely proud of Dad with this award and his later work for Mother Teresa, but I allowed his achievements to highlight my own worthlessness by comparison, something he wouldn’t have wanted.

Upstairs was a desk where Dad often worked; it was made partly from red leather with a gilded edge. He’d busy himself there with accounts, insurance and the occasional heartfelt letter to a politician. The desk also had school reports stacked away in brown envelopes. One time during this blue period I saw a report of mine from 1975, two years before I became ill. My school year back then consisted of over 80 girl pupils, yet I managed to come second out of those 80-something girls in the end of term exams. The pupil above went on to study sciences at Cambridge and the girl below took up medicine at Oxford.

I thought back to my recent GCE certificate in 1981 and the critical words of the Headmistress, sneering that my grades were inadequate. Fetching the certificate of eight respectable ‘O’ Levels, I threw it into the back of a cupboard where it never saw the light of day again. Failure was now my middle name.

The whispering words of ‘conversion hysteria’ went round and round in my head like a spell, urging me to hail the psychiatrist's theory just as the witches from Macbeth hailed the prospective King's authority.

"But her opinion wasn't scientific," came my defence in struggling to find a ray of logic. Admittedly, I also lacked scientific evidence to support my own claims: apart from the initial virus, all medical tests done since then were negative.

In the stifling isolation I even wondered if I was going mad, or maybe the illness somehow feigned madness like other Shakespearian royalty. I was a medical mystery, an experiment for doctors to play with but now left unexplored on the laboratory shelf.

Anna-Liza came bravely to visit me, sitting on my bed endeavouring to offer comfort. Her compassionate questions exposed my depression, making the atmosphere awkward for us both. Sudha, my friend from hospital, wrote regularly but I felt unable to respond. The cloud of sorrow also spread to members of my family – depression is more infectious than enthusiasm. My existence was affecting them in a big way, which only added to my sense of worthlessness. Worst of all, I started looking for blame amidst my family, wondering if something they'd done was the cause of my suffering. That idea was planted in my head by the psychiatrist four years ago. One fateful hour with that woman was all it had taken to seriously screw me up.

Meanwhile, the enclosing fields turned from harvest gold to frozen fallow, the freeze continuing around my icy emotions which were unable to shed tears for the death of my favourite aunt in Yorkshire.

With my emotions in tatters, obviously I needed some kind of help. But who was there to turn to? I contemplated returning to my GP like some humiliated animal, its head hung low from shame, confessing that now I really was suffering from depression as he once suggested. The thought of taking antidepressants didn't bother me: my fear was being sent back to the psychiatrist. "I'm not giving in to them," came my stubborn determination in what had become a patient doctor staring contest.

Doctors didn't understand. Teachers didn't understand. No professional person seemed to understand. That's exactly *why* I was depressed, because no-one understood my physical illness in the first place.

My parents felt my desperation, becoming especially upset when I told them how ugly I was.

"Don't say such things! You're a beautiful girl!" Mum lamented, forcing me to look at a photograph of my smiling face.

"But I don't smile anymore," came out some wooden words.

On hearing this she promptly dragged me to a hypnotist, with Dad at the wheel, all the way to Chatham, North Kent. Lying on the therapist's couch I awaited some kind of levitation as he clicked his fingers. But it was all very ordinary with no out-of-body experience, just positive thoughts said out loud to boost my self-esteem, played to spacey music. It was therapeutic to off-load my problems to someone but the illness was still with me; he couldn't take away muscle weakness and the toxic feeling in my body.

Once home again, decision-making became impossible, being unable to choose between wearing trousers or a skirt, then concluding it didn't matter anyway as I was such a miserable person no-one would want my company.

Then one morning I stumbled to the bathroom for a plain and boring bath, void of soapy bubbles and heady fragrances to pamper myself with. Through the thick, wooden door drifted a tune from Mum's portable radio which she carried around with her to do the housework.

It was Radio 2 and the muffled sounds jelled into a recognisable song, *Walk On With Hope In Your Heart* by Gerry and the Pacemakers. But at 19 I had no hope left, no more inner strength to do daily battle with. It was time to give up.

Whilst staring at each ripple in the bathwater, formed by rhythmic drips from the taps, pictures of Dad's razor blades flashed into my mind. They were just a few feet away in the medicine cabinet which was also stacked with packets of painkillers.

'Out, out brief candle!
Life's but a walking shadow, a poor player,
That struts and frets his hour upon the stage
And then is heard no more:' (14)

Why was I thinking like this? Fear wrapped around me with the bath towel; terror dressed me like a shroud in preparation for my grave.

"Get out! Get out!" screamed a survival instinct from somewhere deep within my subconscious.

Where did that come from, the survival instinct, when I wanted to die?

'Do not let your hearts be troubled. Trust in God;
trust also in me
Peace I leave with you; my peace I give you…' (15)

These words came from St. John's Gospel. Why were they in my mind when I was so weary of living?

'ask and you will receive and your joy will be
complete…' (16)

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14. *Macbeth* Act V. v.
15. St. John's Gospel, ch.14 v.1, v.27.
16. St. John's Gospel, ch. 16 v.24.

Empty of hope, I could no longer dredge up any effort to live again, yet these Biblical words were a lifebelt, saving me from drowning.

Perhaps I'd heard them in the ancient village church lavished with wall paintings, heavy with the scent of chrysanthemums and communion wine. Maybe they were spoken at the school Christian Union when some of us braved the teasing comments of agnostic friends.

"Peace, joy, peace, joy," I mouthed over and over again.

Back in my bedroom, I reached hastily for my Bible. It was easy to find as the cover was bright green with yellow lettering. I flicked through each coloured page, complete with miniscule handwritten notes until I arrived at St. John's Gospel. There I found a drawing of a vine twisted round a trellis, with lavish grapes framing the hopeful words of Jesus before His crucifixion. The creeping growth of the vine with its tendrils felt just like my own depression within. The passage described Jesus as a gardener, pruning back the vine. Perhaps He could dig down into my soul and pluck out the rooted sorrow?

Month rolled into month and the depression continued but there was no bloodshed, unlike Macbeth. Dad's little trophy, symbolic for the prevention of a bloodbath, reminded me of my own merciful outcome.

Across the fields nestled the village of Wye, which also took shelter in the North Downs as did Brook. A prayer group known as the Wye Healing Prayer Group met regularly in people's modest homes to pray for the sick. My name was on their list and by the age of 20 the depression had lifted.

With healthier emotions, delayed tears were shed for my deceased aunt whom I was unable to grieve for previously. (They were also shed for our ginger pet cat, run over by the postman during my dark period.) The physical disease was still with me, 'it', the unnamed condition since the virus, but now I had the weapons of peace and joy to do battle with it.

‘To the succeeding royalty he leaves
The healing benediction. With this strange virtue
He hath a heavenly gift of prophecy,
And sundry blessings hang about his throne
That speak him full of grace.’ (17)

I too had received a healing benediction, a slow recovery from depression but from divine not human grace. Yet unlike the Shakespearian king, I wasn’t successive royalty nor did I have a gift of prophecy, so was blinded from seeing the instantaneous physical healing which would come much later.

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17. *Macbeth* IV. iii.

PART TWO

REMISSION
&
RELAPSE

6. *Repair Job*

The luscious scenery was painted with every shade of green: jade hilltops, emerald gardens and turquoise dragonflies which darted back and forth over the brook. This time I could see the colour of our village; the newly received peace and joy acted on my senses, dispersing any grey outlook.

Rest had been my medicine, an antiquated concept at odds with the emerging Yuppie trend. Freedom from school pressure and essay deadlines had allowed my body to recuperate; that combined with supplements from a new, local health food shop made my energy levels soar.

It was the mid-1980s, a time of scary movies and equally scary haircuts. *Top of the Pops* played slower disco beats and tinny keyboard melodies as we witnessed the birth of Madonna and yelped along with Michael Jackson to his *Thriller* album.

Baggies were still in fashion, now so wide that teenagers tripped over their feet. I was more into stretch leggings. Socialism was on its way out and individualism took over society, shaped by Thatcherite ideals.

The latter societal shift came at the wrong time because I was desperate for a sense of community. With my school friends at university I felt stuck in a rural village, beautiful as it was, with no future lined up. Thank goodness for church which accepted society's misfits. This acceptance was found more in non-establishment churches, free from the Tory party at prayer image which can be strong in the south-east.

My new friends weren't exactly the budding doctors and lawyers from grammar school, but rather youngsters scarred by previous drug addiction, depression and general hopelessness. We had two things in common:

little direction for our lives and a desire to seek God. My parents were gracious to these people as they stepped over our doorstep, although eyebrows were raised at the length of several men's hair and the whiff of joss sticks on the girls' Oxfam dresses.

It was with one of these church friends that I joined an aerobics class. The country was being swept by an aerobics craze from Jane Fonda, who made a best selling record on how to feel fab and have a great bottom. As we lined up on our mats with Jane Fonda clones, The Jacksons' song *Can You Feel It*? boomed out from the loudspeakers, a cue for us ladies to thrust out our chests.

"Go for the burn! WORK THAT BUTT!" shrieked the aerobics instructor hysterically.

My friend went for the burn and felt great, barely glowing from perspiration. But as for me, the burning sensation stayed in my muscles for days; so my leotard and bandana had to be put to one side. Exercise was still out, although at least I could walk again and enjoy the panoramic views of the North Downs, even climbing the hill slopes to hear the skylarks sing.

Our village was the sort where a car was essential, not a luxury, for any contact with greater civilisation. Seeing a bus was something of a novelty. Not wanting to be outdone by other youngsters in their four-wheel quest for freedom, I too started learning to drive. This was when I discovered that having short-term memory loss was a distinct disadvantage. Unable to store fresh information in my memory for long meant I had to write everything down before forgetting it, making my bedroom littered with notes from my driving lessons.

'Left foot up, right foot down – just like a yo-yo,' echoed the words from my Polish driving instructor.

'When reversing, check mirrors to see no-one's standing behind,' was another helpful note I kept reading.

My instructor was generally subdued in character with an occasional flash of temper. It flashed more than usual when he found out that I'd failed my test.

"Why do you have that big smile on your face?" he fumed in his strong Eastern European accent.

"I'm relieved that I didn't kill anybody!" came my honest reply.

Under a different instructor I managed to pass and was so elated that I leaned over to hug my examiner, who simultaneously leaned back in fright.

My four-wheel freedom led me one day to the next door village of Wye. It was here that a social visit turned into an important event when a former neighbour of mine from Brook, about my age, offered me tea in her snug cottage. This young, married woman had been struck down by a virus sometime before, leaving her weak and bedridden for a couple of years.

"I thought I was dying," she exclaimed, reliving her torment whilst pouring a calming drink.

"But I had a name given to my illness… M.E.," she continued.

"M.E? What's that stand for?" I inquired, having never previously heard of it.

"Ooh a long name, Myalgic Encephalomyelitis!" she said very carefully. Being a teacher helped her to say it.

Both of us then rattled off several people we knew in Brook who'd suffered from a similar disease. Some even had the same initial virus as me, ECHO 2.

"How are you now?" I asked her, hoping she'd reply in positive terms.

"Fine, although I have to be careful if I get an infection. It takes a while to recover. How about you, Catherine?"

"Oh, fine, no problem. I'm completely over it!" The words haunted me as soon as I said them. Compared to how I used to be, my recovery seemed complete.

Yet I wasn't one hundred per cent and didn't want to face up to that.

"That's wonderful!" she responded, hearing my words but not my thoughts, as we celebrated our recoveries with a second mug of tea.

On leaving her home I felt as if a huge weight had lifted unexpectedly from me. That dark cloud of uncertainty from the days of the psychiatrist had finally started to float away. Myalgic Encephalomyelitis sounded so scientific, so real as opposed to conversion hysteria. But this was self-diagnosis; it would be better hearing it confirmed by a doctor.

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Money doesn't grow on trees, so pressure was upon me to keep up my car, a black Mini bought second-hand from my brother Graham. My long-suffering parents had gone way beyond the call of duty in their financial care. At 22, independence was a good target to have.

"I'm going to get a job!" I declared one morning to my remaining family members, tossing my hair back with a new air of confidence.

Dad looked relieved, whilst Mum seemed concerned. My brother Paul and I were the only offspring left at home, my elder brother and sister having flown the nest by then. Rosemary was married and teaching; Graham was also married and partnered a garage, whilst Paul worked at a printing office.

So began my job search, trying many avenues such as counting diseased beans and selling fuzzy slippers at Marks and Spencer. Playing the piano for ballet classes was slightly more fulfilling, but none of my jobs lasted for long. No matter what I did, I'd always return home exhausted and go straight to bed. A cleaning job for a library lasted only two weeks, when I spent more time sitting down reading books than doing any cleaning. Any form of heavy exercise was out. In fact, anything which involved physical and mental stamina without frequent breaks was out. That left hardly anything else to try!

“What about going back to education, Tat?” suggested Mum, after witnessing my fatigue from a day’s work of searching for strawberry rot in a science lab. (Tat was a term of endearment used only by my mother and sister.)

“At a pace you can manage?” she continued.

Anything was better than the monotony of looking for plant disease all day with a recording of ‘yes’ or ‘no’ columns. So, with my parents’ financial backing I enrolled for one ‘A’ Level per year through Adult Education and correspondence courses. The first ‘A’ Level was English Literature which included the pleasure of studying Dylan Thomas’ *Under Milkwood*. The second was Art which was even more pleasurable and the third was Spanish which was pretty taxing as the only foreign languages studied at home were French and Hausa. The pressure was miniscule, though, compared to being at school which enabled me to pass them all. Equipped with ‘A’ Levels prepared the groundwork for a degree and the chance to be equal to my former school peers, who by now all had degrees. I didn’t want to feel left behind.

History of Art was what I had wanted to study ever since seeing slides at school of Giotto’s frescoes from the Arena Chapel, Italy. But after browsing through university brochures, the academic intensity looked far too much for my battered brain. Enthusiasm was willing but the hypothalamus weak.

However, there was Art College which was practical art with less academia. Mum’s sister, Aunt Sybil, went to Art College and became a gifted portrait painter.

Also, a cousin of Mum’s was a professional designer and could write beautiful calligraphy – she even had a book published. With art already as one of my ‘A’ Levels, perhaps the family talent would rub off on me once I restarted sharpening my pencils?

My black Mini, with peace-loving bumper stickers, became crammed with sketch books, pots of paints and art paraphernalia as I drove around Kent looking for something inspirational to draw. Markets, funfairs and period cottages became frequent subject matter. After a few self-portraits and life drawing classes, the material filled an A1 size portfolio.

An unconditional degree place was awarded by my nearest Art College in Canterbury, along with a grant for my ‘mature age’ of 23. Holding the letter of acceptance was a magical moment, especially in the same bath where suicidal thoughts had plagued me four years earlier. I couldn’t put the letter down even as it became torn and wet from the soapy bubbles. The evening sun streamed through the bathroom window as pastel coloured reflections danced on my aqueous skin. An Impressionist painting was already in the making.

Just as Milkwood’s villagers thrived on gossip, my own village now had something else to talk about. I was off to Art College, a choice which was too weird for some of them to handle.

7. Canvas and Turpentine

‘That which doesn’t kill us makes us stronger.’ (18)

These are the words of a pre-World War German philosopher. In keeping with the values of Art College, Nietzsche encouraged human strength over Christian ethics. Depression hadn’t killed me, so I was stronger as a result yet only with God’s help.

Creativity is a strong force and if misguided can be destructive. Apparently, Adolf Hitler was determined to be an artist as a young man but was rejected by the Vienna Academy of Fine Arts, failing the entrance exam. He eked out a small living from painting sketches of Vienna and drawing posters for shopkeepers, but was essentially a frustrated artist. Some believe that if Hitler had been accepted into Art College, he wouldn’t have become the Hitler we all know. Instead, he used his creative force for mass destruction.

My creative drive wasn’t as strong as Hitler’s but when released and channelled in a positive direction, it healed my painful past. Art seemed to balance out the Yin and Yang so to speak. There was no need for anthroposophic therapies: art itself was my therapy.

On a guided tour of Canterbury Art College I was greeted by beefy girls with enormous biceps, soldering together metal scraps for a sculpture. Soldering? That was way too technical for me! Where were bearded French men with berets and dainty watercolours of pink flowers? But this was Art College of the 1980s, attracting the radical and anti-establishment. Any picture resembling the word ‘pretty’ would be quarantined and put down by students and tutors alike. The more shocking the art, the better.

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18. Friedrich Nietzsche, 1844-1900, German philosopher, poet, critic.

It wasn't just the art work that shocked but the place generally! Hedonism was a new concept for me: if it felt good, do it. Admittedly, my naivety only fuelled the shock element as I was just a 'Brook' girl, a country bumpkin. At 23 I saw my first fully naked man and had to draw him. During his breaks from modelling, he'd follow me around the studio completely starkers, clutching a polystyrene cup of scalding coffee held a little too close for comfort to his meat and two veg.

The shock element continued with partying students high on dope and couples being openly gay and lesbian. I was also informed by a student that a few of the girls had slept with their tutors in the hope of gaining better grades. For someone who'd spent their teenage years mostly confined to four walls surrounded by sheep, the whole thing was a baptism of fire, drowning in erupted molten rock!

Yet the place was also inspiring, being a hive of creativity with students swarming around the campus, making art in their individual space. One site was a maze of fine artists' studios where art was portrayed in its most aesthetic sense. Another block was home to graphic designers which had more of an office feel about it as they worked to deadlines. The Fashion Department was full of smiley girls who seemed to enjoy what they were doing more than anyone else. Last but not least were the architects, an erudite bunch who intellectually outshone the rest of us. We could all roam freely from building to building, absorbing each others' creative ideas. That combined with Canterbury's own blend of bohemian living made it a slightly unorthodox education: the college was a little island afloat in a surrounding sea of commerce. But at least it was afloat.

With my own unusual background, it was hard for me to fit in there. Socially, I hung around with the architects but my concentration problems made me feel unconfident with their intellect. The fine artists whom I studied with could be anarchic, latching on to troublesome protests in London sometimes (tut tut). I wasn't against them protesting but didn't like the anti-social behaviour. In my soporific village, where I commuted from daily, the closest thing to anti-social behaviour was a dog lifting its leg on Dad's newly planted marigolds.

So art became my friend, soothing me, inspiring me, always there for my emotions to confide in. The traditional subjects of life painting, portraits and landscapes were followed by more imaginary work. There was no holding me back with colour, as my life until then had been lived out mostly in grey. Stretched, primed canvases, virgin white, wrapped up with the constant whiff of floating turpentine will always remind me of jumbled studios in the Art Block: old paint on sticky floorboards and an all-pervasive worship of the glories of the human mind.

The turps smell continued up the corridor towards video and photography, where girls had to be wary of wandering hands in the dark room!

"Let me just squeeze by," was a routine saying from the tutor, leaving his hands on girls' hips for longer than it took to develop a photo.

Weekly lectures encouraged us to think with our art, so our work wouldn't just be self-therapy. Philosophy was touched upon but rarely history of art. Discussing Michelangelo's sexual preferences seemed more important to some tutors than teaching us his date of birth and the names of his sculptures. Ideas took preference over facts.

Student sculptures dominated the grounds with their contorted shapes, whilst printmakers spent most of their time cleaning presses and cleaning up generally. As a fine artist, sculpture and printmaking were part of my course but I could never do much of them. Lifting bowls of plaster of Paris and pushing the handle on the huge rollers of the etching press caused immediate muscle weakness. In fact, the poisoned feeling never left me: the more I did, the more it came on. My blood felt bathed in poison, like continual flu. I often took Wednesdays off, to break up the gruelling week and found refuge most afternoons in the library, sometimes putting my head on the desk for a snooze. The dreaded curse, ‘it’, still hadn’t left, but reared its ugly head periodically as a taunting reminder.

With no diagnosis or medical advice, I ignored the symptoms, battling on with my degree and producing over one thousand art pieces. The human figure was my favourite subject, perhaps an unconscious choice in celebration of my much improved health. Portraiture, too, inspired me as I attempted to combine anatomical accuracy with character expression.

My parents were thrilled that I was on a degree course but found it difficult to relate to my work. Dad commented more on my essay writing as he could relate to words better than pictures. He found it very amusing one summer when I painted pictures of the Ayatollah Khomeini in the garden shed, surrounded by lawn mowers and sacks of compost. This was during my political phase. Mum enjoyed pencil drawings but admitted tentatively her confusion over my portraits.

“Why’s he got a yellow face? It looks like he’s got jaundice!” she commented over one of my paintings of Dad.

Anna-Liza visited me at Art College, intrigued by the concept of painting all day long. She was newly wed, her husband being into philosophy. They talked about emigrating to Canada.

In the summer of 1988 the college took on a different feel for a week due to graduation ceremonies. Wine glasses glistened row upon row on long tables next to a platform with standing microphones; the quad area was dominated by a large marquee. Fine artists though, weren't included in these ceremonies which insinuated that their education was inferior. Maybe the real reason was tradition's incompatibility with the anti-establishment trend.

Enjoying the ceremony, nevertheless, made me reflect on how kind life had been to me lately compared to previous times. I had only one more year to go for degree completion. Things were swimming along so nicely that perhaps I could strive for something else, maybe even a husband? There was only one person I'd met by then who might do. His name was John, but he lived all the way across the Atlantic in the USA, or the land of the free and the home of the brave as he kept telling me.

8. *Rapunzel's Prince*

My story with John is an unusual one. After first meeting him in 1984 when I was 21, I presumed that I'd never see him again. He came to England on holiday, visiting his sister who attended the same church as me. One Sunday morning when John attended church with her, I was transfixed by this handsome, charming American man sitting nearby. So much so that I remember little of the service except for gazing intently at John's profile, whilst making enquiries as to who this striking newcomer might be.

A romance didn't blossom at first during his two week holiday. For a start, I'd never had a boyfriend before and was far too shy in making the first move. John also fancied me but said nothing at the time. We both wanted our heads to rule our hearts: a holiday romance would be painful, knowing he would soon be returning to the States. But on walking away after saying a fond farewell, he called me back, asking for my address. Things were hotting up.

On his return home we wrote on and off as innocent pen pals. The main thing we had in common was art: we were both painters, enjoying portraiture and figure work the most. John was determined to be a successful artist, even contemplating moving from Michigan to New York for fame and fortune. His paintings were already popular in the Cleveland area of Ohio, on show with their bright colours over many a sofa or fireplace.

Four years went by after our first, brief meeting and the occasional platonic letter. During that time I'd set John aside in my heart, giving him my commitment although he knew nothing of this. We had no photo of one another, making the relationship an increasingly metaphysical one. Obviously my 'commitment' idea needed sorting out: either it was all in my head or there was some substance to it. The only way to find out was to fly across the Atlantic and see this person whose face was becoming a hazy memory.

Our relationship was built on drama right from the start. Pan Am Flight 103 was my ticket to the States, my first experience of flying and a plane which also crossed the minds of terrorists. (Apparently, my plane had received a terrorist threat but the passengers weren’t told.) Two or three flights after mine came a duplicate flight, same number, same route which became the doomed one. The tragic news reached me in the States, with John comforting me on my close call.

Before that near miss, I was to have some good drama happen though. On my arrival at Detroit airport, butterflies in the pit of my stomach took such a hold on me that I too was on the edge of flying. John was also nervous and arrived hours before the plane touched down. I wasn’t sure if the small guy smiling at me in the welcome area was him or not: he didn’t look like any of the photos he’d sent recently to me for identification purposes. With his long hair and bushy eyebrows he looked more like a greatly slimmed down version of Meatloaf. I liked how this smiling guy dressed, in layers of woollens and tweeds, a mixture of the intelligentsia and bohemian. He also liked how I dressed, especially my wide belt and Peruvian hat which covered my long, hennaed hair. Finally, we were together again.

Two things stick in my mind of the Polish town Hamtramck, Michigan, where John drove me to his artistic flat – the cold and the bright sunlight. It was the cold, though, that won hands down as the number one memory: bitter cold which bit into your flesh and throbbed in your bones, freezing the water pipes and forming glassy pavements where Hamtramck cats grew an extra coat to keep warm. The frigid weather brought out warmth of neighbourliness as folk checked up on one another, loaning jump leads for their blocks of ice on wheels. Meanwhile, the cold pushed John and me closer together in his stylish home which resembled an art gallery more than someone's living quarters. John introduced me to America's love of jazz, blues and filter coffee, all of which I quickly took to.

As the December sun poured through his blind-free lounge, we shared the radiators with our coffee mugs, keeping our bodies and beverages simultaneously warm. All the time, the cold worked its purpose in nudging us further together as the two of us became one huddled-up mass, shaped into an abstract statue. On the second day we held hands and by day three we kissed in his kitchen, where we'd taken refuge for warmth. Amazingly on the sixth day we found ourselves engaged. We joke that John liked my hat so much that he asked me to marry him!

The first person to learn of our engagement wasn't a neighbour or one of our parents but the postman. He knocked on the door moments after we'd drawn gold rings on our fingers with a felt-tip pen.

"We've just got engaged! You're the first person to know!" John exclaimed to him in the sparkling snow.

"Congratulations!" he chuckled with his Mid-Western friendliness, saluting us with a letter.

It was public: this American artist whom I barely knew was now my fiancé. I couldn't even remember the colour of his eyes, convinced they were blue, only to discover long after our engagement that they were a gorgeous chocolate brown.

Christmas was a wonderful time to be engaged, especially in the whitest of light where everything glistened from the snow and seasonal decorations, shining with people's anticipatory joy. The celebration seemed to be just for us.

After the two-week love affair, it was time for my ticket home to England. The goodbye was heartbreaking and it was nerve-racking flying back with Pam Am the morning after the 103 tragedy.

My parents were still reeling from my close call and knew nothing of my engagement. After meeting me at Heathrow, we all took a train back to Kent and I caught my mother’s eye glancing several times at my engagement ring (a real one which had replaced the felt-tip version). She seemed highly perturbed because she, like Dad, had never met my fiancé. Waiting for the right moment to break the news was a bit like waiting for the right time to release King Kong into the railway carriage. There was never going to be a good moment.

I passed a letter addressed to Dad, written by John back in the States asking for my hand in marriage. Mum stopped glancing at my ring, turning her glance instead towards the letter. She looked positively horrified. Meanwhile, my heart was thumping so loudly that I could see it jump out from my chest cavity and bounce up and down the gangway.

Then, relief: sheer, utter tranquillity. On opening up the letter, Dad seemed more relieved than me, glad that happiness was mine to grasp. He smiled blissfully, his face glowing with joy. Mum, however, still looked horrified.

Once home, most people shared my joy, thrilled at my run of good news. Art college students though, tended to be sceptical of the engagement, puzzled that John and I weren’t planning to live together first of all.

“But you don’t know him!” exclaimed my anxious mother, who had major concerns about the whole thing.

This was true, yet our engagement felt so right: like dominoes falling down in place; like strawberries complementing champagne. I tried reassuring her that a bond had grown during the four years John and I wrote as pen pals, praying for each other during that time.

Seeing one another in the flesh was merely the icing on the wedding cake!

"You're special because of all those years I nursed you!" she finally cried, hugging me tightly into her breast. "Have you told him how ill you used to be?"

"Not yet, but I will," came my hesitant response.

My sister and brothers were happy for me, glad to be involved in the wedding plans. As for John's family, his mother was overjoyed, although understandably upset at the thought of her son leaving the States to live in England. His family and friends generally supported the engagement, although shocked at the speed of the decision. Some thought it was all a joke and told us so. John wished that his Dad had been alive so he could tell him the good news: his Dad had passed away when John was 16.

Looking at the stack of holiday photos in my bedroom made me savour this wonderful transformation in my life. Six years previously in this same room, my head had been filled with suicidal feelings. Since then, I'd made it to Art College and now my body was floating with that weightless feeling of being in love, my head in the clouds, yet coming down to land with an exciting wedding plan wrapped in happy-ever-after gift paper. I was reliving my favourite children's story of Rapunzel, being rescued from my lonely tower by my Prince of dreams. Perhaps that's why John has never wanted me to cut my hair.

The Prince felt the same way in that he'd also been rescued from a lonely life. This was hard to imagine when he was the life and soul of parties, attracting crowds with his magnetic pull of entertainment and humour.

We had our lives all mapped out. John would move to England so I could finish my degree. We'd both pursue careers in the arts as college tutors, alongside exhibiting our own work. We’d have two children, a boy called Mavrick and a girl called Naylin and probably move back to the States in the course of time.

As my mother entered the word ‘wedding’ into her diary for 2nd September, I sympathised with her caution because she still hadn’t met her future son-in-law; neither had Dad. A time for John to meet the parents was well overdue, so over he came during a dull, murky English February, too wet for the daffodils to open up.

Mum was her usual hospitable self, running around making sure John had everything he needed. Dad saw the opportunity to answer the ‘permission’ letter read on the train with his reply, “The wedding doesn’t bother me. You can do as you like!” Mum however, stared intently at John’s newly grown ponytail.

The four of us trundled into the kitchen for John’s first ever cup of hot tea, watching the condensation and steam form a misty foreground with the breathtaking views through the window. A sense of peace descended upon us and I felt proud of my family and of England’s green, green grass of home.

“Has Catherine told you that she used to be very ill? We think she may have had something called M.E.,” travelled my mother’s voice across the kitchen table, jarring us slightly with the serious topic. Sad memories were suddenly evoked as she spoke in a wavering voice of concern.

John commented that he’d never heard of M.E. before and for a moment looked very troubled indeed.

“But you’re fine now, aren’t you?” he said quickly, turning to me.

“It doesn’t seem to bother me anymore,” came my truthful reply.

I put the recent exhaustion that I’d experienced down to my degree and wedding plans, never once contemplating a return of the dreaded curse. My health confession then encouraged John to tell me of his bouts of depression; there was panic in his voice, as if this admission might trigger rejection. I told him about my depression at 19, reassuring him that I understood it. We went into the marriage truly believing that each other's illnesses wouldn't be a burden.

John returned to the States, visiting again once more before moving permanently to England. The engagement proved to be stressful as most plans were made over the phone when phone calls were £1 per minute. Excitement over wedding plans was mixed with strain in the bureaucratic effort of merely getting John to live over here. As the USA doesn't belong to the Commonwealth, a ludicrous amount of red tape had to be cut through before wedding rings could be slipped on to our fingers. Affidavits, Home Office interviews and curiously a trip to Canterbury Cathedral for a special licence were all conducted. The licence was based on an archaic English law that stated a spinster must have written church permission to marry someone from overseas, if a church wedding was required!

The stress of red tape was punctuated with anticipatory highs as I visited the home of a fashion student for several wedding dress fittings. She and I went to the same Art College. The gown was ivory white satin, edged with lace and pearls with a massive bow at the back, a creative touch from the 17-year-old student who designed it. My dress became one of her projects as part of her course work. Meetings with florists, sending invitations and choosing gold rings all put life back into the reason for battling with bureaucracy. The most romantic thing of course was receiving John's love letters, sent once or twice a week. The postman yet again played a part in our joy, as I'd drive the opposite way to college in the hope that there might be a transatlantic letter for me. The letters were always given with a celebratory Royal Mail grin.

Nine months passed quickly from the snowy days of Hamtramck, with 2nd September rolling around only days after the finishing touches to the satin gown. We were married in my village church, adding yet another Turner family occasion within the sacred Norman surroundings. The sepia-coloured wall paintings of saints and angels came alive with a special presence, strengthening the public witness to this event. As melodies floated up the aisle from a string quartet and my sister's organ playing, the content of the hymns and readings centred round the theme of fruit, indicating our procreative hopes. The heavy fragrance inside from pastel-coloured flowers reminded us that nature was all around, with the hills of the North Downs rejoicing over the wedding day.

My maiden name was replaced with the Austrian word Ashenfelter, meaning 'from a burnt field', probably a farming reference. It was a surname which I hated at first because of its harsh Germanic sound, but its uniqueness eventually won me over. We probably were and still are, the only Ashenfelters in the whole UK! John's Mom and stepfather flew over from the States, whilst his childhood friend became the Best Man. John looked dapper in his black embroidered tuxedo, with yellow cravat and carnation. His ponytail 'experiment' was still in process!

The very next day, my old school friend Anna-Liza emigrated to Canada in order to support her husband's career. She gave up her BBC job for this, drawing out similar qualities of sacrifice that John had made for me, with both of them crossing the Atlantic in opposite directions.

The fairy story was now complete. Rapunzel was running away with her Prince to a life of future happiness. But in our case, the last chapter was to be rewritten, a cruel, undeserving section that had no place in a children’s book. In our version, Rapunzel found herself recaptured and marched back into the lonely, dark tower, alongside her Prince who was destined for a similar fate. The two became prisoners for an indefinite period of time, imprisoned in an even more horrible cell than before. This room had no window with no means of escape.

Instead of successful careers, my degree became in jeopardy from long-term absence, with John renouncing his career for ready money in order to make ends meet. Instead of a babe-in-arms, my fingers curled shakily around the handle of a walking stick, purchased weeks after the wedding. A spell was cast upon us right from the start as our plans tumbled down from the tall tower, crashing into smithereens on the ground below.

9. *'For better, for worse… '*

'...for better for worse, for richer for poorer,
in sickness and in health...' (19)

These were the vows we'd just pledged to one another, presuming they'd be put into practice when we got old and grey, drawing our pensions after a long and happy life. But we were held to these promises immediately whilst only in our twenties. John had just turned 29 and I would turn 26 in the following month of October.

Lying in the darkened bedroom of our first home in Canterbury, my thoughts drifted back to Sudha, my Nepalese friend from the London hospital 10 years previously. I remembered her showing me a photo from her wedding day in Kathmandu when she could still stand. The paralytic illness struck her soon afterwards. My fate now joined forces with hers as my crisp, satin wedding dress lay listless, like me, on the bed. It shimmered even in the dark, like a beacon of hope, making me smile momentarily through my pain. But John and I didn't have much to smile about.

"I've only just got her," he murmured, sitting on the edge of the bed squeezing my hand. I didn't dare tell him how much it hurt to be touched, as each loving hug pressed into my sore muscles.

There had been warning signs during the engagement which John had picked up on, such as the times when I lay down after discussing simple wedding plans, the conversations quickly draining my mind. Then there were the tears which happened completely irrationally, leaving us both bewildered.

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19. *The Book of Common Prayer,* 1552 version, from the Chapter of *The Solemnization of Matrimony,* Ebury Press 1992.

But it was the week before the wedding when the signs were at their greatest: raised neck glands combined with all-over muscle weakness, making it difficult for me to walk very far.

My body and brain had ‘crashed’ (20). I was not the prize John thought he was getting, ‘the picture of health’ he described me as in the halcyon Hamtramck days.

A whole new world was on our doorstep for him to explore, the ancient city of Canterbury in a county brimming with medieval castles. Yet already from day one, the loneliness of his single life was set to continue from the isolation brought on by my illness.

This crash was neither from wedding nerves, as some suggested, nor from stress. When the poisoned feeling started flowing through my veins and light started hurting my eyes, I knew exactly what it was. This was the curse, ‘it’, the demon let loose again to scourge me, no longer content with just stealing my teenage years but now destroying marital bliss. This was the same disease that struck me after the virus, in the sleepy agricultural village of Brook when I was 14. The same condition that sometimes left and sometimes came back; perhaps it had never really left. The disease that was nameless, although perhaps it was something called M.E.

As a teenager I had hidden my disability, having no obvious outward signs. But now a walking stick became necessary. I hated it, insisting that my wooden stick be replaced by a fold-up plastic one which could fit into a bag, out of sight.

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20. Relapses of M.E. can occur several years after remission. See *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document* by Bruce M. Carruthers and Marjorie I. Van de Sande. Page 1. See Footnote 6 for publishing details.

“Use your stick, Catherine. You must use it to save your energy,” John would say, hoping that my sudden descent into disability was just a temporary blip.

I had to use it to help guide me in a straight line, otherwise my legs would veer off at diagonals when walking. Without my stick, the entire left side of my body would lean over. It must have looked bad because on one occasion a complete stranger was so concerned that he stopped me in the street near our home.

“Excuse me, but are you alright? You’re leaning over to one side and look as if you’re about to fall,” he inquired, as a street lamp lit up his kind face.

“Yes, I’m fine. It’s just my illness!” I replied, embarrassed yet touched by his fuss.

But when two college students on the campus rushed up with their arms outstretched, as if to catch me, I began to wonder what on earth my walking must have looked like.

What had caused this horrific relapse, making me resemble some kind of freak? There were many possible causes, all of them perhaps contributing to the cocktail of catastrophe: my degree, a part-time job and exercising to lose weight were all culprits. The bureaucracy of getting John to live in England had been a nightmare.

I’d simply overdone it, big-time, going way beyond my body’s limitations. There is, however, one particular cause that I blame the most – the contraceptive pill. (Although we longed for children, we wanted to wait until I finished my degree.) Within two weeks of taking it I became breathless and my blood sugar levels plummeted, along with a host of other problems. I quickly mentioned my concern to a new GP in Canterbury but he dismissed any link with the Pill; instead, he gave me reassurance to continue with it. Both of us at the time seemed ignorant of the leaflet’s warning:

‘*The following conditions require careful observation while you are taking the Pill: ...the disease of the nervous system called Multiple Sclerosis...*’ (21) M.E., like Multiple Sclerosis, is a disease of the Central Nervous System. ‘ *...The worsening ...of any of these conditions may indicate that the oral contraceptive should be stopped.*’ (22)

After the doctor’s reassurance, I continued on it for another six years. I wanted to come off it in case it was making my illness worse, but eventually became too ill to even try for children, so stayed on it. The Pill became a vicious circle.

John, in the meantime, had a promised job fall through: he had been awarded a part-time teaching job in Ashford as an art teacher. In spite of an interview and a verbal promise, he arrived in England to discover that his job had collapsed. So, to aid job prospects he cut off his ponytail (which pleased my mother) and ventured off into Canterbury High Street in search of employment. He eventually landed a job designing T-shirts at a place called Squirt. The idea was for crowds to watch John squirt fabulous designs from tubes of paint straight onto the cotton tops. Excitement mounted with one of John’s original designs, The Big Apple, which sold out quickly in Canterbury and became marketed in London. But despite his Big Apple popularity, Squirt wasn’t really what John was about, especially when he had to listen to the same music video over and over again, usually Status Quo running him down, down, deeper and down!

Status Quo aside, John’s transition to England and married life could only be described as desperate. He’d left everything in the States to marry me and set up home in England.

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21. leaflet accompanying Schering’s combined Pill, Logynon, 1989.
22. ibid

He knew nobody in the UK and ached to have the company of his American friends. He'd no idea how to help me with the disease that had stolen away our honeymoon period. To cap it all, a Baptist church we'd joined refused at first to pray for my healing unless I renounced the acupuncture treatment I was receiving. They believed, naively, that acupuncture came from the Devil. Everywhere John turned to for support seemed to crumble beneath him, prolonging his isolation.

My parents of course, were greatly saddened by my sudden demise and tragic start to our marriage. What upset them the most was seeing me drag my legs along the floor, something that had never happened to me before with the illness. When my legs got unbearably painful they would then become weak and eventually paralysed. There was a definite pattern to the change of sensation in my legs. Mercifully, the paralysis was only temporary and after a few hours some feeling would return once more.

"You look just like the children in Nigeria who had polio," (23) Mum recounted, fighting back tears when she saw me shuffling along the floor on my bottom, my legs straight out in front of me.

Dad, too, saw me in this state. Once, he waited a while outside our front door after hearing my muffled voice from inside, telling him it would take several goes for me to reach up and turn the door handle. He, like Mum, remembered the polio victims from their Nigerian days in the 1950s. That helped to ease his shock in seeing his daughter like that.

My mother wrote out a verse for me from a saint whom I'd never heard of before, St. Teresa of Avila.

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23. Echo viruses and polio come from the same 'family' of enteroviruses. See work by Dr. Elizabeth Dowsett, whose papers linking polio and M.E. are available from the 25% M.E. Group (contact details at back of book).

It was one of few commentaries on the subject of suffering that struck a chord with me, becoming my spiritual life belt; this was similar to when I clung to scripture at the age of 19 to survive.

'Let nothing disturb you;
let nothing dismay you;
all things pass;
God never changes.
Patience attains
all it strives for.
He who has God
finds he lacks nothing.
God alone suffices.' (24)

"All things pass," was my assuagement, longing for our circumstances to be liberated, just as Eastern Europe was melting away from the Cold War as shown by media coverage all around us. Freedom became contagious from one Eastern Block country to another, due to the collapse of the Berlin Wall. If that huge wall could come a tumblin' down, so could the tower of Rapunzel and her Prince.

There were few highlights from those post-marital months but an unexpected one was the discovery of fennel tea. It was recommended by my acupuncturist, a tall, lean Dutch man, to aid my digestion. However, John and I must have poured far too many fennel seeds into the pan of boiling water because the effect didn't just benefit the digestive system. On smelling it, let alone drinking it, we both became as high as kites, giggling, our sides splitting over the silliest of things. It was like children knowing when they shouldn't laugh at something, yet the strain upon them not to laugh makes them do just that.

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24. Quote from St. Teresa of Avila, 1515-1582, taken from St. Teresa's Bookmark.

This time, I ended up on the floor not due to weak legs, but from uncontrollable giggles, with John rolling around just as hysterically.

The fennel episodes were a welcome and refreshing diversion. If John and I were to sum up our first year of marriage, we’d both probably dig out the memory of our decrepit Talbot Horizon breaking down at the numerous Canterbury roundabouts. My elder brother tried desperately hard to fix it and keep it going, as we couldn’t afford anything else!

Individually, John’s memories are playing computer games to blot out his loneliness and his pain of watching me suffer. They became his drug. He also remembers the educational trips around Safeway's supermarket, when ‘cookie’ meant ‘biscuit’ but ‘biscuit’ didn’t mean ‘scone’!

My memories are of staggering with a stick through the narrow streets of Canterbury, wondering if I’d make it home in time before my legs packed up. I also lived in daily fear that John might leave me.

Perhaps we should have drunk more fennel tea together and giggled a bit more often?

Family photo outside our house in Brook, Kent, 1970.
Left to right: my brother Graham, Dad, my sister Rosemary, Mum, me at the front aged 6, two family friends and my brother Paul at the front

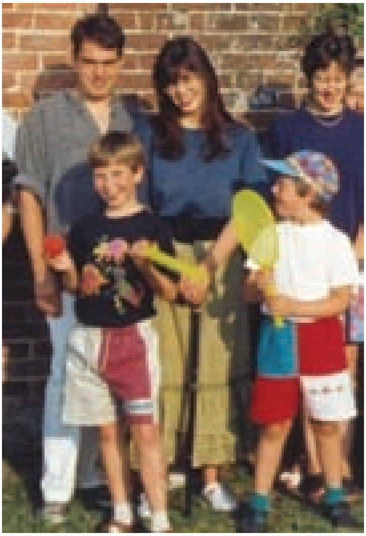
At a time of remission, three years into M.E.
Here, playing the piano aged 17, at my grandmother’s house in York

John and I on our wedding day, September 2nd 1989

Hazel and Alan Turner, my Mum and Dad, at our wedding

A family day out at Bedgebury Pinetum, Kent 1995.
Left to right: Dad, Matthew (nephew), John, me, Nicole (sister-in-law), Mum (hiding), Rosemary, James and Robert (nephews), Isabel (niece) in front, Aunty Joan, Bill (brother-in-law) and Graham

Propped up with a stick
(detail of the day out)



This painting is how many people remember me with M.E.:
dressed warmly with my seat-stick

Family photo in Hyde Park, London, 1996.
Left to right: Nicole, me, Isabel, Melanie (Isabel's friend) and Graham

In Hyde Park, 1996

An Easter card drawn by my nine-year-old nephew Matthew for me in 1997. The empty wheelchair was somewhat prophetic, as my healing occurred shortly afterwards

I climbed this huge fallen tree in Hawkhurst just two days after my healing. My legs were instantly strong after the prayer

10. Labelled with Scorn

As well as his large, grey duffle bag full of art text books, John also brought with him a host of music cassette tapes, mostly of the black soul variety from across the Atlantic. Gospel, blues and jazz were a complete novelty to me until I met John, as I was brought up mostly on classical, disco and pop. But when Aretha Franklin's soulful voice boomed around the house with her song 'Think', the only thing I could think of was to ask John to turn it down. I liked her music but loud sound made me distressed, causing me to shake. Even Mozart's quieter, sweet musical phrases turned to painful confusion in my head. My eyes were also sensitive: light had the same effect of causing distress and I often wore sunglasses, both indoors and out. John said I looked like Bianca Jagger in my glamorous dark shades from Miss Selfridge's, along with a stylish warm hat that I rarely took off. (Although Bianca Jagger didn't wear earplugs to my knowledge; neither did she wear layers of thermals in mild weather, with fingerless gloves clutching a walking stick. Still, beauty is in the eye of the beholder and I took his compliment well.)

In spite of this occasional flash of glamour, surely a diagnosis of my condition was way overdue? Merely referring to it as 'possibly M.E.' was inadequate. It had been 12 years since I first became ill as a teenager and 11 since the discovery of the ECHO 2 virus. So, off I went to my new Canterbury GP to request an M.E. test.

"Do you think I have M.E.?" I asked him, after he commented on how pale I looked.

"Well, you might have but I don't want to put you in a box with a label," he babbled, making little sense.

Label? I either had M.E. or I didn't. He told me that I couldn't be tested for M.E. as no diagnostic test was available in the UK. He did think, though, that I should be checked out by a neurologist which I was happy about doing. (25)

When a few routine blood tests came back as normal (once again), the neurologist seemed more interested in the two years of depression from my late teens rather than my current complex neurological problems.

"Tell me more about those two years of depression," he probed. My heart sank: the depression was ages ago and not the reason why I came to see him. He didn't conduct brain scans which might have shown abnormalities (provided of course that they were read by those trained to read them). He preferred to call my condition 'Post-Viral Fatigue Syndrome', even though the post-viral bit had been going on for more than a decade.

I had prepared myself for a disagreement over the diagnosis, but nothing had prepared me for the insults and triviality directed by doctors towards my disability.

"A little old lady can do better than you. Surely you can try harder?" sneered the neurologist, as I struggled to raise my legs in a medical test. The ensuing pain and weakness made me cry, but he was unmoved. He finished the appointment by saying that I knew more about M.E. than he did which was shockingly honest for a consultant, yet it was also disturbing because I hardly knew anything at all.

Meanwhile my legs kept on burning and my body started bruising from falling over at home.

Other doctors continued to disbelieve my efforts in medical tests, with one saying that I could have breathed harder into a machine which tested for lung capacity.

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25. Since the 1980s, Dr. Byron Hyde from Canada has been using several different kinds of brain scans to help make a diagnosis of M.E. These are SPECT, MRI, PET and QEEG scans. Currently, these are almost unheard of as tests for M.E. in the UK on the NHS.

My reading was barely off the zero mark. In addition, he didn't seem to believe that M.E. existed. Providentially, another doctor diagnosed me as asthmatic and was quick to give me the necessary treatment.

As I did the rounds from GP to GP, hoping that each one would be better than the last, all that was recommended to me was to exercise, including doing aerobics! One doctor even told me to look after John more, when it was *me who came to the surgery for help!* Sadly, medical attitudes towards M.E. hadn't really changed since my teenage days.

John too, started getting fed up with 'advice' from doctors, especially when at one time he heard my distressed voice on the end of a phone pleading with him to come and collect me. I'd been doing my 'treatment' of going for little walks each day, only to discover that I couldn't walk back home. My legs had packed up, forcing me to squat on the pavement, provoking strange looks from passers-by. Doctors' advice had made me worse.

It was in Castle Street, not far from the remains of a Norman Castle, that John came across a timely intervention one day. He'd been walking the streets of Canterbury in his heavy, sheepskin coat (which was more apt for shovelling American snow than for English strolling), when he saw a shiny plaque on a house. Being the visually oriented person that he is, he went up to the plaque and discovered that the house was an acupuncture clinic. (This was the acupuncturist who recommended the giggling fennel tea!) My parents had tried acupuncture treatment for various ailments with great success and they urged me soon afterwards to attend this particular clinic. As orthodox medicine had only offered bad advice so far, John and I felt we had nothing to lose. The acupuncturist ended up being very knowledgeable, giving a scientific explanation behind his diagnosis of M.E., linking the condition to its viral onset. He firmly believed that this was the illness I was suffering from. So finally, after 12 years of being in the dark, I received a diagnosis. I had M.E.

The diagnosis brought overwhelming relief as up until then I'd only presumed that I had M.E. No orthodox doctor had given me that label but the acupuncturist was the closest yet to that goal. He also had a few letters after his name which looked impressive.

Armed with an official diagnosis I searched long and hard for information about M.E. The first place I tried was a local bookshop where I picked up a couple of books on the subject. It was enlightening to discover how much biomedical research had already been done, giving credibility to my illness; also that M.E. had been around for a long time, the first recorded outbreak being in 1934. (26)

With science on my side, I felt bold in telling others of my recent diagnosis, anticipating a reaction of compassion and support which had been lacking from most doctors. Shockingly, the general public jeered at me with a similar attitude.

"M.E? We've all got that! We all get tired!"

"M.E. is quite a fashionable thing to have."

"Isn't M.E. just depression?"

"I've heard that M.E. is just that, dwelling on the 'me' bit. You're too absorbed with yourself. That's why you're ill."

The comments continued from neighbours, shop assistants and Joe Public. The most hurtful, though, was from a relative who told my mother that having a baby would sort me out.

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26. Los Angeles County General Hospital, USA, 1934.

As this illness was ruining my life and now John's, I found the public scorn incomprehensible. It was like being a leper or an AIDS victim, struggling to find acceptance in society. At least leprosy and AIDS were believed by doctors: M.E. had the double whammy of both medical and societal prejudice.

Why did this attitude prevail? It wasn't helped by the phrase 'Yuppie Flu' which popped up in textbooks, a derogatory term from the 1980s media which had unfortunately stuck more than mud in people's minds. That explained the public's perception, but why the hostility from doctors?

Further reading revealed some hurtful events that again I wasn't prepared for. The medical prejudice started, apparently, in 1970 when a psychiatrist, Dr. Colin McEvedy, wrote a PhD stating that all recorded M.E. outbreaks to date were nothing more than mass hysteria. His theory was published in *Time* magazine and accepted without question by both the public and medical profession. (27)

On reading this, a cold shiver went down my spine. But worse was to come. Around the time John and I got engaged in 1988, another psychiatrist called Simon Wessely came on the medical scene. He not only disbelieves in M.E. but has shaped the views of doctors, insurance companies and the Government.

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27. McEvedy and his tutor Alfred Beard had two papers published in 1970 which claimed M.E. to be nothing more than hysteria. Scientific evidence was dismissed and no M.E. patients were examined or interviewed in these papers. Much later on, in 2005, Colin McEvedy was interviewed by M.E. specialist Dr. Byron Hyde. In that interview, McEvedy states that he wrote the first of the papers in 1970 to gain 'an easy PhD'. Hyde concludes that this PhD 'was a total fraud.' See *A new and simple definition of Myalgic Encephalomyelitis and a new, simple definition of Chronic Fatigue Syndrome,* Byron Hyde MD. (*www.nightingale.ca*)

He informs them that M.E. doesn’t exist and that sufferers merely think that they are ill. He advises that state benefits should be withdrawn from these patients; also that they must change how they perceive their illness, agreeing to exercise their way back to fitness and work. (28)

I threw the papers on the floor, hurting my arms in the process. As rage and offence welled up inside me, I thought of times at Art college when my weak fingers couldn’t curl round the paint brushes; of the times when John had to cut up my food and even lift me on and off the toilet.

Then there was the lady in Canterbury who used a motorised wheelchair; she also had M.E. The student who made my wedding dress had recently been diagnosed with M.E. as well, her calf muscles cramping up, causing her to limp.

Were we all pretending, craving some sort of masochistic attention?

These papers explained everything: the lack of compassion, the smirks and mockery from others.

Why were such doctors allowed to get away with writing such things about my illness? It was like reading extracts from *Mein Kampf* which says evil untruths about the Jewish race, or George Orwell’s *1984* when history is rewritten by Big Brother.

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28. Tragically, Professor Simon Wessely’s writings on M.E. abound in published medical magazines. Margaret Williams has written a paper, *Denigration by Design*, [Abridged version, March 2000] which exposes Wessely’s work and that of psychiatrists of the ‘Wessely School’ as being generally unscientific by neglecting much biomedical evidence of M.E. Their work is, in many areas, simply untrue regarding M.E. See introduction for further information.

The scientific evidence of M.E. was being ignored and replaced by psychological lies, just as Big Brother's Party claimed to have invented aeroplanes, when aeroplanes existed long before their claim. Lies, lies and more lies. (29)

As the rain beat down in our cold, dark home which rarely caught the sun, I wished that I had a plane to fly away in. I'm sure John did too. But where would we fly to? The whole world was probably being brainwashed by this filth, permeating the medical profession and straining my new fragile marriage.

My head soon found its way into my hands as I crumpled up on the sofa, wailing inconsolably from what I'd just read, my voice travelling through the walls of our terraced home, audible on the street outside. Despite so many neighbours in close proximity, I never felt so alone.

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29. The use of the word 'lies' here, expresses how an M.E. sufferer feels when faced with literature diagnosing their illness as a somatoform disorder, i.e. a mental disorder exhibited through physical symptoms, which thus ignores biomedical evidence of M.E. Also the character of an M.E. sufferer can also be lied about and defamed through certain medical literature and popular writings.

11. *Complementary Cure*

Being surrounded by ancient English history, from Dover Castle to Chaucer's *Canterbury Tales*, John was inspired to design some original board games which was something he'd done back in the States. Cold Siege was my favourite, in which enemy sides attempted to battle out victory before the arrival of a harsh winter, pre-empting frozen castle moats, iced up catapults and starved attack dogs.

John's own board game designs were influenced by a strategy game called Kingmaker, which he bought one day in a little shop devoted to game playing in the Westgate part of Canterbury. Kingmaker concentrated on the Tudor battle of the War of the Roses and was complete with heraldic symbols. It seemed to go on forever, causing me to yawn after only five minutes of playing. I felt we had enough real battles in our lives without reliving more!

Another game John designed was The Vikings. The board was a map of Northern Europe, meticulously coloured in by hand which showed Danish raiders sacking parts of the world. It was test-played by a local games club with welcome results. I was immensely proud of John's ability to produce strategy games, from the concept through to the design and even the production, all of it handcrafted with minute cut-out cardboard pieces.

Canterbury was a great place to explore, especially as the Cathedral and its grounds were free to the public back then. The Cathedral was the heart of the city, with narrow, vein-like streets shooting off from its pulsating, powerful presence. A stone's throw from the Cathedral was Sweeney Todd's in Butchery Lane, a lively restaurant named after a sadistic barber. The 'death by chocolate' dessert put us on a caffeine high for weeks;

that followed by a cup of giggling fennel tea at home made life worth living! We could afford to eat out very occasionally as John had left his work at Squirt, being promoted to the demanding profession of secondary school teaching. His Viking board game was accepted by York's Viking Museum to sell in their shop but on the condition that John mass-produced it himself. We didn't have the money for that investment: John had to pay off a huge college loan in the States and we were also flying through money in search of a complementary cure for my health. (30)

The acupuncture clinic in Castle Street felt like stepping back in time, way back to a former civilisation. Detailed maps of the human body, bordered by Chinese lettering, hung on the walls showing the channels of Qi (or energy). The rooms of the clinic were bare and sparse with little furniture, maintaining a kind of Feng Shui balance. The thought of having needles stuck into my body terrified me, especially as my muscles were painful to touch. Would I look like a voodoo hedgehog after treatment, with the acupuncturist casting a spell over my disease? When you're desperate, you try anything, even looking like a hedgehog.

On trying it though, there was no hint of voodooism at all but a methodical, scientific approach steeped in ancient Chinese tradition. The fact that the treatment had lasted so long, centuries before Christ and outdating orthodox medicine, was one reason I kept returning.

The concept of meridians, reading pulses and burning moxa, all went over my head. Yet acupuncture helped me; you don't have to understand something for it to work. The pulses were the most mysterious; they weren't in the form of reading pulses in the wrist, but analysing energies in the lower forearm.

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30. John's game-making *did* help to get him another teaching job later on. Nothing's wasted.

“Have you just had something cold to eat, perhaps some ice cream?” asked my acupuncturist in his heavy Dutch accent. Holland and China didn’t seem to go together, somehow.

“Yes, I have, about half an hour ago,” came my amazed reply.

He could tell that I’d eaten ice cream just from feeling my arms! John and I found this so disturbing that we avoided romantic physical contact on the days I had treatment, in case the acupuncturist could detect that too.

Acupuncture helped me with my breathing, muscle weakness and temperature control. Gloves and thermals were no longer my second skin and I could enjoy sunny days without diving for sunglasses and shade. What helped most of all was a liquid herb called ‘Tieh Ta Yao Gin’ which stained my legs bright orange, like a tropical bird. It helped to take away my leg pain by increasing the blood flow; it was also used, apparently, to heal bruises for Chinese wrestlers! So I stocked up on it, filling the bathroom shelves to overflowing because it was transported literally on a slow boat from China.

The search for a complementary cure continued, with the acupuncturist recommending huge vitamin pills which looked like something for dog mange. Boxes of exotic herbs were delivered straight to our doorstep from the Amazon rainforest. I read that Hitler took the same herbal supplements as I did from the Amazon, which wasn’t very comforting. I didn’t want that on my medical records, in case I was labelled wrongly as having delusions of grandeur.

All these medicines cost a bomb especially as I sometimes had three acupuncture treatments a week. It was way too much for John to pay for as a new employee of the teaching profession, and definitely too much for Squirt. As for my college grant, that was mostly used up during the first week of each term, although not all on fennel tea. So my faithful parents stepped in once again, insisting on paying for all the acupuncture treatment. It was wonderful to observe John’s relationship with my Dad blossom into an affectionate one: they were similar personalities, putting spiritual values over material ones and living very much for the moment. Their bonding helped to heal John’s traumatic loss of his own father who’d died suddenly, a while back, in tragic circumstances.

Meanwhile, I had a college degree to finish which required every ounce of my energy. Standing and talking drained me so much that John wrote out and photocopied some leaflets to students in the college corridors and canteen. It read something like this:

‘I have M.E. This means that I get fatigued very easily, especially by standing to talk and by conversations generally. Please don’t talk to me whilst I’m in college as I must put all my energy into my degree. Phone calls at home to chat are very welcome. My phone number is 0227 … ’

I didn’t feel comfortable in handing out these leaflets, especially as some of those I gave them to had attended our wedding. The degree, however, was slipping through my fingers unless I did more work. So I handed them out and waited by the phone in the evenings, hoping it would ring for a friendly chat. But not one person I handed the leaflets to phoned me: obviously they didn’t understand.

Despite this, students were caring in other ways, especially by opening doors for me as my hands struggled to turn handles. My hands also struggled to curl round pencils or paintbrushes, so much so that sometimes I was forced to return home early and rest. College tutors were generally supportive, more so than teachers at school and even handed me my own key to the building so I could come and go as I pleased, including at weekends! My art work continued to take on a political feel, inspired by the ‘fatwah’ imposed upon Salman Rushdie for his book *Satanic Verses;* also, by the protests in Eastern Europe when citizens smashed down the Iron Curtain. Tutors weren’t used to such illustrative Fine Art and had trouble accepting my work because it didn’t fit into the Canterbury Art College style.

When the fumes from turps and oil paints accumulated in the studios, weakening my body as a result, it was tempting to throw in the towel and quit. John spurred me on as he gallantly typed up my handwritten pages for my dissertation. At the graduation party, a brilliant blues band played; there was nowhere to sit and because I couldn’t dance, I sat on the sticky, beer stained floor, watching John dance with everyone else. He was such a funky dancer, having learnt that from his black friends in the States. I loved watching him dance but felt downcast that I couldn’t join in.

Yet I had my piece of paper, my degree in Fine Art, despite the fact that my work was different to other students. The certificate, though, didn’t mean art to me so much as the pain and perseverance behind it.

12. *Vicious Circles*

The eyes of the fly stared saucer-shaped at my own drooping eyelids before it darted about, intermittently crawling over my tender, sensitive skin. Just as I would nod off, it would fly back over my face eventually settling on my hair. The fly swat was in the kitchen but I was too weak to get off the sofa due to a previous poor night's sleep. (Lack of sleep caused astonishing muscle weakness and even slurred speech, so a long daytime nap was essential for my recovery.) The more the fly buzzed, the more I was awake; the more I was awake, the weaker I got; the weaker I got, the less strength I had to murder it. This vicious circle seemed to typify life with M.E.

Later, when John came home and observed my distress, he thrashed the daylights out of the fly as only an American can, being influenced I'm sure by the Constitution's right to defend oneself.

Another vicious circle which was soon to rear its monstrous head couldn't be crushed as easily as the fly. This one came from the Department of Social Security. I hadn't previously experienced the 'privilege' of Britain's benefit system, of 'easy hand-outs' as we're led to believe; I thought that a disability payment would be easy for me to get, seeing as I walked with a stick and spent a good deal of time dragging my legs on the floor. Amazingly it wasn't easy at all, especially as there was no straightforward benefit to suit my circumstances. Unemployment benefit was solely for those who were looking for a job, which I wasn't because I was ill.

"Try Incapacity," said a concussed-sounding civil servant as she ploughed her way through the admin maze. "That's for sick people."

But Incapacity Benefit is only payable if the claimant has had enough NI contributions paid in by their employer. I didn’t have an employer because I was too ill to work in the first place! (31)

“Try Severe Disablement Allowance,” said another civil servant, sounding like the monotone drone of a Dalek. But SDA is given only to those who are at least 80% disabled. Despite my disability, I wasn’t that bad (yet). So, I was too ill to work but not ill enough to be on benefits!

When my last pot of Amazon herbs ran out, I felt too embarrassed to ask my parents for more money. They were still paying for the acupuncture. I tried to get Evening Primrose Oil on the NHS as it helped with muscle strength but it wasn’t prescribed for M.E., only for eczema and mastitis. Illness became a huge drain on our finances, especially without any NHS support.

“The cost of living in this country is much greater than in the States,” commented John, as he filled up our rusty Talbot Horizon after yet another increase in petrol price, or ‘gas’ as he called it. “Why don’t we try living there?” he asked with persuasion.

But the thought of moving country overwhelmed me: temperature extremes in the US and learning to drive on the other side of the road all seemed too much. (John had passed his British driving test, learning to switch from an automatic to a manual and drive on the left, that is the right [or wrong?] side of the road!) However, the main reason I wanted to stay in England was because of my family as they understood my illness. So we stayed in ‘rip-off Britain’ as John called my beautiful country!

Yet England didn’t seem that great a trade-off, after all. An official from the DSS (32) pronounced me ‘fit for work’ even though I couldn’t do the washing up at home!

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31. NI stands for National Insurance contributions.
32. DSS stands for The Department of Social Security.

There was prejudice against M.E. from every authoritative decision-maker: from drug prescriptions to benefits. When the Community Charge came along, a massive local tax, there was no money left for seeking a complementary cure.

“I’m going to have to work,” I groaned to John one evening from the sofa, my usual place of rest, “ …to pay for my medicines.”

John put his computer on the pause button and turned to me with a frantic look.

“Don’t be ridiculous, Catherine!” he exclaimed, his American accent stronger than usual. “You’re too weak to do the grocery shopping, let alone go to work!”

He was right: I often ended up squatting in the aisles of Sainsbury’s or Safeway’s, balancing between a stick in one hand whilst struggling with a trolley in the other.

The only profession I could think of going into was teaching. I figured that once I got my qualification I could do supply work (or substitute teaching as it’s called in the States). Just one day a week would pay for the acupuncture, herbs and Evening Primrose Oil. The missionary idea from my teenage days had fizzled out: visions of David Livingstone hacking down hazardous forests in hostile conditions, was something I no longer wanted to be part of. It was hostile enough for me to stagger down the pavement with my stick contending with dog mess.

As for John, he never wanted to be a school teacher: he was always more interested in the collegiate level of art teaching. The school he taught at in Canterbury made national news, not due to outstanding grades or any special achievement but because of a pupil riot. The kids went crazy when they heard that some of their favourite teachers were made redundant, pulling up flower beds and desecrating the school as a result. John’s introduction to English schools had been tough, with pupils throwing paint rockets at our Talbot Horizon (which almost improved it) and teasing him with their version of the American National Anthem. John warned me, “Don’t go into teaching, Catherine. They’ll run rings round you.”

But I couldn’t think of an alternative solution. I needed my medicines to prevent deterioration of my health. So we uprooted from Canterbury and planted ourselves in Palmers Green, North London, which was the nearest course to train me as an art teacher. It didn’t look like London though due to little, old Greek women in black buying aubergines; instead it looked more like Cyprus without the sunshine. John didn’t mind too much about giving up his job in Canterbury as he didn’t like it.

“Don’t worry, darling, there’ll be plenty of work in London, I’m sure. If not, you can always sign on the dole – everyone else does,” I told him naively.

But London was at the height of a recession when jobs were like gold dust. As for signing on the dole, that was a myth: John had given up his job in Kent so wasn’t entitled to any Social Security money for at least six months. We were virtually penniless, at one stage having only 10p to our name and selling our television to pay for the rent. So much for me and my bright ideas.

John started brushing up on his sopranino skills, thinking that he might have to go busking again as he did in Canterbury, when we were first married and poor. Instead, he found ready money at a local butcher’s, designing posters in exchange for meat and a few extra coins. Bright cartoon pictures of Porky Pig and Larry Lamb paraded the windows of the butcher’s shop, the animals looking so cute that customers considered becoming vegetarians! Our poverty drove us to being first in the queue for free Harvest Suppers; first due to not only my weak legs but also due to our hungry appetites. Our clothes came from jumble sales, where we even bartered for the prices. At least Palmers Green, being relatively wealthy, had some stylish bargains.

With London on our doorstep, John as an American was anxious to explore the capital but we couldn’t afford the tube fares most of the time, let alone a pizza takeaway. All of this strife and uncertainty enveloping our lives was due to the Government’s refusal to recognise M.E. and not pay for my £40 a week sickness benefit. If I could have just had that sickness benefit, I wouldn’t have had to study for my qualification because the benefit would have paid for my complementary cure. We wouldn’t have moved to London and John wouldn’t have become unemployed.

As for my teaching course, I didn’t tell others that I had M.E., pretending instead that my walking problems were due to a bad back and sprained ankle. Telling the truth would encourage disparaging comments and an unwanted watchful eye, waiting for me to fail. My walking stick folded up into three parts, held together by an elastic cord. I used it outside the college grounds and schools but folded it up once inside. Pupils brought work to my desk and carried my books and art equipment for me, whilst I looked in desperation for somewhere to sit down. Furniture of any kind became my life-saver, hanging onto it for support, pretending I was a laid-back teacher with a casual stance. The pupils found my jumbled-up language entertaining, such as ‘to kill two stones with one bird’ and asking them to open the door when I meant the window. Once home, John watched me drag my legs along the floor from using them too much in the daytime.

“You must be one heck of a good actress, convincing them that nothing’s wrong with you,” he observed, visibly upset.

The whole thing resembled a mask, such as when the Queen smiles in public although she might have a headache, or a ballerina who keeps on dancing although her feet might be bleeding.

Despite this, the Sixth Formers showered me with gifts and cards once my course was completed and the Head of Art commented that I was one of her best student teachers. My conscientiousness made up for my lack of physical strength as I was presented with yet another piece of paper, a teaching qualification, to place alongside my art degree.

But John had more bits of paper than me, including a Masters Degree; yet he was using his to churn out Charlie the Cow and Vince the Venison pictures. Was it all really worth the hard studying and sacrifice?

When we cancelled a social engagement which included a free meal, it was obvious that we had to leave recession-gripped London. We couldn’t afford the petrol to travel to our free dinner. John started applying for teaching jobs outside the capital and we ended up in expensive Kent again, although this time in the quaint market town of Cranbrook with its crammed, white weatherboard houses. I got a job in a Sussex school where I was the only Art teacher and John got a job at a rough and tumble secondary school in Cranbrook. My job was only part-time, enough to pay for my complementary medicines, which is what our time in London was all about. Yet within a year I gave it up: my legs wouldn’t work to check toilets for daring smokers, a duty assigned to me, and my arms wouldn’t work to unpack boxes of materials delivered to the Art Department. Cutting tape with scissors weakened my hands. I tried teaching Adult Education, including Art ‘A’ Level which I loved doing, but had to give that up for similar reasons of weakness. Someone suggested teaching from a motorised wheelchair but my brain was so scrambled that lesson plans were becoming more and more muddled in my head.

My body was now in a worse state than when we lived in Canterbury. Despite being able to pay for the herbal medicines and acupuncture, ironically they weren’t helping much any more as the M.E. was becoming progressive. No-one had told me the golden rule of M.E. self-help, which is never to push yourself to the maximum but always to do less than you can, saving energy for the body to heal itself. It was too late for that golden rule to work.

With sore throats and colds picked up from schools and continual bouts of bronchitis, I knew that the portraiture class I taught would be the last time I ever worked. The homes we rented were often bronchitis traps as landlords merely painted over mould-drenched walls. We couldn’t afford to buy a home in the over-priced south-east, making us vulnerable tenants.

After my last teaching class, my legs packed up for an entire fortnight, just from the effort of standing for two hours. I lay down on the sitting room sofa, unable to drag myself upstairs to use the toilet. Without a downstairs loo, I used an empty ice cream carton for two weeks as a substitute; a point of unfamiliar humiliation. A commode would have been more practical but neither of us would accept how ill I’d become.

We moved again, to a local downstairs flat without stairs (complete with a fresh lick of paint to cover the damp walls). If only I hadn’t felt pressurised to go to work or do my course, perhaps my health would have improved. There was no way we could buy a home now, even with John working full-time.

The worst vicious circle of all was literally trying to stay alive: the effort of breathing actually made me out of breath. There was welcome relief on seeing the rosy fingers of dawn curling round the bedroom curtains, announcing to me in my semi-conscious state that I’d made it through the night.

PART THREE

SEVERE DISABILITY

13. *An Accepted Sorrow*

The sun grew hotter and hotter, transforming Kent into a corner of the Mediterranean, although the lack of cypress trees was a bit of a giveaway. The broad oak trees around us looked so inviting under their shade, with ash and beech proudly stating their English heritage. Yet the land was scorched by pounding sun rays, mercilessly sucking out the life-giving sap of the once greenery. We'd moved to a little town called Hawkhurst, steeped in smugglers' secret tunnels lying under floorboards of pubs and churches. It was July 1995, marked by a heatwave that went on month after month. Our new flat had no stairs, one reason why we'd moved there; my legs felt the benefit immediately from a more compact home. We'd downsized but the country view from our back window certainly hadn't: it was stunning, of rolling Wealden hills, sheep, horses and woods with a glistening lake. The beauty of the uplifting view couldn't be exaggerated even if you tried. It reminded me of my childhood home in Brook, on the other side of the county.

John attempted to capture the scenery through a large painting, eventually hung in our new home. During the summer holiday he spent day after day in the sizzling heat working on a long canvas; the yellow tones looked like rapeseed on the picture but they represented the parched fields and dry land. Various shades of yellow contrasted with the cerulean sky, the colours as bright as a Van Gogh painting.

"Another beautiful day!" neighbours commented on the global warming effect.

But to me each hot day felt like miserable isolation in a desert: my body couldn't cope with the heat, just as it couldn't cope with the cold. Dull, overcast, mild weather suited me perfectly but not extremes. The fan heater was switched from the winter setting to a current of chilly air directed straight at me, keeping me cool as I couldn’t perspire. (Apparently, women don’t sweat, they glow instead.) How I longed for one drop of perspiration or glow to drip from my body and cool me down! The ironic thing was that in a few months time I’d be back to my thermals and layers of socks during the autumn weather due to my body temperature in constant disarray. I’d been known to wear a woolly hat in bed, probably one of the best contraceptives around.

Through the open windows came the sound of noisy lawnmowers and screaming children having summer fun, making my earplugs plunge further and further down the ear canals, blocking out background noise to alleviate my distress. I thought back to times as a child when shouts of summer games never bothered me, and as a baby when I’d only go to sleep with the sound of the vacuum cleaner on (so I’m told). Now, I felt like such a party pooper due to the progressive effects of M.E. because every sound was heightened.

“I’m always going to have M.E., John. It’s getting worse every month,” I sighed, as he turned on the kitchen tap for me, my own hands too weak to do so.

“That’s very sad,” he responded, staring out of the open window, avoiding any eye contact that might have triggered pent-up sorrow.

All the healing from the acupuncture treatment had been undone as a result of my teaching course and going to work. Back came my Bianca Jagger shades to block out light, although hers weren’t clip-ons like mine.

With a new home came a new GP, the first GP who actually tried to treat me after 17 years of M.E. She was like a blossom in the wilderness.

“Let’s give it a go!” was her motto as I showed her the latest M.E. information.

Our relationship was based on good old-fashioned trust – she knew I wasn’t going to sue her if treatments were unsuccessful. She even got me a consultant in London who was an M.E. specialist. The trips up there were exhausting but worthwhile.

When it rains it pours, so the saying goes. In spite of the heat wave, medical support did suddenly pour. Besides my new GP and consultant, I also found myself taking part in a medical experiment at a nearby hospital. As the sun continued to beat down, the phone rang one afternoon with the voice of a pleasant-sounding young man on the other end. He was a registrar, of Greek extraction, interested in M.E. research and hormonal levels. Just before our meeting, I prepared myself for the usual line of defence with doctors, gathering my emotional armour.

“I’m not a hypochondriac, or couch potato and don’t spend all day flicking through Australian TV soaps... I really am very ill,” my mind rehearsed over and over again. But my bubble of medical hope soon burst on finding out that the registrar was a psychiatrist. I felt too awkward, though, about cancelling the appointment.

“If he’s another one who tells me to join an aerobics class, I’ll trip him up with my sticks,” I conspired.

Thankfully, on meeting him, there was no climate of scepticism and he believed every word I said.

“My background is immunology and I’m convinced M.E. has a physical cause,” he said (33), his hands gesticulating with enthusiasm on explaining the project.

That distinctly brought music to my ears, coming from a doctor. But coming from a psychiatrist it felt more like The Philharmonic Orchestra with fireworks!

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33. Dr. Soutzos discovered that M.E. sufferers had an excess of the sleep hormone melatonin in the daytime (*InterAction* Issue 27, 1998: 4). Another doctor, Dr. Vesselinova-Jenkins, discovered that M.E. sufferers had too little melatonin at night, causing a sleep reversal pattern (*InterAction* Issue 25, 1998:26).

"Perhaps one or two sensible psychiatrists exist after all?" I pondered with hesitation.

Despite these three doctors being welcome lights in almost two decades of prolonged medical darkness, their help came a bit too late for comfort. Medicines which worked for a few weeks or months wore off after a while, causing dashed hopes and further disillusionment. Boxes of the Chinese herb 'Tieh Ta Yao Gin' no longer helped me. We threw 10 bottles of it away as we didn't know of any Sumo wrestlers who might want the potion.

It was difficult to accept the fact that medicine which once helped no longer did. It was humiliating to accept that I needed constant practical help. It was crushing to realise that I had become ill enough to be on the highest disability benefit, assessed as over 80% disabled.

How does one accept this? Where does the process of acceptance begin and how does one enter it? The great halls of learning at my Grammar School had been faultless in their teaching of Latin verbs and Pythagoras' Theorem but were lacking in life's preparation for disability, career loss and social isolation.

Finally, acceptance was forced upon me when I handed money to a complete stranger in a fish and chip shop. He was standing in the queue and I requested that he placed my order. My legs were too weak to stand in the queue, so I gave him a £10 note whilst I sat on my seat-stick in the corner of the shop. The meal, correct change and words of compassion were all promptly delivered. With my frequent bouts of hypoglycaemia, nothing could come between me and my food, even if that meant encountering humiliation.

The process of acceptance continued, eroding away the pride of independence so entrenched within my spirit. I watched helplessly as my sister Rosemary and a nearby friend cleaned and hoovered. A team of local helpers later evolved, their sleeves rolled up, ready to tackle decay and disablement. There was Betty who made our bathroom tiles sparkle like a TV advert; Mary, who left fresh lasagnes on our doorstep; Joan, who worked at the supermarket and pushed the trolley for me and Elsa who'd run me around in her taxi at short notice, fitting in little unpaid errands. It was degrading at first watching other women iron John's shirts, confirming my failure as a housewife. Acceptance was certainly painful.

Severe Disablement Allowance (the state benefit given if you're over 80% disabled) was difficult to get. I was refused it at first even though I used a wheelchair! My MP at the time was a Government heavyweight in the Cabinet and he intervened successfully for me. When the benefit was finally awarded, the State decided my illness was 'permanent', with my GP adding that treatments were ineffective for my condition. Permanent disability? Ineffective treatments? How could I cope with all this emotionally?

The words 'permanent disability' jumped out from the cold, impersonal, typed letter, crushing any hope of recovery. I had two clear choices: to either deny my disability or accept it. Denial was the easiest path to take, one which consumed less energy as it ignored the truth. Acceptance was by far the harder choice being an act of the will – viewing the situation with all its warts, wrinkles and cellulite so to speak. Once the painful shock of seeing things in fluorescent light was over, I could move on and get on with my life, even though that meant 'being' rather than 'doing'.

When acceptance won through, it became easier to talk to others about the illness and how it affected me. Beforehand, I wanted to avoid the subject altogether.

My friendship with Anna-Liza had gone a bit rocky as I distanced myself from her for a while, upset that my career had come to a grinding halt whilst hers was flourishing as a producer for Canadian radio. The process of acceptance healed this rift of my making and our friendship became stronger than ever.

One thing which was enormously easy to accept was a new car to replace our rusty Talbot Horizon; no battle of the will there! Our new second-hand car was a rust-free white Rover, from my brother Graham’s garage. John and I felt like royalty as we drove it around the rolling Wealden hills.

There was one area of acceptance though, that was too painful to accept: that was the subject of children, or rather lack of them. We both longed for children, excited over the idea of parenthood. It was one reason we got married, to create and raise Anglo-American hybrids, even choosing their names before they were born. There was nothing wrong with my reproductive plumbing but going through labour or having a Caesaraen would have finished me off. I couldn’t take chemical drugs without a severe reaction: even a local dental anaesthetic made me go unconscious; consequently, extensive surgery and drugs were unthinkable. Apart from all this, being on call 24/7 for a baby was a joke in my condition because other people already looked after me!

Sweet little photos of friends’ babies sent a poisoned arrow straight through my heart, as they fell out from letters and greetings cards. They were sent with love and rapturous joy which could be sensed through the words of excited handwriting; but the poison from the arrow came from my own inability to accept my motherless condition. John said kindly that he didn’t mind the childless label, yet I knew deep down that he longed to be a father and was protecting me from feeling a failure.

Something else which was difficult to accept was the wheelchair. Although I had my own, the battle to accept it didn’t come overnight either, just like all the other hurdles to be crossed. In fact, using a wheelchair in public took me an incredible six years to accept.

14. Positively Disabled

The wheelchair at first filled me with horror. There was something so final about it, as if it was one step nearer the grave. My fear was that people might look down on me with condescension because of the low position of the wheelchair.

John and I both kept putting off my use of a wheelchair. For him the reason was due to sadness, a reminder of his wife's further deterioration; for me it was a mixture of pride and dread.

"What if I see someone I know, especially someone I used to teach?" I'd panic with a timeless excuse. "How embarrassing for them and for me!"

It was when my walking distance became reduced to a maximum of 50 yards, that it dawned on me that the wheelchair itself wasn't the stumbling block but rather my attitude. If my attitude didn't change and also John's, my dreary existence would consist of little more than staring at the same four walls.

What changed it was a trip to the National Portrait Gallery in London. I longed for a day out somewhere and John agreed to give the wheelchair a go. Sumptuous paintings sprung up everywhere which I could now view with ease from my new mode of transport.

"Why on earth haven't I used a wheelchair before?" I scolded myself for being such a martyr for pride.

The first wheelchair came from the Red Cross on a temporary loan. A huge barrier seemed to break down when John and I collected it together as a couple. We both gradually accepted the metal monstrosity. Yet when we got home, the wheelchair seemed so out of place with the rest of our furniture, even when it was folded up. There was nowhere to store it so I disguised it with patterned cloth, turning it into an avant-garde chair.

The loan wheelchair was swiftly replaced by one of my very own, a gift from an aunt and uncle in Hertfordshire. The fact that it was my own made it easier to accept, especially as the value ran into hundreds of pounds. Instead of disguising it, I warned people to be careful with it; the metal footrests and cushioned armrests were extensions of my own limbs, as my identity emerged with this once hated object. The wheelchair became my legs, my freedom; the former hatred of it was replaced by a strange kind of fondness.

Once John and I accepted being seen in public with it, we had another hurdle to overcome – that of the public's attitude to disability. Intrusive comments shocked us both; that, combined with frequent lack of access made me wish, sometimes, that I'd stayed at home.

The public seemed to think they had a right to know what was wrong with me.

"Is your illness temporary or permanent?" inquired a middle-aged man in a pinstriped suit at Charing Cross Station. He was a complete stranger, didn't even start with a 'Good Morning', yet felt he could get away with intrusive questions.

"What's wrong with you?" was another question frequently asked by other strangers. They seemed threatened when looking at a young person in a wheelchair.

If people didn't ask rude questions, they'd ignore me altogether, talking to my carer over my head as if I was deaf or stupid or both.

"The upstairs floor of the castle is out of bounds to wheelchairs, I'm afraid," said a guide to John at Hever Castle, completely ignoring my existence.

"I can walk a few steps if that will help," I responded, trying to have a say in my fate.

"Oh, you can walk, then?" she suddenly turned to me, surprised that I could even speak.

"I've got a teaching qualification, you know," I found myself snapping at her.

"I'm not a complete imbecile!"

It was tough. Guides weren't trained properly in communication skills and I wasn't prepared for the dreadful stares given by crowds just because of the wheelchair. Why couldn't people see past the metal frame, to my personality, to the real me? I longed to talk about art, music and poetry, not my illness.

"Just relax and be your normal selves with me," I wanted to tell all the staring faces. "Treat me the same as everyone else. If you feel like smiling, then smile. If you want to talk to me, then talk. The only difference is that I might need some extra practical help. Otherwise, there's no difference."

At traffic lights, people revved their engines as my pusher puffed their hardest, often to discover that where we were heading wasn't wheelchair compatible after all. Shops with narrow aisles, no lifts, and pavements which finished without warning all caused us disappointment.

"Where's the ramp?" I'd jeer out loud, embarrassing my carer. Now that I had first-hand experience of lack of access, I had every sympathy with disabled political activists.

John pushed me the most in the chair, with my Dad and brother Graham also treating me to days out. Women friends also helped to push, but you have to be physically strong for such a task. Although my size wasn't that of a Dawn French, it wasn't a Kate Moss either. My arms were too weak to propel myself, so although the wheelchair brought freedom, the freedom wasn't released until someone offered to push me.

It's true that you don't always see something unless you're looking for it. Now that my identity was that of being officially disabled, John and I became aware of the media's representations of disability. Once again, we were shocked at how the wheelchair was shown to be an object of derision in films and programmes: the disabled person was usually elderly and laughed at. Perhaps it had always been like that in the media but we'd never taken much notice of it before.

There also appeared to be a division between 'the well world' and 'the disabled world', a segregation which was, in my opinion, unwelcome. Even access to buildings was separate for those who could walk compared to those who couldn't. My family treated me to a theatre trip only to be told that I had to enter through a different door whilst they entered through another. They congregated in the bar to have a drink before the show, whilst my pusher and I had to go straight to the seated theatre area, as our corridor didn't stop off at the bar. The logistics of access meant that I couldn't join my family for a drink (even if it was my coveted drink of mineral water with a slice of lemon).

Even the word 'disabled' seemed negative, as if the metamorphosis of that condition was a bad thing. Yet it wasn't all bad, especially when I got to know people of other disabilities who'd lived with their 'different' life for a lot longer than I had.

One such person was David, a local middle-aged man who was blind from birth. I met David at a supermarket in Cranbrook; we were both sitting on a plastic bench behind the check-out counters, lined up with the elderly whilst other people did our shopping. I didn't take to this new identity group very easily, of sitting next to a row of society's 'misfits', the weak separated from the strong.

David was an intelligent man although recently made redundant. Whilst wiling the time away, he asked me to describe myself to him.

"Well, today I'm wearing dazzling blue nail varnish and a bright red scarf… "

"Colour means nothing to me, Catherine," he responded with a smile.

For a moment I studied his thick dark glasses and felt so tactless by my throwaway comment. I hadn't really stopped to think about a world without colour. How awful it must be for David.

"But I can't walk very well," I went on, trying to convey concepts blind people could understand.

Then as someone handed David his shopping, he turned to me on leaving the store. "I'll go away today grateful I can walk because of meeting you," he beamed.

"And I'll go away grateful I can see colour," I replied.

Despite our obvious line of public segregation, my new identity group of the blind, lame and tired toddlers was teaching me a new enlightenment. Our weaknesses had been exposed by enabled strength all around us, yet values exchanged by David and me were probably the best trade done in the shop all morning. Gratefulness couldn't be bought at the till; only grasped behind dark glasses and walking sticks.

Another disability group I got involved with were those suffering from learning disabilities, especially Down's syndrome. A stone's throw away from our flat was a home for them; about once a month, I'd totter in on my sticks and teach them some music. One lad carried my guitar, something he relished doing, whilst another would get me a chair. My hands couldn't play for long and my voice quickly ran out of breath, yet it was my contribution to society no matter how small. At first, I found these people to be shocking to look at, their friendliness an invasion of my privacy and their lack of intelligence an irritating hindrance to conversation. But the more I got to know them, the more an inner beauty unfolded from their kindness and I saw past their awkward speech, just like seeing past a wheelchair.

Although they were a bit strange looking, their love for life made them more beautiful than frosty faced models strutting on a catwalk.

My family's reaction to the wheelchair was generally favourable. My niece Isabel was very keen to push me when she was only five years old! My father enjoyed the opportunity of being my carer for the day and he and I exchanged many giggles when shop aisles weren't wide enough for my wheels, making us knock down displays of slippers. It still took John a long time to accept the wheelchair but each trip out made him more confident and comfortable with this essential extension of our union. Wherever I went, the wheelchair came too, making three of us in the marriage!

Disability was now a part of us both: John couldn't escape it any more than I could. It was a part of him as much as his American accent and love of basketball and it was a part of me as much as my auburn hair and love of art.

The sitting room looked like a mobility aid shop, with magazines on disabled travel scattered around and how to update wheelchairs. The kitchen too, teemed with further evidence of weakness: gadgets to turn on taps, special utensils to cut up food and devices for unscrewing jar tops. My hands could no longer grip properly, twist or chop anything up. Even a seat was put in the shower so I could sit down and wash.

Disability affected my appearance: flat shoes were a must but they always looked so ugly, especially with dresses. My clothes were often baggy so as not to hurt my muscles and my bra was a size bigger for the same reasons, causing my boobs to sag! Being unable to exercise and having to eat every few hours to stabilise my blood sugar meant that pounds of flesh were creeping up on my figure. This was when the Down's syndrome people helped my perspective, confirming that inner beauty is more important than outward appearance.

The wheelchair had changed my viewpoint, both literally as passers-by loomed high above me in the streets and also philosophically. It opened up a world of culture and enjoyment after my pride had been overcome. The bedroom ended up being its storage space, folded in the corner, making me dream of future trips out to museums, galleries and gardens before nodding off to sleep at night. Like children who fall in and out of favour in the playground, the wheelchair, once an enemy, had become a best friend.

15. *Rainbows Through The Rain*

‘O joy that seekest me through pain
I cannot close my heart to thee
I trace the rainbow through the rain
And feel the promise is not vain
That morn shall tearless be.’ (34)

One enemy which never became a friend was pain, a constant companion, which like a Siamese twin never left my side or my mind. When I tried to ignore it, it nagged incessantly like a demon on my shoulder every time I moved or even stayed still. Just as Art College hadn’t prepared me for a lifetime of disability, I was equally ill-equipped to cope mentally with pain. How does one overcome a continual burning sensation, making the muscles and nerves feel on fire, giving no respite even in sweet slumber?

Of course, writers of books had all the answers. Pain is there for a reason, to be welcomed and hailed as a contributor to strength of character. Some suggested that God should be thanked for pain because He should be thanked for all things. I found such comments to be insulting to both God and sufferer, mindful that even Jesus shed tears during His dark agony in Gethsemane. Authors of books appeared to know *about* pain, using debating techniques, but few if any had *experienced* the battering power of pain’s negative force.

Emotionally, the only way I could cope with pain was to stay positive. My willpower was quivering on a tightrope, ready to crash and come tumbling down the moment I stopped thinking positively. If anyone poured out their problems, I would ‘crash’ as a result, unable to cope as I needed every ounce of energy to fight the pain.

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34. From the hymn *O love that will not let me go* by G. Matheson.

Depressing news headlines were switched off and films like *Bambi* were tolerated infinitely better than *Reservoir Dogs.* Maybe this wrapped in cotton wool world wasn't reality, but if it helped me to stay on top of things then that's all that really mattered. Staying positive, no matter how, was my coping mechanism.

"You're not walking very well today, Catherine," commented a neighbour who carried my shopping, whilst simultaneously casting an eye over my awkward ataxia.

"No, but at least I can walk a few steps. Yesterday I was bedridden."

This kind of attitude, of denying my pain, became the norm. I could accept my disability and the wheelchair, yet facing up to moment-by-moment pain was something I didn't have the energy to do. There was no energy left to willingly accept it. Pain was by far the most challenging of all symptoms to deal with.

Some artists from The Mouth And Foot Organisation say that painting is the best distraction therapy for them from pain. Despite my love of art, I personally found painting to be too tiring, whereas playing the piano worked better for me as a distraction therapy. Most days my hands were too weak to play, but when feeling in them occurred, an evocative Chopin prelude would penetrate into the pain grooves, providing some fleeting healing like calendula cream on heated pox.

Every touch, every pressure was a painful experience, from the weight of a tray on my lap to putting on a pair of socks. Getting dressed was akin to torture especially if tights were worn, their synthetic tightness highlighting the anatomical tightness of my bruised muscles.

"Mind Auntie Catherine's legs!" was an order frequently given to my young nephews and niece as they played around me. Each child in their own individual character reacted differently to the warning, some being mindful to keep away whilst others purposefully touched my legs for a reaction.

‘Tyger, tyger burning bright… (35)
Burn baby burn… (36) Eternal fire burns within… (37)

My scrambled mind, surfacing now and again for some kind of desperate hope, could only think of lyrics which all had one word in common... *burn.* There was no better word to describe the despairing sensation in my legs and arms. Even the name Ashenfelter derived from the word burn, due to ashes from the farmers’ burnt fields at the end of harvest. Was I doomed to live out my own names, including that of Catherine which means to purify?

But philosophical reasoning doesn’t last long when you can’t see beyond one day at a time; when you don’t know how you can mentally survive the hours between sunrise to sunset; when nerves feel so raw that you feel like a burns victim without the outer, only inner scars.

John felt helpless much of the time whilst watching me suffer: hearing my weeping groaning was too much for him to bear, forcing him to go into a different room and check up on me periodically. Few painkillers were prescribed to me due to doctors’ lack of knowledge about M.E; this was combined with my inability to take many drugs anyway, because of side-effects. Even one aspirin tablet made me semi-conscious due to my brain’s frightening reactions to chemicals.

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35. From *The Tyger* by William Blake (1757-1827).
36. From the song *Pipes of Peace* by Paul McCartney, Columbia Records 1983.
37. From *The Divine Comedy*, Inferno, Canto VIII 73-75, by Dante, from *World Masterpieces,* Third Edition, Volume 1, copyright ©W.W. Norton & Company Inc. New York, 1973.

Meanwhile, John's exasperation grew at so few medical ideas to help me – such little research into the crippling pain. Coming from the States, it was shocking for him to see how his wife was left to fend for herself, to come up with her own ideas of treatment without a single scan or blood test to even diagnose her disease.

John talked about taking me to the States for better treatment, yet that treatment wasn't guaranteed, only hoped for. We'd also have to pay for it with money we didn't have as we had no American medical insurance. The final arbiter was moving country: I still couldn't face doing that as the change would be too demanding.

Meanwhile, my exasperation grew as my calf muscles cramped up after a few moments of walking; standing was worse, making them cramp up even more. They felt as if they'd run a marathon whereas all they'd done was stand for about 20 seconds.

'When I was in [the fire], I had been glad to reel,
Therefrom to cool me, into boiling glass,
Such burning beyond measure did I feel.' (38)

"What does it feel like?" asked John, kneeling by my side. He wanted to understand as much as possible.

"It's as if rubber bands have been wrapped around every inch of my legs, from the ankles to the thighs, with the bands pulled tighter and tighter. It's horrible… My legs just feel crippled!" (39)

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38. From *The Divine Comedy*, Purgatario, Canto XXVII 49-51, by Dante. The bracketed words are my own insertion to help with the context. See Footnote 37 for publishing details.

39. Scientific causes of M.E. pain are complex. Damage to the Central Nervous System causes dysfunctional processing areas of the brain. There has also been shown to be a build-up of lactic acid, a lack of oxygen to the muscles and damaged blood vessel linings causing constriction.

Another vivid description of the pain was as if scalding hot water was being poured continually over my muscles; an invisible sensation to others, yet one which locked me up as its prisoner with no available key to let myself out.

My voice broke up when focusing on the description. John was no stranger to pain, enduring frequent migraines which flattened him out from sickness. My constant pain, though, was a new level of consciousness for us both. The best cure seemed to be lying completely still with my legs up high on a pile of cushions.

John and I entered our own Dante's Inferno, of flames without respite. The experience took me beyond myself, my human frailty too inadequate to deal with such torment. It was similar to the depression days at 19 when God became more real to me than at any previous time.

Christ's crucifixion became my empathy, my strength. His twisted body was like my contorted body when I walked with sticks; His wounds were like my burning pain and even the insults He bore were like the insults hurled at me when some didn't believe in my disease. The fact that God understood pain was enough to keep me going, continuing in His strength alone as He took over from my battle-weary spirit.

'Thou hast drawn me up to freedom from a slave
By all those paths, all those ways known to thee
Through which thou had'st such potency to save.
Continue thy magnificence in me,
So that my soul, which thou hast healed of scar,
May please thy sight when from the body free.' (40)

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40. From *The Divine Comedy*, Paradiso, Canto XXXI 85-90, Dante. See Footnote 37 for publishing details.

My soul seemed to have transcended from my own physical strength to a supernatural source, allowing me to distance myself somewhat from the Inferno, as if I was being carried through the flames by God. The name of Jesus Christ became like oxygen, breathing in hope of escaping the burning heat. His name took on a new sensitivity with me, causing me sorrow when His name was blasphemed and trivialised in every day language. The power of His name became my new medicine, whilst the thought of Heaven, Paradiso, became my eventual hope. This was indeed some transcendence from the immediate, ordinary surroundings around me: the pictures on the walls, my folded-up wheelchair and the ever mounting pile of washing-up in the sink.

Tracing the rainbow through the rain was another matter, though. A rainbow is a natural beauty, logically explained by science yet also touching the aesthetic senses within us.

> ‘O joy that seekest me through pain’ (41)

How can one be joyful when my body felt as if it was like Guy Fawkes on a bonfire? But joy isn’t the same as happiness: they are entirely different experiences.

Happiness is a fleeting feeling that can disappear as quickly as it comes. Happiness is when a child receives his favourite ice lolly, or when a man finally sleeps with the woman of his dreams; happiness could also be a cigar called Hamlet.

Whereas joy is a strength discovered when you don’t get your ice lolly, your cigar or your favourite partner. It supersedes happiness and is a supernatural gift, not from the human realm.

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41. See Footnote 34.

So I found that I could be joyful in pain, as masochistic as that may sound. Joy was the result of peace and acceptance; a similar search for joy had taken place through my former years of depression, although now the search was through pain. The infantile lyrics of a favourite childhood song echoed in the halls of my mind, its simplicity strangely powerful in once again matching my own search for hope.

‘Red and yellow and pink and green
Purple and orange and blue.
I can sing a rainbow, sing a rainbow,
Sing a rainbow too.’ (42)

But the rainbow disappeared from time to time, there one minute, gone the next, hidden by unexpected clouds.

“I can’t go on any more!” I wailed to my poor mother down the phone, as new medication for pain control began to wear off. The decision had to be made whether to increase the medicine which would have made me a zombie, unable to speak and only grunt, or live with increasing pain levels. What a decision! Most people my age only made decisions such as choosing between fish and chips or ravioli for tea.

I didn’t want to be a zombie: quality of life is what living is about. So the pain continued.

Mum and John bore the brunt of the emotional effects of my disease, but they didn’t really have anyone in turn to offload onto. My stress was affecting them, making me feel guilty. “If you’re not taking away my pain, you’ve got to help me live with it,” I cried hourly to the ancient Aramaic name of Jesus, Yeshua, Joshua, the One who saves.

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42. *Sing A Rainbow* by Arthur Hamilton. The song was made popular in the 1960s by singer Cilla Black, under Parlophone/EMI, release date 1966. It was taken from the film *Pete Kelly’s Blues.*

The rainbow was glimpsed at the end of each day as relief accompanied me to bed; relief that I'd made it through another day, the pain battle being won either triumphantly or narrowly. Yet it was won! A rush of adrenaline would confirm my survival.

But the adrenaline was quickly replaced by pain's nagging reminder, as the weight of the duvet hurt my legs and the stiffness of muscles interrupted my sleep, making it difficult to turn in bed. The next battle was to get through the night, usually achieved by being drugged to the eyeballs. (I didn't mind being a zombie at night, only in the daytime.) On awakening, the same fight with pain would be faced all over again: the psyching up of getting dressed, the effort of moving and explaining to new people who didn't understand.

The rainbow was often hazy through my teary eyes, the colours undefined, merely an abstract blur like a Rothko painting. Yet my Saviour assured me that the rainbow did exist as He carried me through the flames. He could see it.

16. *Love On The Rocks*

Altera dies alterum discrimen. John finished writing the Latin inscription in his calligraphic hand, added a decorative squiggle, then framed and mounted it on a wall in our home. The sentence translated into *Another day another crisis*, a household saying he invented as a teenager.

"It's the Ashenfelter motto!" he said, half proudly and half crestfallen. Obviously he felt it was still appropriate in our marriage.

Writing the plaque was John's way of dealing with a frightening deterioration in my health, when each day brought a new symptom, a new sensitivity that hadn't been there before. There was the wrong kind of light and the right kind of light for him to deal with; the wrong kind of heat and the right kind of heat; the wrong kind of question and the right kind of answer. I'd wake up in the morning not knowing which part of my body would work; would both hands work, only one or neither hand? The same sort of thing went for my brain; would I be able to hold a conversation on a given day?

"I wish you were how you used to be in Hamtramck, when we got engaged," John often said.

The exciting, chilly days of Michigan which had been melted by our warm, invigorating romance, seemed a hazy memory in the long and distant past.

The illness forced us to live separate lives in many respects, the reasons we once got together no longer being quite so apparent. John would brush shoulders with teachers in the daytime, enjoying the occasional intelligent conversation, whereas my day often consisted of little more than watching the antics of our neighbour's cat jumping on and off the windowsill! John started going out to places by himself, something I encouraged him to do, not wanting him to resent me.

Trips to the USA were planned without me as I couldn't handle the long flight. Holidays abroad together were impossible, making my postcard album even more precious of friends' wishes sent from faraway places. John hated going out socially without me but he needed a change of scenery and to have his own batteries recharged. Being a carer for someone can, at times, be as gruelling as being the patient.

It was on one occasion, though, that I began to get rather nervous of our increasingly divided lives. John came back in buoyant mood from a Maidstone nightclub, his jazzy waistcoat drenched with cigarette smoke as we embraced at home in the early hours of the morning.

"Oh Catherine, it was so funny! A girl came up to me in a strong Kentish accent and said, 'My mate wants to dance wiv yer! She really fancies yer!' " (Her expletives excluded!)

We both laughed hysterically in the hushed quiet of our farmland flat, mainly at John's impersonation of a Maidstone accent with his American twang; yet inside I was hurt at how life was treating us. That should have been *me* with him at the nightclub; *me* going with him on holiday, to the pub and not him on his lonesome.

I was afraid that John just saw me as a disabled person, no longer the aspiring artist or musician he saw me as when we first met. He said he married me for my intelligence but now I just twisted and slurred my words around, often forgetting what I'd said halfway through a sentence. He performed daily caring tasks before leaving for work, taking caps off my medicine bottles and unscrewing jars for my lunch, all before 8 a.m. If the electricity was low, he'd clamber up on a step ladder to put money through the meter: my weak legs and arms couldn't do that.

As for a day out anywhere, it was like preparing for an expedition up Mount Everest. Would there be wheelchair access? Was there nearby parking? Were there eating and drinking facilities for my hypoglycaemia? A downstairs toilet or a lift (which worked) to the upstairs toilet?

John couldn’t just take me out on the spur of the moment due to all the planning. Things that healthy people never think about had to be sorted out ahead of time, otherwise it could ruin a day’s outing.

* * *

Strain and stress can cause an emotional pus beneath the skin of the psyche; if unattended it will grow and grow until it eventually bursts. Chronic illness can contribute to that build-up: John could no longer cope with my deterioration and I couldn’t cope with his ongoing depression. The M.E. was enough of a drain on him, but on top of this his teaching job made him almost as exhausted as I was.

We loved one another, were a Christian couple, yet were simply drained by each other’s problems. It was unbelievable when we began to talk seriously about splitting up when our love was so strong. We just couldn’t go on with things as they were and saw the temptation of being alone as a way out.

There are many things we have learnt as a couple which the challenge of marriage has shown us: one of these is that no person is above doing, saying or thinking the unthinkable, including Christians. The other is to never, ever say that things can’t get worse.

Members of my family could sense our tension, culminating with my Dad offering John the holiday of a lifetime in Tunisia. This included a trip through the Sahara Desert, staying in luxury five star hotels surrounded by sand dunes and salt lakes in the middle of nowhere! He paid for John’s trip and it proved to be the best holiday John ever had. Meanwhile, I had friends come to stay at our flat for company and practical care.

Despite the wonderful memory of Tunisia, our same, fraught situation remained unchanged on John’s return home. He decided to apply for a teaching job in the States at his old Art College because his current English job was getting him down. He knew that I wouldn’t be well enough to move country with him, so we talked about seeing each other in the college holidays. I, too, started thinking about where and with whom I should live, being unsure as I didn’t want to move back with my parents, as much as they would have had me. I wanted the little independence available to me, yet I needed daily care. Rapunzel and her Prince were desperate to get out of the dark tower, seeking ways of escape but not the same escape routes.

Destiny decided that John wouldn’t get the American post, making us still together for the time being.

Then there were John’s own health problems: he warned me before we married about his tendency to get depressed, but I thought back then that I could deal with it. The reality was that I had no energy left to be his carer, using it all up to fight my daily pain. Of course, the M.E. had made John’s depression worse and was something he didn’t expect to contend with in the marriage. An agony aunt might advise that we were the wrong kind of people for each other but our uncertainties were overruled by the solemnity of our wedding vows.

The marital fruit seemed empty, though: no children, thwarted careers, a lack of income from my part to purchase a home and not even socialising or holidaying together. Instead, our marital fruit was something we didn’t anticipate: a spiritual journey through our weaknesses to discovering God and unravelling the injustice of the M.E. scene. We weren't producing fruit such as oranges and lemons but a more unusual kind such as papaws and prickly pears.

As well as often living separate lives, we were living more and more in separate rooms. John's stony face and frequent sighing from depression made me want to stay away from him; meanwhile, he would be in another room so as not to hear me sobbing from pain, the sound of which sent him over the edge almost as much as it did me.

In moments when our flame rekindled, the physical exertion drained me to the point of paralysis, making me as helpless as Leda embraced by the Swan! So the fun aspect of our lives was also seriously curtailed.

The emotional pus got bigger and bigger until one day it burst. In October 1995, I knew that I couldn't take another day of John's depression. This was upsetting for both of us as he needed my support and I wanted to help him, not let him struggle alone in gloom and doom. My limited energy had all leaked out like a deflated balloon, darting about in the air until gravity had pulled it empty to the ground.

"If you don't see the doctor about your depression, I'm going to have to leave you," I blurted out, almost without thinking and not having a clue where I would go in my condition.

Our fairy tale marriage had turned into a true story of embarrassing failure.

Amazingly and much to my relief, John saw the doctor soon after the ultimatum. Just telling his GP about the depression made John feel instantly better; it was no longer his own secret burden crushing his soul.

Once more, we were still together.

A counsellor came round to our flat whom I didn't get on with, especially as he told me to take up an aerobics class for the M.E. He made me angrier after his visits than before he came round. John clicked with him a bit better than me but the counselling didn’t clear up any emotional pus, just poked and probed around at it, failing to mop up what had come to a head. Apparently, we were meant to do the mopping up ourselves after he had done the poking around. The counselling also made us sound just like Basil and Sybil Fawlty, bickering away at one another.

One evening, John brought home a shattered ceramic vase someone had knocked over at school. It looked irreparable but John persevered with mending it until the cracks could barely be seen. Perhaps one day, the cracks in our marriage would be sealed so much that they would hardly be noticed? The analogy inspired me, although the polyfilla took a while to arrive for us.

Papaws and prickly pears are, after all, an exotic type of fruit, hard to find in this country and amongst the most expensive in a supermarket. The fruit in our lives, whilst bitter at times, was nevertheless special and different from the rest.

17. Pass the Baileys

The stylised visage of the Madonna and Child looked down at me from the sitting room wall, as if some spiritual presence was watching concernedly over our home. This Christmas card was at the very top of a mass of cards held together by patterned ribbon and stood out from the rest: with its Mona Lisa-like face it looked alive, the haloed baby breathing contentedly on its mother’s breast to the sounds of Polish music playing quietly on our stereo.

The Polish theme at Christmas returned regularly for John and me, first greeting us in the American Polish town of Hamtramck where we got engaged whilst listening to Polish carols on the radio. Our stereo was now playing stirring orchestral music (the volume low for my delicate ears) with a tenacious soprano echoing the words of mothers, including those from the Madonna, grieving over the sorrowful fate of their children. This was hardly cheery Rudolf the Red-Nosed Reindeer stuff, yet the powerful Polish lyrics strengthened our spirits to endure yet another M.E. Christmas inspired by the resilience of a Polish nation.

An M.E. Christmas is very different to the usual one celebrated by people in their thirties, the decade John and I had now entered. Dark shades, earplugs and quiet rooms don’t go very far with celebratory atmospheres. As for our many Christmas cards (mainly from staff and pupils at John’s school), they stayed up well after Christmas into March and almost Easter. I couldn’t reach up to take them down and John didn’t want them to come down as he felt supported by them through people’s thoughts. Our home resembled a modern day Miss Havisham’s, as spring sunshine filtered through the windows touching cards of sparkling snow scenes, the seasons out of kilter with one another. As for the

Madonna and Child picture, it shone brighter than ever in the watery March light.

An M.E. Christmas had to be planned months beforehand. In fact, Christmas was never far from my mind all year round because of the cards staying up until spring; in addition, catalogue orders had to be placed well ahead of time: they were a lifesaver (so long as they arrived before the big day) as the cold wintry weather stopped me from shopping in my wheelchair. The choice of catalogue gifts, however, left much to be desired… frogs singing ‘Silent Night’ (battery not supplied) and personalised nail clippers were just a few seasonal delights to be had!

An M.E. Christmas meant more pain and exhaustion than usual as I was reduced to crawling on my hands and knees in a futile effort to pack my suitcase. John and I always spent Christmas at my parents’ house in Brook; it was an exciting break for me as my parents’ home was the only place I’d stay because they understood my illness. John enjoyed spending time with Dad who introduced him to the Irish cream liqueur of Baileys. Their home had introduced John to hot tea years before; now it was introducing him to the hard stuff!

Being disabled can force you to the sidelines of activity, making you feel left out even when others do their best to include you. Whilst fun and laughter filled my parents’ house, I would spend much of the time lying down in a quiet, darkened room with black bin liners pinned over the windows. Even a sliver of silver moonlight filtering through would wake me up. The room had to be pitch-black or my brain would go hyper from too much stimulation. It was here, in the darkened room, that I would reel in agony as the burning pain in my body reached its height merely from the effort of going to stay somewhere. Flashing lights on the Christmas tree also had to be turned off for the sake of my eyes. Worse of all, the Baileys had to pass me by, as did any product with a drop of alcohol.

My family were very attentive to my needs and I hated feeling a party pooper, unable to join in with the surrounding hilarity. All family members would gather on Christmas Eve to sing carols round the beautiful black piano decorated with orange wood engravings. A favourite of Dad's was Berlioz's 'A Shepherd's Farewell' which he would sing with his majestic baritone voice. We were all musical, the talent being passed down to my nephews and niece who brought along violins, guitars and percussion instruments for our group singsong.

My mother and sister would be at my bedside, holding my hand as I writhed upstairs from nerve pain, reverting to my childhood nickname of 'Tat'. Shockingly, things hadn't really changed since I was a teenager: I still had the same disease; I was suffering on the same bed and the same sofa; I was still the same burden for my family. Even the traditional Christmas cake, made by my mother's capable hands, sat invitingly on the sideboard. She'd used the same recipe as when I was 14 and stirred the mixture whilst listening to Kate Bush. The main thing which had changed since then was the worsening of my illness; yet I was also married, had a degree and teaching qualification (to look on the bright side).

Despite feeling down, my parents' home reminded me that the effort of going there had all been worthwhile. The sitting room was bathed in a low wattage, soft rose light, making the scene Cosy with a capital 'C'. The Christmas tree was always small but set high on a large, crepe paper clad table, the colours of red, green and gold dominating. At the base of the tree, on the table surface, would sit hand-knitted toys from our childhood days. (This was our mother's choice to put them out, not ours!) The tree was decorated so heavily with ornaments collected over time that it leaned slightly, like the Tower of Pisa. Each ornament had a history to it... ones purchased from America, gifts from nearby overseas students, others hand-made from relatives now deceased. Their reminders made their presence felt more strongly in the room, the spirits of Christmas past. Yet the atmosphere was peaceful and uplifting, not eerie. Neighbours who popped in with greetings cards often commented on the welcoming atmosphere which cheered them on their way.

Christmas cards were stuck up with tape on huge, vertically hung sections of red paper, several sheets of which filled the walls: yet the backing sheets weren't enough for the quantity of cards received by my parents, many of them contacts from former Nigerian days. Cards would poke out from every ornament, around the Yorkshire heirlooms brought out only for this season, around the Victorian Father Christmas whose white beard felt softer every year.

But it was the candles that completed the atmospheric touch, in the window sill by the Yule log and over the television set, heating up the air current to make metallic angels chime. The glimmers of the red hot coals from the hearth also gladdened the heart of any downcast soul, with the smell of spirits (the alcoholic kind) never being too far away.

John was always made to feel welcome by my parents, so he rarely felt homesick at Christmas. Nevertheless, a jolly American greetings card with a red cardinal brought him joy when sent across the Atlantic. All my siblings would be at Brook: brothers Paul and Graham, sister Rosemary plus their other halves and children.

Outside, Brook still looked beautiful no matter what the winter weather was like. Frost made it magical, gloom made it mystical and sun made it magnificent. It was good to be there. Brook had a great community feel over Christmastide, with a flock of villagers going door to door carolling, a lantern lighting their way. Midnight Communion was another great Brook tradition, a social as much as a spiritual one, with folk staggering back from church at one in the morning, their faces alight with the renewal that Christmas morning alone brings.

But these were only memories, fond ones yet simultaneously upsetting: my spiritual input now came mostly from televised church services which lacked the same kind of intimacy. These memories made me aware of my inadequacy, of what I could no longer do: cards had to be handed over to others to post, as my legs wouldn't hold up in the long Christmas queues; crackers had to be pulled for me at the festive dinner table as my arms lacked the strength. (I did my best to enter into the laughter of a cheap plastic gift made in Hong Kong and the accompanying corny joke.) Even opening the fridge door in my necessary endeavour to pre-empt hypoglycaemia, set off symptoms of shivering and pain. Constant, warm temperature was a must but I couldn't have it too hot either!

As each Christmas passed, the glowing coal fire and atmospheric candles started to affect my breathing more and more, making it so shallow that I could no longer be near them. Enjoyable things were slowly being denied to me, eventually making Christmas devoid of pleasure.

In a couple of weeks it would be the New Year. I'd have to sleep all day on New Year's Eve in order to bring in 1st January. John sometimes had to bring in the New Year without me: once in 1994, he'd been invited to a teacher's home for a games evening, something John especially enjoys participating in. It would have been too much for me to attend as well, what with concentrating on the games, staying up until midnight and dealing with the host's dogs brushing against my legs. I insisted John went to the party as we ourselves had no plans, but it wasn't the same for him, singing Auld Lang Sine without me.

In our quiet, non-celebratory home, I phoned Sudha who still lived in London, to wish her a better year. She was sorry to hear of my deterioration and she too was suffering a great deal, from sores as a result of continually sitting in her wheelchair. Her cheery festive greeting had a joyous strength to it, something only obtained from going beyond yourself, which circumstances had done to her many times over.

I switched on the radio in bed to hear the chimes of Big Ben, a truly British institution to start off the Janus month, but the loneliness of the occasion brought things to an emotional head. Would I ever be able to participate fully in fun and laughter again, to enjoy life to the full? At 31 my existence was of less quality than an average old-age pensioner. John's life wasn't lived to the full either, at his blossoming age of 34. More important than anything else, would I ever be able to enjoy a chilled, smooth, delicious glass of Baileys? As the label says, it is a ' *...perfect marriage of fresh Irish cream, finest spirits, Irish whiskey and chocolate flavours. Enjoy the experience with friends, over ice, blended with ice or in coffee.'* (43)

What a tease.

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43. Taken from the label *Baileys,* the original Irish cream. R&A Bailey & Co., Nangor Road, Dublin 12.

18. *Still Life*

‘ ...commune with your heart upon your bed, and be still.’ (44)

Our paintings on all four walls of our Wealden flat mirrored my own pace of life: the brightly coloured landscape that was sizzled to a stillness during the 1995 heat wave when John captured its ochre scorched views; the portrait biro sketch John did of me in Hamtramck where I fell fast asleep on his studio floor, its fragile paper torn on one side, surviving well our troubled engagement and marriage years. Then there were my own paintings of ballroom dancers, castles and traditional still lifes which grew even stiller under the spell of Father Time, as our artistic hands clasped strongly in a public statement declaring that it was art which threw John and me together.

The poetic stillness continued as I rested, stretched out, not dead but neither properly alive. The more I slept the healthier my Sleeping Beauty appearance became which was a cruel jinx to play on my burning muscles, which never relented from pain. Most of the day was spent lying down, my weak neck and torso unable to sit up for long.

So many things put me in a semi-comatose state: the mere effort of doing, thinking and talking was one thing. But more frightening than that were effects from external sources such as medicines, alcohol and chemicals. A whiff of petrol caught from a passing garage would stop my brain from ticking over momentarily and even a drop of sherry in a trifle would make me flop like a raggedy doll.

The most alarming reaction to chemicals came from trips to the dentist.

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44. Psalm 4 v.4.

"Oh my God! I've never seen anything like this before! Quick, rush some blood to her head!" my panicky dentist ordered her assistant as they tipped back my chair, making my head close to the ground.

All that had been administered was a drop of ethanol to clean a tooth; my brain decided it didn't like it and shut down both my ability to speak and to open my eyes. I could hear the freaked-out dentist but couldn't respond.

Local anaesthetics had exactly the same reaction, leaving me weeks to recover in the quiet sanctuary of our home, when my speech would finally return (45).

Although the chemical reaction was the most dramatic of all, the most frequent problem which plummeted me into unconsciousness was hypoglycaemia. For John, this was the most terrifying of all my symptoms which also had the additional burden of needing to be controlled on a daily basis. Others thought I was greedy or just making a fuss until they witnessed one of my hypo attacks which soon shut them up! In Tolkien's book, *The Hobbit*, little men with furry feet talk about second breakfasts, high teas and suppers inbetween their main meals. It would have suited me well to be a Hobbit because I had to eat every two hours otherwise I'd go into a coma (46). My existence was tied to a fridge which was chock-a-block with slices of cheese in cling film, ready for me to take on going out anywhere. John said it was like looking after a giant pet mouse. My diet had to be high in protein to slow down my insulin. A bowl of cereal in the morning triggered a hypo attack, whereas baked beans and bacon thwarted one.

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45. Alcohol and chemical intolerance is due to neuroimmune dysfunction in M.E.

46. There is decreased glucose metabolism in M.E. as demonstrated by PET scans of the brain.

Meat, cheese, eggs, then more meat, cheese and eggs; it was like the diet of *Rocky*, the boxer played by Sylvester Stallone. Even my speech during an attack sounded like his slurred, often incomprehensible words!

Meals had to be served bang on time, or else havoc broke out. Special social occasions often ended up with me being carried out of a restaurant if the meal was running late, followed by a trip to casualty where a disgusting drink of milk and sugar was poured down my throat to bring me round. I couldn't just 'hang on' for another five minutes at a restaurant before a meal arrived; garnishing it with extra salad as an apology for its lateness did little good. By that time I'd slumped over in a heap on the table. My consultant told me that theoretically I could die from a hypoglycaemic attack alone. I've always wondered since what a 'theoretical death' must be like?

The hypoglycaemia started with taking the Pill back in 1989. Because the major M.E. relapse also coincided with the Pill, John and I decided it would be a good idea for me to come off it altogether. This was a huge risk as I was in no fit state to become pregnant.

There was immediate improvement the moment I came off the Pill, confirming our suspicions. My walking was better, co-ordination less jerky and even my breathing was less shallow. My mother commented that it was 'like a miracle' as I walked through nearby woods with her, still needing one stick, yet able to endeavour deep into the violet carpet of thick bluebells. The remission was short-lived, however. An infection and further dental treatment set me right back again to the point of being worse than before; all that had been cured by coming off the drug came back with a vengeance. It did prove, though, that the Pill had contributed to the wedding relapse and that it wasn't just due to the 'stress of marriage' as some had suggested.

‘ ...and all the air a solemn stillness holds,’ (47)

Being forced to lie so still taught me enormous self-discipline. There was no choice. It was the only way to muster up energy for a phone conversation because I had to lie still for hours before and then hours afterwards to recover. Brain activity was occurring less and less for me: reading, talking and even thinking what to write for a shopping list were all becoming too taxing. After about half an hour of brain activity, my mind would suddenly shut down, as if a plug was pulled out from a socket, halting the energy source. The only way for the ‘plug’ to be reinstated was yet again to lie still in a deathly quiet, darkened room, where my brain would receive little stimulation so that it could heal.

My faculties were going one by one. Not only were my brain and walking faulty, but to my horror my throat started having difficulty in swallowing. There was something particularly distressing about that. It started gradually but the gulps to pass even small amounts of saliva down my throat became increasingly strenuous.

‘ ...my words like silent raindrops fell and echoed in the wells of silence.’ (48)

Fear started to grip me of things I might not be able to cope with: the worst fear was if I should ever need a general anaesthetic from an unexpected operation. It would only take something like appendicitis or a car accident to necessitate the use of one. These were circumstances beyond my control.

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47. *Elegy Written in a Country Churchyard* Thomas Gray (1716-1771).

48. From the song *The Sound of Silence* Paul Simon, 1964 copyright ©2003 Sony Music Entertainment Inc.

(I’d heard that some M.E. sufferers are fine after anaesthetics; others have permanent relapses, whilst a minority are warned to never have one at all as the consequences might be fatal. With my reaction to drugs and chemicals, John and I both felt that tragically I could well fit into the latter category.)

With that kind of uncertainty hovering around, my mind continued to switch back and forth between struggling on earth and longing for Heaven, not just because of the pain but from fear of life getting unbearable. This forced my hope to be in Christ, not doctors, not medicine nor even in getting better. The less my body worked, the more my soul was in touch with a spiritual avenue. Yet, this vulnerable state of being propped up by supernatural realms to keep going, seemed strangely fulfilling. Acknowledging my need of God seemed to be the answer to Monty Python’s search of *The Meaning Of Life.*

The Afterlife seemed closer than it should have been for a woman in her early thirties; so, when others commented about miracles happening, it was hurtful rather than hopeful. John and I needed people to help us face the gloomy future, not deny it.

“You never know, you might suddenly get better one day!” said a smiling friend to me round the supermarket as she pushed my shopping trolley. I pulled a face in disagreement; she said it to be hopeful but I found her words insensitive as my health was getting worse.

‘False’ hopes were raised again shortly afterwards by a letter from one of John’s favourite American uncles. A greetings card was padded with 50 dollars and a heartfelt note which read,

‘Let’s hope Catherine finds a miracle cure soon!’

The dollars were gratefully received but his message only served to wind me up. John was thrilled to hear from him regardless of false miracle hopes. People had prayed for my healing for almost 20 years, yet I was deteriorating. Why should things suddenly change for me now?

Life wasn't all bad in a wheelchair, anyway. I could still have trips out somewhere now and again which were enjoyable and something to look forward to. One such trip was planned to Tunbridge Wells on Monday 7th July 1997, only a few weeks away: it was my favourite local place for a day out. Mum and Dad had taken me there before whilst John was at work. (Dad enjoyed immensely the opportunity of pushing me in the wheelchair. I do wonder if he was making up unconsciously for the time when he was away from me for the first eighteen months of my life, working in Nigeria. The wheelchair, after all, is just an adult version of a pram for those who can't walk.) He liked to help me shop for clothes and I particularly needed some new summer dresses; my thighs were putting on weight from the high protein Sylvester Stallone diet!

But when that day was to finally roll around, it wasn't going to be like the previous shopping trips we'd had as a family to Tunbridge Wells. Unknown to us at the time, God was planning something too beautiful for words; something beyond my wildest dreams and way beyond my level of faith.

The belief of healing from others continued at the end of a church service in a tiny little chapel in Cranbrook, a few miles from our flat. I hardly made it to church anymore: the effort of sitting through a service, often in the cold, usually left me worse for wear. The church was from the denomination of Congregationalism, derived from Oliver Cromwell and had an average congregation of about fifteen worshippers, mostly elderly. I didn't care what denomination it was and only attended because of the late service time and the fact that most people walked with a stick. Their frailties made me feel right at home, despite the whopping age gap.

John attended more often than me. I felt that his youthful good looks were a waste with such an elderly congregation, although it probably kept him out of trouble! One June morning, a few weeks before the planned Tunbridge Wells outing, John drove me to church where there was a visiting speaker. The speaker was also elderly, like most of the others, but with a good sense of humour. At the end of the service after the blessing, I noticed that the speaker seemed a bit on edge; then, just as everyone was about to leave, he marched up to me and laid his hands on my head. This impromptu act wasn't the norm for our congregation. I was seated at the front, unable to stand for the entire service, clutching my faithful walking sticks.

"Lord, we pray for this young girl, that you will deliver her from the illness which is causing her sorrow. Make her well and whole again, in the name of our Saviour Jesus Christ. Amen."

His hands trembled on my head from saying the prayer but his voice was strong, authoritative and far from trembling. He spoke with such certainty that I expected that I might indeed be well. On leaving the church, though, the heavy burden of M.E. was still with me.

The gesture from the visiting speaker somehow gave me real hope and left me touched and deeply grateful. His desire for me to be well which he demonstrated so publicly, filled me with a beautiful peace that felt like waterfalls gently washing over my sick body.

"Do you believe in miracles?" I challenged John back at home, whilst he was marking a stack of homework. "I mean ones that still happen today?"

"Yes," he said emphatically, unruffled by my bluntness. "Why, don't you?"

"I don't know. I used to but I'm not sure anymore." My voice trailed off into what seemed like a fantasy world of people picking up their wheelchairs after a single prayer.

I'd no problem believing in miracles from the Bible; if Christ was God then anything was possible, including supernatural acts. But if miracles still happened today, then why hadn't I received one?

For nearly 20 years of M.E. I'd attended healing services, been anointed with special oil from the Holy Land and had so much prayer that the knees of saints were becoming arthritic. It was far easier to disbelieve in modern day healings and go into denial of their existence: then, I wouldn't have to accept the awful reality that miracles were passing me by. I admired John's faith in believing they could still happen today.

"Try and think of miracles as answers to prayers," he explained, attempting to expand my closed mind.

That helped a bit. I couldn't pray for a miracle, for me or for someone else because I didn't have the faith for that. I did, however, have a smaller amount of faith for one thing: to pray that God would heal me of my hypoglycaemia which was the bane of our lives.

The summer of 1997 started off being grey and dull, the kind of weather that triggers despondency because summer never quite arrives. During our miracle chat and summer gloom, a woman's smiley face looked up at me from a book cover on the coffee table. Her magnetic smile was in contrast to the Mordor grey clouds gathering outside the sitting room window. The photo was that of Jennifer Rees Larcombe, the sister-in-law of our local church pastor, Peter. He'd lent me the book, an autobiography, which describes how Jen had five attacks of encephalitis leading to severe M.E. She spent many nights dying in intensive care over an eight year period but after a simple prayer she'd been instantly healed in the summer of 1990.

Once again, another trip to the little Cranbrook chapel became an intrinsic link in shaping my concealed future. Like the last service, the congregation was small and elderly with a stillness about it that almost put me to sleep. Also, like before, the significant event came at the very end. There was no visiting speaker this time, the service instead being taken by Peter, the pastor.

“Jen is coming to Cranbrook next week, to look after my mother for the day. Perhaps we could get you to meet her?” he suggested as the congregation was leaving. My heart leapt at the thought of meeting her, yet I wouldn't expect to be healed as she had been. My reason for going was to help *her* in some way as she'd recently suffered a broken marriage. I didn't know how I could encourage her but just wanted to.

However, whilst making transport plans for that day, it didn't look as if I'd meet up with Jen after all. John would have dropped me off but he needed the car for a special school meeting. Then, my mother phoned.

“Catherine, you must see this woman, even if I have to pay for a taxi!” came her strict instruction.

My protests at the unnecessary expense of a taxi were swamped by both my mother and sister, who became equally insistent that my meeting with Jen should take place.

“You must see her, Catherine, even if I have to drive you there myself,” ordered Rosemary.

This was crazy. My sister had never ordered me to do anything before: it wasn't in her nature.

“Why are they making a fuss over this? I can see Jen another time, perhaps, when it's easier for John to drop me off. It's not as if I'm going to have a healing miracle, or something, is it?!” I reflected, as Thursday, the day in store, drew ever closer. In fact, I'd decided *not* to ask Jen to pray for my healing: it seemed too presumptuous, somehow. I was also unconvinced of miracles happening in our modern age and still slightly sceptical of Jen's own healing.

"Was she really healed?" I started quizzing Peter the pastor all over again. "It wasn't just a remission?"

He went on to explain how the colour and texture of her skin had changed after the prayer, as well as her being able to lift up her wheelchair over her head.

My mother's insistence won the day and a taxi was booked to take me the short distance from Hawkhurst to Cranbrook for Thursday 3rd July, to meet up with Jen. This was a few days before the planned family trip to Tunbridge Wells, meaning that I'd have some time to rest on the days in between.

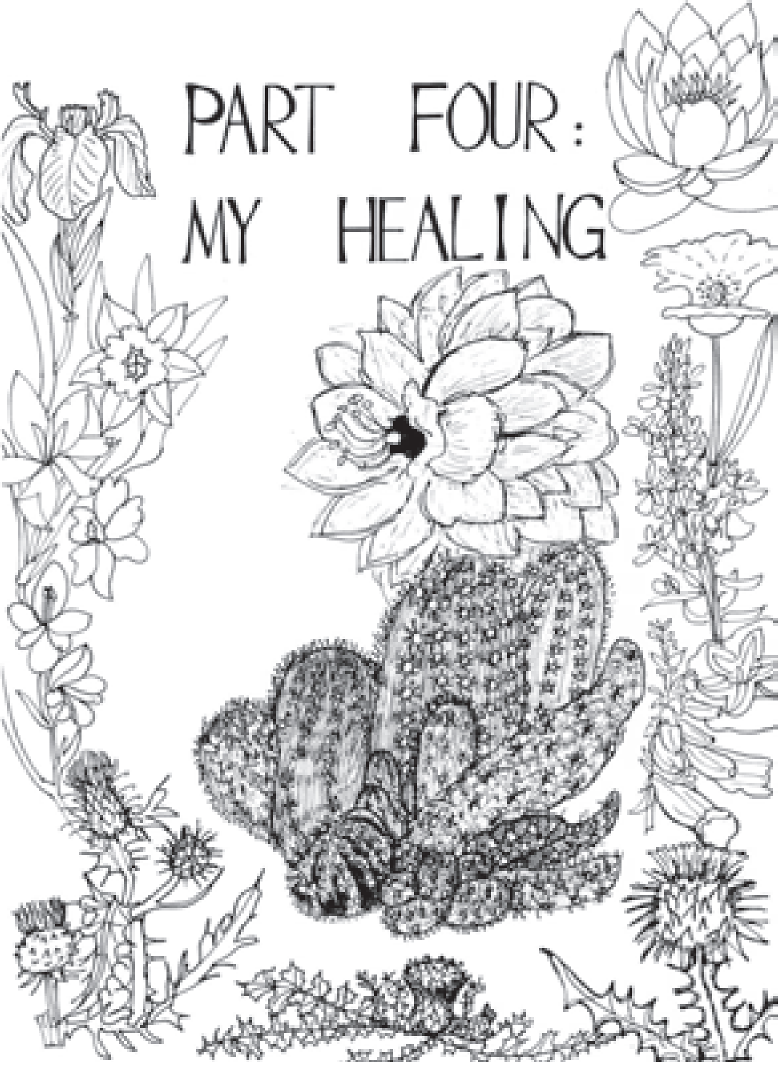
Once the meeting was set in stone, excitement welled up within me about the forthcoming day; a special excitement, similar to when I flew across the Atlantic to see John which resulted in our engagement. This scheduled meeting with Jen had the same effect of an impending life-changing joy: it was a knowing, a conviction, far stronger than just a feeling. But I didn't know how it would be special or life-changing for me.

As Monday turned to Tuesday and Tuesday to Wednesday, the suspense grew so much that it was hard to contain.

A lot can happen in the space of a day: world wars can be announced and ended, engagements made and broken, tragedy turned to ecstasy and joy to grief. But of even more wonder are events which can happen in a split second: the creation of a spark, a fertilised egg and even miracles, perhaps?

Unknown to us all, the Ashenfelter motto of *'Another day, another crisis,'* was to be cut some slack. Mercy was on its way.

PART FOUR: MY HEALING



19. My Glorious Day

Thursday, 3rd July 1997 finally arrived, bringing along the continuing summer gloom of stifling grey clouds. For what became the most wondrous day of my life, it began quite ordinarily. I woke up feeling even more horrible than usual due to a bad night's sleep, so much so that I contemplated cancelling the meeting with Jen. But the same conviction kept growing that I had to meet up with her that day, that nothing must stop the plans in place and that I would be profoundly changed forever, in a way that was unclear to me. Due to my uncertainty over modern day healings, this change wouldn't be physical, so perhaps it would be a change of attitude, of even more acceptance if that were possible?

'Ain't no mountain high enough
Ain't no valley low enough
Ain't no river wide enough
To keep me from you.' (49)

The lyrics of the Motown song floated through my head, confirming how I felt about the forthcoming day. I must get to see Jen even if the taxi driver gave me a fireman's lift.

As the waiting minutes washed away into a sea of taxi lateness, I was worried that the taxi wouldn't show up at all, let alone the impending excitement of a fireman's lift.

Then the phone rang.

"It's been unusually busy this morning and we're short of drivers. Would it be alright to collect you at one o'clock rather than midday?" the taxi service explained.

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49. *Ain't no mountain high enough* by Nickolas Ashford and Valerie Simpson. Jobete Music Co. Inc (ASCAP) 1970 © 1994 Motown Record Company L.P. The song was made famous by Diana Ross.

I felt there was no option, so tentatively replied, “Yes,” and left a message on Peter the pastor’s answering machine, hoping that Jen would check it. I had no personal contact numbers for Jen at all and the scheduled meeting was now being delayed.

All these extra phone calls were using up my precious energy, draining my reserves to walk to the side of the road and be collected. My walking that day was dreadful: my legs felt like lead as they dragged along the shingle driveway, supported by my aluminium seat-stick. After making it to the road, the three pronged stick folded out into a little seat on which I waited for the taxi... and waited and waited. The clouds got darker and my anxiety got greater as I sat vulnerably by the roadside.

Finally, one of the passing cars indicated to pull over. The time by then was twenty past one.

“Sorry for being so late, love,” said a man’s kind voice on getting out. “We had a problem with the changeover of cars. It’s never happened before.” His soft voice seemed incompatible with his rugged face which resembled a boxer’s.

I didn’t even know if Jen would still be at Peter’s house. What if she hadn’t checked the answering machine, especially as she was only visiting?

To make matters worse, the driver didn’t speed like a typical taxi but instead dawdled along as if we were out for a country afternoon drive. Then just as I thought we were finally there, the driver got lost.

“I don’t know this estate terribly well. Do you know which house it is, love?” His apologetic voice played on my forgiving nature, although deep down my adrenalin rushed through my veins like steam mounting in a pressure cooker.

All the houses suddenly looked alike as we drove around street after street. The driver had the address but was unfamiliar with it. We could have done with James Bond on this urgent mission because each passing second was shaping my destiny.

“That’s it!” I screamed, recognising Peter’s house as the driver slammed on the brakes.

An unfamiliar car was parked outside: maybe that was Jen’s and she hadn’t left after all? But I wasn’t sure. The taxi driver helped me out of the car, giving me his arm to aid my walking. Jen was still there but only just. To my horror she was putting on her coat and rattling her car keys. She was about to leave.

“You must be Catherine,” she said, giving me a warm embrace. “I was expecting you much earlier. I’m afraid I have to go now because I’m rather late for work. Let me give you a lift back home.”

The message had got twisted somewhere along the lines of communication. Peter, whose house it was, told Jen that my visit would be in the morning whereas I’d said midday. In addition, Jen hadn’t checked my latest message on the answering machine.

“But I’ve come specially by taxi. He’s not collecting me for another two hours,” came my devastated reply. All this effort, all this hope seemed to be a waste of time and energy. My soul felt crushed and my face showed it. To make matters worse, I found myself telling Jen what she should do.

“Don’t go – you mustn’t!” I pleaded with her.

“But someone is waiting for me: I have an important meeting to attend. Let me give you a lift back home, to save the taxi. We can chat in the car. Go on, let me,” she repeated again.

“Can’t you spare just a few minutes? Please, PLEASE!” begged my voice.

This behaviour of mine was completely out of character. It was similar to the impulse of my engagement with John, when destiny’s driving force hurled us together, in spite of reasoning and logic. Why was I telling a woman I'd never met before that she couldn't go to work?

Jen sighed reluctantly.

"Alright, but just a short time," she agreed, taking off her coat.

We went into Peter's study, a place brimming over with books and artefacts all crammed into a tiny little room, which was big enough for just a few chairs.

Jen's first impression of me can't have been too good as there was an awful stony silence between us. She looked bemused yet concerned and I felt downright ashamed of keeping her from her daily business.

"How long have you had M.E. for, Catherine?" said Jen, finally breaking the ice.

Her question broke more than just the ice and to my further humiliation I started wailing with grief right in front of her. It was loud, uncontrollable and completely unexpected. It was also acutely embarrassing. Jen's concerned look changed more to one of compassion.

"It's all I've ever known since I was 14. It's horrible! Everything's horrible!" the shaky words came tumbling out, distorted by heartache.

I fumbled around in my pockets for some tissues but couldn't find any, so used my sleeve instead. What a fool I was in front of Jen. She'd probably go away thinking I was some kind of madwoman. Jen didn't seem to mind my outburst and just gave me her full attention.

"I'm so sorry, I really am," her gentle voice spoke in hushed tones.

"The pain in my legs never stops hurting," I continued. "I want to work and have a career and children but I can't... and sometimes my husband gets so depressed. But it's alright. If this is what God wants, then it has to be alright. I've learnt a lot of important things from the illness, like what's important in life and what isn't. I'm glad for what the illness has taught me, I suppose."

Then I paused, drained by my tears.

"You've been ill a long time, haven't you Catherine? Shall we say a little prayer together?" Jen concluded.

That was just what I wanted to hear, *the offer of a prayer*, yet I was never going to ask her to pray for me. I didn't feel right in seeking such a healing that she claimed to have. Instead, I felt it important to accept my disability.

It was all over so quickly with hardly time to blink. A few simple prayer requests from us both, not wrapped in flowery theology but straight from the heart. Jen did pray for my healing and we prayed for others we knew who were sick. I thanked God for Jen's miracle and asked that she might be encouraged in some way as she was crushed from her broken marriage. We made no demands from God, merely requests; our prayers, on the surface of things, seemed plain and unremarkable. The time together was rounded off in the name of Jesus.

And that was it: no flashes of lightning, no spacey music, no heat coming from her hands. In fact Jen didn't even touch me during the prayer. There was no hypnotic trance, no communion or format of service. There were no added effects at all, just a few moments of complete ordinariness in the even more ordinary market town of Cranbrook, where people were going about their daily, ordinary business on a grey Thursday afternoon.

The one special effect (if you could call it that) came from song birds singing in the garden, their cheerful sounds a welcome relief to the intense, bewildering encounter Jen had received from me.

After the prayers, I felt the most beautiful peace I'd ever experienced: it was as if something wonderful was being poured over me. The peace was so unlike anything else that it didn’t seem to belong to our fragmented world. It was like a visit from another time, another person perhaps? During those seconds of rapturous peace, I pictured myself with a new pair of legs in Heaven when I’d be running around, free from pain. But this wouldn’t happen yet: my healing would only come in Heaven, of that I was sure.

“I’m afraid I really must go now,” announced Jen, bringing me back down to earth. “It’s been lovely meeting you but I’m running terribly late. Can someone make Catherine a nice cup of tea? She can’t walk very well,” Jen called out to a handful of people caring for Peter’s mother in the next room.

When the incredible peace left, I felt disappointed that my time with Jen had been so short and still felt a bit of a fool for crying. What if the people in the next room had heard me?

The chair I’d been sitting on in the study was a low chair, too low for me to push up from with my legs. So I grabbed my seat-stick to help me get up.

“Wait a minute... my legs feel different,” I realised, rather shocked. They felt normal, strong and free from pain. The elastic band sensation of muscle tightness had completely gone from all over both legs.

Remarkably, I needed no help in pushing up from the low chair, my legs instead springing up with the speed of a jack-in-the-box. My seat-stick seemed lighter than usual, as light as a feather, which was perplexing. As I stood up to say goodbye to Jen, the bones and muscles in my back began moving around, slotting into a different position as if a realignment was going on. My back became upright, no longer stooped over.

“Thank you for praying,” I said to Jen as we embraced one another warmly, neither of us aware of the extent her prayer had done.

After she left, I walked from the study into the sitting room with huge strides. My walking was normal, not jerky or uncoordinated, with the former little, shuffling steps gone.

There were three people in there: a friend of Jen’s and a hairdresser who was setting the hair of Peter’s mother. I sat down amidst bags of curlers and prickly brushes, observing Peter’s elderly mother who looked blissfully happy sitting under the hair dryer, grinning from ear to ear.

Someone handed me a cup of tea which I welcomely guzzled down. It was ages before the taxi was due, so I joined in with the perky conversation, amazed at my new stamina.

After my second cup of tea, I paid a visit to the downstairs loo. It was in this tiny bathroom that suspicion arose of a possible miracle having just taken place. It was during the moment when I turned on the taps, on and then off, that my face lit up with joy. I repeated the action again and again, out of amazement that my hands were strong enough to do it. Such a simple, longed for task, was now pure rapture! In the corner, the raised toilet seat and similar disability equipment for Peter’s mother seemed at odds with my renewed strength as I jogged on the spot, bent up and down and pushed against the wall to test out what seemed like a new body of mine. What had happened in those few moments of prayer? Was I the recipient of a modern day healing or was this some cruel coincidence of a temporary remission?

Whilst doing aerobics quietly so no-one else could hear (dodging support frames and grab rails in the bathroom), my watch showed that it was time for the taxi to arrive. Thankfully, it was a different taxi driver, so no explaining was necessary as to why I looked and walked much better than two hours previously!

On the journey home, the sun broke through the gloomy clouds like a Constable painting, its warm rays filling the car, suggesting some kind of hope. Once home, a form stared at me from the dining room table of three items I'd ordered from a disability catalogue: easy grip tap turners, a jar opener plus a waterproof cape to cover me when outside in my wheelchair. I pushed the order form aside, wondering if it would need to be sent off after all because I was walking round and round our little flat like a rat on a wheel with boundless energy.

Around seven o'clock, John returned from a long day of marking exams.

"How did it go with Jen?" he inquired, looking at me oddly as I walked in circles around the room.

"OK I think, but we got the times confused, so I didn't see her for long," came my disappointed reply.

"That's a shame. Catherine, will you stop pacing about like that, else you'll have a relapse. Please lie down!" he ordered.

So I lay down on the sofa, not needing to at all. It was then I noticed a castor holder had become loose underneath and without even doubting my capability of lifting heavy furniture, I picked up the sofa like Superwoman, turned it on one side and fixed the holder back in place. John and I stared into each other's scared eyes.

"I didn't think you could do that," he gulped.

"Neither did I. Maybe I'm healed," my voice quavered.

"Yes, maybe you are," he replied, his own voice trembling.

John was used to me asking for help in picking up a bag of sugar, yet here I was turning over a sofa all by myself.

When shock like that happens, the unexpected verging on the supernatural, your mind doesn't know what to do. Consequently, you put it to the back of your mind and wait to see what unfolds. But as John observed me walking and talking differently, I could see his mind working overtime. My speech was energised, animated, not slurred from fatigue or stopping in the middle of sentences searching for the next word. As for my walking, it was just normal. We spent the evening exchanging a lot of odd looks, with a ‘different me’ being unravelled as time progressed.

At eleven o’clock I finally stopped hours of reading; my concentration and comprehension were vastly improved.

“I haven’t read like that since I was 14,” I reflected on closing a book. My mind flashed back to Highworth School for Girls, to Miss Etolen, my glamorous Spanish teacher, to the girls’ drab, grey uniforms and gypsy tart for lunch. Although that was nearly 20 years ago, my concentration now seemed to have suddenly picked up from back then, to how good it used to be just before the M.E. curse.

“Aren’t you tired out? I’m going to bed now,” announced John looking at the clock on the piano.

“I’ll be there in a few minutes,” came my chirpy response.

On finally going to bed, I took my usual medicine for insomnia but didn’t sleep very well after all. I was upset that I hadn’t encouraged Jen that day, which was my reason for going and still bemused by my forcefulness in stopping her from going to work. In addition, the suspicion that something miraculous had occurred in my life kept me awake and I couldn’t wait until morning came to see if I felt just as wonderful.

20. In the Twinkling of an Eye!

‘For now the Heavenly Power
Makes all things new,
And thaws the cold, and fills
The flower with dew;
The blackbirds have their wills,
The poets too.’ (50)

At around five a.m. the next morning I was wide awake, having been stirred from restless sleep by the orchestrated dawn chorus. It was the loudest bird song I’d ever heard, the varying tones and pitches layering so harmoniously that a conductor may have been present. Blackbird sopranos interspersed over the harmonies, so melodiously that I tried to work out what they might be saying. Not only was it the loudest dawn chorus that I’d ever heard but it was also the most beautiful and moving. Songbirds were singing when Jen prayed for me the day before and here they were again, waking me up with what seemed like a celebratory announcement.

As I lay in bed with John still fast asleep next to me, my body felt so, so healthy. My blood felt pure and cleansed as if I’d had a blood transfusion in the night, no longer fluey and heavy with malaise. My bones, muscles and now my blood were new all over, in the same way as I’d received a new brain the previous evening. In fact, I hadn’t realised how toxic my blood had felt for almost two decades: my body had got so used to feeling continually poisoned that to me poisoned was ‘normal’.

“Is this what it’s like to be healthy? But it’s a marvellous feeling! Why aren’t healthy people smiling all the time if they feel like this?” I wondered, suddenly angry that healthy people complain so much.

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50. *Early Spring* by Lord Alfred Tennyson, English poet (1809-92).

When the bedside alarm went off at seven, I flung the duvet in John’s direction, leapt out of bed and put on some coffee to brew.

“Will you promise me you won’t overdo it today?” John gave a strong admonition before leaving for work. “You were going crazy last night doing all kinds of things – please rest.”

But I had no intention of resting and as John drove off, I felt like joining him in a day’s work. Back in the flat, I wondered how on earth I’d fill the hours stretched before me. In the corner of the bedroom stood an old wardrobe, a family heirloom in need of a restorative touch. So I cut out a large square of sandpaper and started rubbing down the wardrobe vigorously.

“Catherine, you fool!” I scolded myself. “Your arms will really hurt from doing this and be paralysed for months afterwards, maybe permanently!”

I waited, hesitatingly, for the ensuing pain but it never came. Instead, my arms were incredibly strong, the strongest since whacking a hockey ball around at school in my early teens. I could almost smell the grass and clay mud from the hockey field, as I relived that memory of returned strength, slightly remorseful that I’d given my hockey boots away.

Sanding down the wardrobe had created a mess of golden particles everywhere. I sighed heavily because Betty, our cleaning lady, wasn’t due in until the following week. John would have to clear it up when he came home. “Unless I do it?” I wavered.

Me? Lift the heavy vacuum? That was unthinkable. Before my lips mouthed the words, “you stupid woman,” the vacuum was in my hands as I ran it through the bedroom, the bathroom and finally the sitting room. With its loud motor ringing in my ears, I dropped to my knees as tears of happiness streamed down my face.

“Thank you God! Thank you so very much!” I shouted out loud. “Something wonderful has happened!”

Picking myself up, I saw a favourite pair of jeans through the wardrobe door. Their heavy material meant I could no longer wear them as they pressed too tightly against my sore muscles. Tentatively I pulled them on: my legs no longer hurt! On strutting round the flat, I felt like a Parisian model even though the jeans cost only 50p from Oxfam.

Two days after Jen’s prayer was a Saturday. Weekends were normally a quiet affair in the Ashenfelter household, with me transferring from bed to sofa to armchair and back to bed again, with John wondering how to spend his free time whilst watching me in pain.

“Let’s go for a walk!” I exploded with enthusiasm, pulling him off the sofa during an easy-going Saturday morning. This time, the idea of doing the unthinkable wasn’t daunting to me but exciting.

The weather was glorious, the surrounding hills and fields basking in radiant July sunshine, eager to be explored. John was hesitant of my walk suggestion but became convinced from my joy which pulled him off the sofa like an irrepressible magnet. He insisted we took one of my walking sticks ‘just in case’.

Once outside, I ran up the pavement whilst John told me to slow down. We made our way to a nearby nature reserve which John had often ventured into on his own, appreciating the beautiful solitude. (I’d stumbled into it with my sticks once or twice before with M.E., but my family had to push me back up the gentle slope due to my ‘locked legs’.) Now here I was hand in hand with John, jumping on and off tree stumps and soaring round and round in circles with the zest of a six-year-old! It was just as well we had the place to ourselves that morning because I went completely berserk! We tossed my stick high into the air, sometimes catching it, sometimes letting it fall to the ground, with John watching me able to bend down and pick it up. My calf muscles were *so strong* as I rejected all help John offered me. I could do everything for myself.

After excessive screaming, general riotous mayhem and striding up 45° slopes, we decided to rest a while on a bench overlooking a lily-clad pond. It was a bit hazy from a mixture of morning mist and dazzling sunshine, with a flock of ducks swimming through the lilies, enjoying the warm sun rays on their little feathered backs. As John and I absorbed the idyllic Wealden setting, the ducks started swimming towards us, probably hoping for a crust of bread or two. But they didn't stop in the water: instead they waddled out one by one, clambered up a slippery slope and came right up to us at our feet. About eight ducks were there quacking, not leaving us alone and even when they realised no food was to be had they just hung around and stayed, acting like pets. We couldn't shake them off, even when we started walking away, as they followed us around the nature reserve for a short while. It was as if the ducks, along with the whole of nature, could sense the news of my renewed health and wanted to celebrate it with us, just like the resounding dawn chorus the day before.

On our way through the nooks and crannies of the overgrown flora, we saw a large tree on its side, strewn across our pathway. It had been left there since the hurricane of 1987. Instead of circling it, I decided to climb on top of it and find a way through the mass of branches six feet off the ground.

"Be careful!" John warned me, wishing I'd come down. He thought, understandably, that my poor balance and co-ordination would make me tumble to the ground amidst prickly thorns and nettles.

Nervously, I placed one foot in front of the other, attempting to find secure places to step onto. My body didn’t waver or go into spasms from trying to walk in a straight line; instead my walking was smooth over broken tree bark. The problems of balance and co-ordination were gone.

Whilst breaking my six foot jump with the help of sturdy branches, John looked troubled.

“It’s shocking for me to see you like this, especially watching you run,” he explained on the walk back home. Perhaps he was also thinking, like me, how long will this last?

* * *

The following day was Sunday, so we set off for church, to the same little Congregational Church in Cranbrook which had organised my meeting with Jen. There were obvious differences compared to the last time I was there only two weeks previously: this time I stood up for all the hymns instead of sitting down and even my singing was different. My voice was stronger, louder and able to sing a greater range of notes.

Before the service I’d whispered to Peter the pastor, Jen’s brother-in-law, “I think I might be healed!”

He just smiled.

Discovering the symptoms which had disappeared was becoming emotionally overwhelming. So many of them had gone but had *all* of them been taken away? Was this a partial healing or full recovery? No voice from the sky was going to tell me; it would have to be unravelled by each second of every new day.

Pain, weakness, concentration difficulties, poor balance and co-ordination, the toxic feeling in my blood... all these had gone in the last few days. What else might go? The hypoglycaemia, the bad reaction to drugs and local anaesthetics as well? Or might they stay? In order to find out what had and what hadn’t disappeared, I started to make a list of symptoms in a GONE column and a HASN’T GONE column.

Monday, 7th July 1997 was the planned trip with my parents to Tunbridge Wells, or Royal Tunbridge Wells if you want to impress. I’d told my parents ahead of time that ‘something wonderful’ had happened since the prayer with Jen but their cautious voices on the phone showed that they dared not believe their wildest dreams might have come true.

There was a tentative knock on the door, with Mum standing there looking hesitant and unsure whether to share in my radiant, aural joy that greeted her.

“Something wonderful has happened, Mum! It really has!” I repeated, embracing her warmly.

Dad acted as if nothing had changed and went to pack my wheelchair in the boot of his car.

“No Dad, that’s not necessary. I’ve felt fine lately!” I tried stopping him, knowing full well that my legs wouldn’t need the wheelchair that morning.

“You might get tired later. We’ll take it just in case,” he insisted.

“ ...and your seat-stick,” added Mum. “Please take that. Tunbridge Wells is a bit hilly.”

Outside, we were greeted with yet another brilliantly sunny day. Summer had finally arrived. The heavy car door, previously impossible for me to open, became a simple and manageable task. The stuffy heat on the journey didn’t bother me which was remarkable; instead I enjoyed watching the sunlight filter in between gaps of trees and through leaves, dancing on people’s hair, highlighting their tones and colours. Enjoying looking at the effects of light seemed a new experience all over again, no longer having to dive for a pair of sunglasses to protect my delicate eyes.

“There’s a disabled bay!” said Dad, spotting one in the Tunbridge Wells multi-story car park. He asked for my disabled parking badge to display in the car window. I handed it over with terrible guilt as I felt anything but disabled.

"Can both of you walk with a limp, or something, pretending the badge is for you?" I blushed, requesting that my parents alleviate my shame.

They continued to look perplexed as they hadn't really witnessed any of the 'transformation' I kept talking about, merely commenting on how well I looked. Dad gave into my persistence about leaving the wheelchair in the boot although I did take my seat-stick at their insistence.

Then began the wonder of it all! I ran ahead, rushing into shops spontaneously, sprinting up and down flights of stairs, pushing and pulling open heavy shop doors, holding them open for others to file through. I felt like a teenager all over again, although this time a healthy one.

"I've never seen anything like this!" wept my mother with liberating tears of joy as they attempted to catch up.

The planned trip to Tunbridge Wells turned out to be a confirmation that indeed something remarkable had truly happened.

Only a few weeks before at Dorothy Perkins, Dad had gone up the stairs to the first floor in order to bring down clothes I couldn't get to (there was no public lift available). Now I was leaping up the very same stairs, missing out one or two in my excitement, observing the first floor of fashion with the same awe as looking at a Seventh Wonder of the World.

My poor, long-suffering parents looked relieved when I finally came back downstairs again. They didn't know where I'd been. Apparently, I'd been gone about 40 minutes, filling my arms with brightly coloured outfits, trying on stylish hats and holding up dresses against myself in the mirrors. Wherever there was a queue I just joined it, not always buying anything but just enjoying the pleasure of standing in a queue again. I was a bird set free from its chained cage! I was Rapunzel who'd been given a key to escape the miserable tower, from which she and her Prince had been imprisoned for so long!

Mum had borrowed my seat-stick during this time to provide relief from her advancing arthritis, sitting by the entrance doors of Dorothy Perkins. Dad stood next to her with his arms folded, continuing to look bemused, still not daring to hope that his daughter might be freed from a 20-year-long illness.

It was an odd experience being on the same level as everyone else in a shopping precinct, no longer lower down in a wheelchair. It was also odd to walk at the same pace as everyone else, no longer lagging behind with my sticks. My body felt as if it wasn't my own, as if I was living in somebody else's instead. Perhaps it was my resurrected body? Perhaps it wasn't really Tunbridge Wells but the New Jerusalem? Was the entrance to British Home Stores really the Pearly Gates of Heaven in disguise? It reminded me of a verse from Handel's *Messiah*, taken from the Bible:

> 'In a moment, in the twinkling of an eye, at the last trump: for
> the trumpet shall sound and the dead shall be raised
> incorruptible and we shall be changed.' (51)

Changed my body certainly was and as the verse said, it had occurred in a flash, in the twinkling of an eye. But again, how long would this 'change' last? The list of vanishing symptoms which I'd written down in the 'Gone' column, was now getting so long that it seemed possible that I was *completely* healed from M.E., not partially but totally.

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51. I Corinthians 15 v.52.

This progressively enlightening truth was a discovery too frightening to take in.

As I lifted heavy shopping bags for Mum and Dad back to the car, delayed lunch until two o'clock without going hypoglycaemic, it seemed unnecessary to continue testing out if I was truly healed. I stopped writing the list of vanishing symptoms, instead believing that the impossible seemed to have occurred in my ordinary, mundane life.

On the journey home Dad didn't say much, although he was in obvious deep thought. Mum, on the other hand, was crying from sheer joy, running out of tissues to wipe back her euphoric tears.

"What am I meant to tell people when they ask me how you are?" Dad asked, very confused. My transformation had troubled him greatly.

"She's been healed!" came the quivering voice of my mother.

I, too, knew I'd been healed after that family outing to Tunbridge Wells. The evidence was stronger than any brain scan, blood tests or scientific findings. Just as the Biblical figure of Lazarus didn't need medical tests conducted to prove that he was alive again, neither did I: people could see that Lazarus was alive as he sat for dinner only days after his resurrection (52). Likewise, people could see that I could do normal things again without having had medical help to do this.

My healing, like Lazarus's, hadn't been just a physical 'cure' but a divine touch by the very hand of God. For some reason, He had intervened in the natural course of my prematurely disabling body to restore me to good health, instantly, like a time machine travelling back 20 years to my 14-year-old strength.

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52. John 12 v.2.

‘Knowing’ I was completely healed was a rapturous, exhilarating sensation that left me free from all worries.

I honestly believed that I would never worry about anything ever again. The experience was so beautiful, so magical yet real. Knowing that miracles still occur today made me come alive with an excitement and expectancy that hadn’t previously existed for me.

I couldn’t wait for John to return from work and share with him the certainty of my healing. Once home, I heard his door key turn in the lock and ran up to him with a massive hug.

“I’m completely healed! I know I am!” I sobbed all over his shoulders.

“Yes, I know you are too! I’ve been telling everyone at work!” he replied, just as elated.

The hug was more than just a warm embrace, for as our fingers clasped around each other’s shoulders, they released the awful burden of eight, long, heavy years together of crushing illness and all its impact. The gripping fingers digging into one another’s backs signified that we’d both made it out of the tower together, unexpectedly.

The hug lasted a long time.

As the weeks went by, it became clear that I was indeed completely healed from M.E. Just as it arrived out of the blue on 2nd December 1977 after the ECHO 2 virus, so it left just as suddenly on 3rd July 1997 after prayer. My body, unlike that of Marilyn Monroe’s, hadn’t reached a state of perfection, though. I was still terribly short-sighted, needing glasses and had an in-growing toenail requiring attention. The healing of one specific neurological illness, however, had taken place.

On the following page are listed all the symptoms that left instantly after the prayer; symptoms I’d suffered from persistently for eight years. Many of them I’d had for as long as nineteen and a half years. In addition to these symptoms, there were two others which left at the same time which aren't necessarily associated with M.E: severe period pains (which commenced at the start of the illness aged 14) and damp induced muscle pain.

THE SYMPTOMS WHICH HAD **GONE** COLUMN, AFTER JEN'S PRAYER ON 3RD JULY 1997

1. crippling pain, both muscular and neuropathic, in my legs and arms
2. intermittent muscle paralysis
3. all over muscle weakness and tenderness
4. pins and needles
5. numbness
6. poor balance
7. poor co-ordination
8. joint pain
9. muscle twitches (fasciculations) on legs and arms
10. toxic sensation in my blood
11. acute noise and light sensitivity
12. slow, sometimes slurred speech
13. poor concentration when reading, writing, talking, listening and thinking
14. poor short-term memory, e.g. forgetting what I'd just read
15. physical fatigue after the simplest of tasks e.g. brushing my teeth
16. mental fatigue after the simplest of tasks e.g. a short phone conversation
17. severe low blood sugar problems (hypoglycaemia)
18. faintness when being upright (in addition to faintness from hypoglycaemia)
19. asthma, especially from chemical and dust sensitivities
20. breathlessness after the simplest of physical and

mental tasks
21. intolerance to sugary foods, food preservatives and additives
22. sickness allergy to certain foods, e.g. shellfish
23. intolerance to alcohol
24. severely bad side effects from simple medicines
25. severely bad side effects from local anaesthetics
26. intolerance of hot and cold temperature
27. sensation of ‘brain fog’ when my brain failed to think clearly
28. insomnia
29. reactive exhaustion from busy surroundings e.g. traffic, crowds etc.
30. excessive hair loss
31. daily throat inflammations
32. irritable bowel syndrome
33. inability to perspire
34. essential daytime sleeping
35. inability to cope with much stress
36. being overly anxious
37. inability to overcome common viruses
38. problems with swallowing
39. muscle stiffness
40. clumsiness
41. poor oxygen intake, being unable to be near candles or a log fire
42. poor neuromuscular skills, being unable to work a computer mouse
43. dysphasia (choosing the incorrect word in speech)

It took a while to realise all of these had vanished: my reaction to a dental anaesthetic was non-dramatic and quite boring really on a trip to the dentist soon after the miracle. Boring was jubilant, though, far better than going unconscious in the dentist’s chair. The only side-effects encountered were of me dancing with joy to a jazz CD playing in the waiting room.

How can one describe the sudden withdrawal of an almost life-long disease, the instant removal of all encompassing pain that nagged, tormented and twisted my soul? It was now replaced by muscle and nerve tissue as good as new, scream-free, pinch-friendly which felt wonderful at last to be touched.

The power of music can often speak when words are incapable of communicating. Vaughan Williams' *The Lark Ascending* personifies my own feelings as the lark climbs higher and higher to the clouds, towards freedom in its own little world, oblivious of the turmoil on earth below.

The lark's identity was mine too, newly liberated without a care in the world. One difference though, is that larks don't shed tears whereas mine kept tumbling down plentifully.

21. *The Shock of the New*

The day after the Tunbridge Wells outing, it took me longer than usual to brush my hair. On staring at my reflection in the long bedroom mirror, I realised that my hair had become thicker; it was no longer thin and straggly.

My sister Rosemary remarked on how my skin colour had transformed from sallow to rosy, when she and her three young sons stopped by. (My skin had been increasingly sallow as the disease had progressed.) Others commented on my healthy-looking cheeks, whilst my dentist told me I had life in my face even after her treatment!

“You haven’t got those awful dark rings round your eyes, thank heaven,” noticed my jubilant mother.

Besides thicker hair and healthier skin, my arm muscles had changed in a matter of days, becoming beefier and lozenge shaped. Some were concerned that I might pull a muscle or sprain an ankle but their worry seemed unnecessary. My muscle tone was instantly as good as new, without needing to be worked on. I was more than an inch taller from straightening up and no longer stooping over. My spine, neck and shoulders still tingled from realignment for a further couple of weeks.

It was a shock to wear heels and to squeeze into proper fitting clothes, instead of them hanging off me so as not to hurt my muscles. My arms dangled aimlessly by my side without purpose as my sticks became unused, gathering dust in a corner.

The joy of going out with John was like being on a date with him all over again; out for walks together through the beckoning, patchwork fields nestled under rolling hills; to be together in the fields, instead of watching him from a distance embarking on a walk of solitude.

One afternoon shortly after the healing, we drove to Brighton for a Woody Allen matinée, a double bill. Four hours passed in the cinema, making it early evening when we left.

“Oh my goodness, is that the time? I haven’t eaten for over four hours! I must eat NOW! Quickly – find me something to eat!” I panicked outside to John, presuming a hypo attack was well on its way.

“What are you talking about? You haven’t shown signs of passing out lately. Just calm down!” he responded, wondering if he should start panicking too, given my previous blood sugar problems.

“Oh, I forgot. I don’t have M.E. now, do I? Oh, thank God!”

The reality could only sink in through stages, not all at once. My mind had to be reprogrammed on how to react. It had been set at ‘panic’ mode for so long if meals weren’t eaten frequently; quite rightly so because otherwise I’d collapse in a heap on the floor. But now my mind could be told, “It’s alright, you don’t have hypoglycaemia anymore. You can hang on a bit longer for something to eat and not be glued to a watch.”

During mealtimes, I noticed that even my taste buds had changed because I enjoyed sweet and sour food for the first time ever. I could tolerate marzipan and eat seafood without having to smother it in cheese to disguise the taste. John was flabbergasted as he watched me tuck into fried duck with pineapple, garnished with a satisfactory smile. Some of these foods had previously made me sick, including the smell of steaming mussels. But not anymore.

In supermarkets, hair shampoos and conditioners could all be tossed into a shopping basket without the labels needing to be examined for alcohol. It no longer mattered if alcohol was an ingredient so I just chucked it all in! As for a trip to the hairdressers, that was like winning a prize draw just to have my fringe cut. The pleasure of being pampered with magazines and cappuccinos with chemical sprays no longer affecting me, was sheer bliss. Observing the Joan Collins look-alike customers, with painted toes and manicured nails, showed me that my life was now transformed into the ‘well-world’ although my heart was still with the sick and suffering.

The change was similar with driving a car; Sterling Moss would have quaked in his Maserati had he seen me flying up the Hastings Road in our second-hand Toyota Carrolla. The freedom of driving anywhere whenever I wanted to, lifted me into a state of exhilaration. I’d endeavoured to drive the occasional short journey with M.E. but only with the ruffled wings of furrow-browed angels protecting me. (Previously, breakdown trucks had transported me and the car back home: the car hadn’t always broken down but my body had!) That was now all yesteryear. I could feel the pedals, push and pull the gear lever, concentrate on what I was doing and drive myself back home... in other words, drive properly.

After surviving my own version of Brands Hatch, things continued to change back at our flat. Into the bin went a whole list of things: all my medicines, 15 of them; earplugs which acted more like ear extensions as they were worn so much; old black bin liners, which were sometimes hung over windows to block out day or moonlight. Light and sound had entered my life. Benefit forms for renewal were ripped to shreds by my newly found strength. Kitchen aids were given away: the electrical tin opener and food mixer because I could chop, peel and use my hands. My seat-stick found a new home although I kept my wheelchair and one walking stick as a keepsake.

All my helpers were given the sack but they were thrilled to hear the reason why. Betty, who helped with the housework, was so moved by the news that I made her sit down in case the shock was too much for her.

“I’ve some wonderful news to tell you!” I kept repeating to people: Elsa my taxi driver, Mary our dinner lady, Sid the butcher who no longer needed to deliver minced meat and lamb chops to our door.

Doing all the shopping by myself triggered an adrenaline rush. It was so wonderful to be independent, not having to rely on others for my existence. Thankful tears were shed from carrying heavy shopping bags and tackling piles of ironing, to bending down scrubbing floors and stretching broom high to sweep away cobwebs. Housework was a stimulant now – a pep pill without the side effects.

Watching videos at home was like watching them for the first time: even though I’d seen the films before, my brain had been so sluggish from M.E. that my memory of their content was almost non-existent.

The sense of freedom was so great that I didn’t know how to spend it: freedom in jumping on a train whenever I wanted to, without planning the journey weeks in advance. London... the city was now my oyster as I floated on air along Charing Cross Station. Walking from the platform to the ticket barrier was so easy now: those few yards presented such problems before. The art galleries were my beeline as I flitted from room to room and building to building. My head wasn’t just swimming from this freedom but drowning in it.

“Where shall I go? What can I do next?”

Socialising was a new practice all over again as I could wait to eat with others and enjoy lengthy conversations without lying down after five minutes.

Parking anywhere in a town centre was nothing less than euphoric. It no longer mattered which car park we used because I could walk any distance. Being able to do little things that healthy people wouldn’t think twice about, transported me into another world, making my anger continue with people who'd nothing genuine to complain about.

"Well, what do you want then? There's no ham and mushroom pizzas, only ham and pineapple. Make your mind up!" a woman spoke aggressively on her mobile phone to some recipient (probably her teenage child) in a supermarket.

As for me, I was over the moon from just walking round a supermarket pushing a trolley. To me that was Heaven whether there were ham and mushroom pizzas or not.

I was definitely traumatised from experiencing such a divine intervention. It had been unexpected, so sudden, the impossible taking place in ordinary, everyday time. I'd been singled out, which had made the trauma worse. Why me and not somebody else? I wasn't even seeking healing whereas others were. I'd accepted my disability, sad as it was and had learnt to live with it.

In the days after the miracle my heart became heavy with guilt whenever I saw someone in a wheelchair; the guilt gnawed away at my joy as their eyes conveyed their own personal struggle. At times, the guilt was crushing for me.

I needed counselling but no-one really understood what I was going through; perhaps only those who'd experienced a dramatic healing themselves might have understood. Books entitled *How to adjust to miracles* don't exist in places like W.H. Smith or Waterstone's.

My emotions swung from guilt to exuberant happiness. Feeling happy was a shock in itself. I couldn't be happy with M.E. as I was in constant pain.

John had to adjust to the shock of having a new woman in his life – his wife!

"It was scary," he recounted shortly after the event. "I'd been used to coming home finding you asleep, in pain on the bed or sofa. But you started running up to me telling me about your day, doing housework with the radio blaring. The way you talked and stood was different. You changed so much I wondered, ‘Where’s my wife?’ It was like the former Catherine having a twin sister.”

But the marital adjustment wasn’t entirely a bed of glorious roses. John was no longer my carer and although that brought him relief, it also made him feel unwanted as I constantly refused his help.

“You don’t need me anymore, do you?” he reflected wistfully as he rushed to open a door, out of habit, only later to realise I could turn the door handle by myself.

But worse of all was my feeling of no longer needing God. Gone were the days of praying hourly to Him, from sunrise to sunset, my only previous way of getting through each moment. Just as I no longer needed John’s help, it also looked as if I didn’t need God’s help anymore either. Although I was deeply in love with God and so thankful for what He had done for me, there was no longer the feeling of dependence on Him which had formed a special kind of intimacy.

This new ‘shift’ of strength, away from God and towards me, made me feel uncomfortable and weighed heavily on my mind.

22. Beatific Gift

Like Michelangelo’s fresco at the Sistine Chapel, showing Adam touched by the very hand of God, I too had been singled out by the Divine. As the beggar’s feet and ankles at the Beautiful Gate became instantly strong, my body had experienced that same immediate strength. Was I now meant to unravel a mission, just as Lourdes was founded through Bernadette’s discovery of the healing fountain, in obedience to the vision of her Beautiful Lady?

The missionary idea I’d had at 15 was returning after all. It wasn’t the stereotypical picture of converting groups of natives to a Western lifestyle: instead it was discovering an appointed task, like Frodo and the Ring. The healing had jolted me so much that I felt my life was no longer my own. What was I meant to do with this gift called life, the resurrected Lazarus blood flowing through my veins? Start a family? Go back to teaching? Work at the local Spar grocery shop, rejuvenating the meaning of the word ‘spa’?

As balmy September rolled around, my favourite month of Indian summers, I found myself at a job interview; not at Spar stacking shelves but as a carer for adults with learning disabilities. It was two months after the miracle so my mind was still filled with awe and wonder; in fact it was swimming so much in a pool of adrenalin that I couldn’t concentrate on the interview. All my mind could dwell on was the sheer delight of even thinking of working again; of sitting in a normal position in a normal chair, with pain-free muscles and slur-free speech. Being normal again was still shocking and I simply wasn’t ready for a daily list of mundane tasks to fulfil at a physically and emotionally demanding job. I needed time to adjust as the lark in me was still ascending, the clouds getting closer and closer as my spirit soared higher with no sign of ever descending. I was offered the job but turned it down, explaining why to the man in charge. My infectious recounting of the healing moved him, and helped him to understand my need for ‘time out’. Everything had changed for me: a whole new world had opened up. As my emotions soared higher, so did my guilt as to why *I* had been the benefactor of such a celestial gift, the guilt deepening as time passed by.

“Would you like me to save your place in the queue whilst you go and sit down?” I asked a middle-aged man at Abbey National, who was leaning on a stick.

“No, I’m fine thank you,” he replied, taken aback.

So it continued, with me rushing up to complete strangers with walking sticks and wheelchairs, offering help in carrying their shopping bags. I never once got a gruff reply and some even allowed me to help them.

The simplest thing became a wonderful joy: queuing; ‘popping out’ for a pint of milk; walking to post a letter; inviting folk round for drinks, meals and conversation; vacuuming the carpet of our cleaning lady, Betty, who’d recently become unwell; giving people a lift; stretching up to change a light bulb. The ordinary, the mundane, the once impossible had now become the norm.

It was important that I still viewed the wheelchair as something positive, though. Despite the obvious liberation of being out of one, my perception of it had taken six lengthy years to shape. It wasn’t some kind of negative, sad monstrosity but a sensible invention; my healing hadn’t changed that. Finding strength through weakness and God’s light in darkness had made the wheelchair days special in a desperate way.

The discovery anew of the joyous ordinary continued... hanging up washing; lifting out heavy casserole dishes; running up and down stairs again, again and once more for fun; hooping and hallooing in the car with the radio up so loudly that heads turned in the street to see who the unruly person was; driving and walking to a shoe shop to purchase long, shiny black dancing boots, instead of ordering flat, ugly shoes through the post.

The joy climaxed at a 'healing party' when light shone from beaming white smiles of the partygoers, sharing in the joy of my beatific gift. Eighteen balloons had been blown up, one after the other without a break by my new set of lungs. The floating balloons were emotionally symbolic as my happiness increased each day with confirmation of the miracle proved morning, noon and night by my continuingly healed body.

Even when a chest infection hit me, there was no sign of relapse. Instead, I felt stronger than ever when it left. This was the first time my immune response had been normal for almost 20 years.

Waking up to morning light greeting another healing day, with unknown adventures waiting to be unwrapped, added caravans of happiness onto a long chain of emotion. A smile never left my face and was probably there all night long too, like a Cheshire Cat.

Being free from pain was by far the greatest joy of all! "Kick my legs as hard as you can! They won't hurt anymore!" I encouraged my six-year-old nephew Robert. (He'd always been warned to not touch them.) So he did, kicking and kicking them, watching me smile instead of scream. He let out the most hearty laugh I've ever heard, full of relief, as he rolled on the floor consumed with happiness.

Putting on a pair of tights without an excruciating grimace, or a pair of socks without psyching myself up, sent me beyond the clouds to Pluto. Few could relate to me. My mounting levitation had seemingly no return from outer space.

* * *

Friends of mine also went to see Jen, in the hope of a similar miracle but they came away the same, not healed, although perhaps more peaceful than before.

The beatific gift of healing made me see all good things as gifts: the gifts of marriage, children, friends and now the gift of health. With marriages tumbling down all around, the renewal of my relationship with John was like a fresh start, the former eight years of being together fading into merely an upsetting memory.

Would I have a shrine built to commemorate my healing, perhaps in the little study in Cranbrook where the miracle took place?

“This is the seat Catherine sat on when she was instantly healed... the downstairs bathroom where she first did aerobics to test out her new body… ” I imagined, with a tour guide showing people round. Would the house I was healed in be added to other lists of world-wide shrines? Some had left their sticks and wheelchairs with scribbled notes of thanks at famous places. Should I start to leave my sticks and wheelchair in the house at Cranbrook?

When the flat, ugly shoes in which I was healed wore out from all my recent walking, I thought twice before throwing them away. It was like parting with the special event. Then I realised that there would come a time to part with all the clothes I was healed in. If I kept everything, the focus would be on me and not God. So, after kissing the ropy old shoes with a lingering goodbye, they found their way into the bin.

My name was now in a privileged line along with those who’d also received a dramatic, immediate healing over the centuries: the famous and the lesser known whose sight had been restored; whose haemorrhage had been halted; whose dying baby had been brought back to life.

I’m sure that all these benefactors of a beatific gift had done nothing to deserve their healing, just as I had done nothing to deserve mine. We were merely recipients of abundant mercy.

23. *Through the Grapevine*

After the shockwaves died down, celebration set in. The phone rang off the hook from people who'd 'just heard'; a string of healing messages greeted me on the answering machine when coming back home. Gifts gathered on the doorstep and cards of congratulations filled the little wooden post box at the end of our garden. The grapevine worked overtime with many hearing my news second, third and even fourth-hand; the problem with the grapevine, though, is that it can grossly distort the original story to the point of it becoming untrue.

"Look at you, walking here to do your shopping! We've heard all about what happened: how a healer made you better – some local woman," marvelled the rosy-cheeked butcher whose red eyes matched his bloodstained apron.

"It was God, not a person!" I corrected him quickly. He didn't mind being put right: he was delighted that I could walk again, whether God was behind it or not.

The distorted grapevine continued.

"I know someone who had the same thing happen to her," spoke the certain words of a local tea lady, who'd witnessed me in the past struggling with two sticks.

"She changed her diet and that made her M.E. go away, like yours."

"That's not what happened to me! Mine was an immediate healing!" I reminded her (for the second time).

And so the embellishments of the story continued. The one person, other than me, who was affected most of all by the wondrous act was John. For eight years he'd watched me drag my legs on the floor, had witnessed my brain pack up in mid-stream conversation and had often cut up my food. He'd always longed for me to be as well as the 'halcyon Hamtramck days,' of our engagement period. Now his wish had come true, not slowly but instantly; at last, our lives had a truly happy, fairy-tale ending.

John commented on how the healing had been so frightening that it was like being in the presence of God. That put just a little bit of pressure on me, to say the least, as John tended to think of God every time I walked by!!!

Neither of us could keep our mouths closed from sharing the amazing news, John being just as enthusiastic as I was about telling others. Eventually, we decided to back off from telling so many people as it was becoming too emotionally draining. We needed time for quiet reflection ourselves.

Just after deciding this, there was a knock at the door. I rushed to open it, half expecting it to be a TV camera crew but found instead a door-to-door salesman displaying his delightful goodies.

“Tea towels, dish cloths, shammy leathers love, even birfday cards. I got everythink ’ere love… ” came his tempting invitation.

But my head was still full of miracle wonder.

“I’ve just had a miracle!” I blurted out uncontrollably. “I couldn’t have stood like this talking to you otherwise!”

“You was in a wheelchair?” the salesman responded wide-eyed on hearing my story. “But look at yer now! That’s brill, that is!”

His oven gloves were relegated to second place as his mind raced with this unexpected news. As he left I noticed a spring in his step, not just from making a sale with me of a tea towel, but an energy close to Biblical wonder two millenniums before.

In spite of trying to back off from relaying the miracle story, I couldn’t stop telling people what had happened, no matter how hard I tried or what the reactions might be. The joy was irrepressible like a gurgling, bubbling brook.

After John, the next person who showed great effect was my mother. She kept saying, “God must get the glory for this and no person”. The touching of her younger daughter in this way had filled her with a praise that made her face shine. Dad continued to be reserved: I think he was afraid that I might relapse but as the post-healing period turned from weeks into months, he became more accepting of the ‘happening.’ In early September he and I went to Westminster Cathedral, participating in a thanksgiving service for the life of Mother Teresa who’d recently passed away. Amongst the solemnity of not just her passing but also that of Princess Diana’s around the same time, Dad came to realise that a supernatural event had indeed occurred in my life as I walked miles by his side, past Diana’s flower tributes, all the way to Charing Cross Station. The train journey home was one of reflective joy: we’d had the happiest day together ever as father and daughter despite the sorrowful content of the trip up there.

My brothers and sister were moved by the healing. I have a wonderful memory of my three young nephews following Rosemary and me through the local Hawkhurst Nature Reserve, the same one that John and I had visited in magical discovery shortly after the miracle. Filled with happiness, I grabbed spontaneously several musical instruments from our flat: drums, recorders and maracas, handing them to my nephews to play as we walked along the mauve, marshy orchid pathways, dodging nettles and singing:

Silver and gold have I none,
but such as I have give I thee.
In the name of Jesus Christ
of Nazareth, rise up and walk!

He went walking and leaping
and praising God,
walking and leaping and
praising God.
In the name of Jesus Christ
Of Nazareth, rise up and walk!’ (53)

Like the time with John, we had the Nature Reserve all to ourselves: this was just as well (again) because we belted out the song, its melody cascading through Wealden sky, the piped notes and strong rhythms becoming primordial through the jungle-like mass.

After the joy of John and my family, the next best reaction was from my GP. I wrote her a letter, telling her what had happened; she kept on phoning in response, leaving messages because I was out all the time enjoying my new body! Eventually we met up and gave one another a long, meaningful embrace. She was both delighted and inspired, labelling me as ‘Patient of the Year!’ She had no problem recognising the supernatural event, saying it was ‘an honour to see a healing miracle’.

“The healing has nothing to do with us, the doctors. It’s Something Else, not medicine,” she concluded, acknowledging the source of the miracle with reverence. Her face didn’t look perturbed but uplifted and relieved!

My consultant in London was overwhelmed when I saw him at an outpatient’s appointment. “How much better from M.E. are you? Sixty per cent? Eighty per cent?” he inquired, handing me a symptom chart.

“Well, I don’t think I’ve got it all anymore,” came my bold response to his baffled face.

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53. From the hymn *Silver and Gold* [*Peter and John went to pray.*]. Words and music anonymous, under Copyright Control. From *Complete Mission Praise*, Music Edition, published by Marshall Pickering, copyright © 1999 Peter Horrobin, Greg Leavers and London and Nationwide Missions.

“I think you may be right,” he concluded after a searching pause, discharging me as his patient.

“Who is this woman who prayed for you?” he asked nervously as I left. Unlike my GP, he was definitely perturbed.

What could he say? I’d come up to London all by myself, taken the tube, run up endless flights of stairs and walked along lengthy hospital corridors. The last time he’d seen me I was breathless in a wheelchair, barely able to speak and reliant on a carer.

The local supermarket in Cranbrook quickly became a source of miracle gossip when delighted employees rushed up to me with a hug. They had taken it in turns in the past to push my shopping trolley and even tear off perforated plastic bags for me. But now I whizzed around, cramming the trolley full with anything I could lay my hands on, stretching up high to shelves and dashing back for things I’d forgotten in my haste.

“Are you having a good day or something?” asked the young blonde girl at the checkout. (Her face was the kind that you’d look at twice in a crowd, modelled and immaculate with make-up.)

“Someone’s prayed for me and I’m completely healed!” rushed out my hysterical words.

“Oh wow!” Her mouth dropped open so widely that I could see her back molar teeth. “I think I’ll believe in God now!” she added, proving that blonde women aren’t as dumb as they’re made out to be.

In Hawkhurst, pedestrians crossed the road to look at me, aghast at my normal walking.

“You’re walking a hell of a lot better!” came one man’s stunned response.

I told him it was God; like many others, he didn’t seem to mind my religious conviction because whatever the source, it had worked.

A stranger even came up to me asking, “Are you the miracle lady? I’ve heard all about your healing: it’s wonderful!”

“Thank you,” I responded (although I thought, “Who on earth are you?”).

This was getting freaky, having people I didn’t know single me out! Apparently she was the older sister of a family John knew, who’d heard the story. News certainly travels fast, especially happy news.

Jen, who’d prayed for me, said it was the best news she’d heard ‘for yonks,’ admitting that our faith had been so meagre, making the event point to God even more. She wrote a letter warning me about horrible people who might say that I was never ill in the first place. She had endured that kind of scepticism after her own healing. At the time I dismissed her warning, thinking I’d be spared that kind of hurt.

Our next-door neighbours were thrilled with my obvious marked improvement, embracing me with more healing hugs, with miracle gossip continuing to permeate throughout Hawkhurst. But there was one young man of a scientific persuasion, living right next door to us, who was the first in a long line of sceptics to fulfil Jen’s prophetic warning. It happened over what was meant to be a celebratory meal one evening. During the last six months he had watched me shuffling with two sticks and seen John push my wheelchair to the car, yet his words over the steamy pasta dish transformed him into a venomous puff adder.

“M.E. isn’t a real illness, though, is it?” he spat all over my wondrous tale, damning my joy of being able to even cook for him.

Had he really thought that I was faking a disease all this time? It sounded as if perhaps he had. As my eyes lingered over the garnished garlic bread, I felt like cramming it down a certain orifice of his where the sun don’t shine.

That night I went to bed with a heavy feeling in my stomach; perhaps it was from my first attempt in years at making a sizeable meal for visitors, which tested our digestive systems; or perhaps it was from being disbelieved openly for the first time since the miracle. Maybe it was both.

Sadly, that particular neighbour wasn't the only one to undermine the wonderful event in my life. The NHS counsellor who'd visited John in the past, smirked cynically as John relayed what had happened.

"Let's hope it lasts!" he sneered right in my face. Mind you, he had been the one who'd told me to join an aerobics class but we still thought that he'd be happy for us, which he wasn't. John was visibly upset by his cold reaction.

Elsewhere, the scepticism turned into insults.

"You're mad!"

"You're crazy!"

"M.E. is a fake illness! How can you be cured from something that doesn't exist?" continued more hurtful comments, from people who'd never known me ill.

Once again, I wondered if I should stop telling people, in case the crucifying attitudes kept coming: crucifying it did feel, not to my body but to my heart and soul. But whilst contemplating this, the joy, the wonder of my miracle just couldn't be suppressed and still kept rolling off the tip of my tongue.

There was one reaction, however, which did get to me like no other. During an interview with a DSS official, I had to be assessed regarding my continued entitlement to a disability benefit, which I no longer felt appropriate to receive. As I relayed my healing story to the Dr. Crippen (54) look-alike behind his office desk, he

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54. Dr. Crippen (1862-1910) was an American doctor living in England, executed for murder.

wrote down all sorts of prejudice, unknown to me at the time. I showed him enthusiastically a photo that my brother Graham had taken of me in my wheelchair; the official smiled at the picture like a silent assassin. His assessment was sent to me in the post, revealing that I had scored no points on the physical scale but several, apparently, on the mental health scale. He refused to write what these mental symptoms were, to either my GP or to me but added that they had come to light during the interview process. His opinion is now permanently on my disability records. (55)

His judgement plummeted me into a well of depression for several days, forcing me to draw the curtains, talk to no-one and wanting to be left alone for the hurt to heal.

I couldn't please the NHS when I had M.E. and I couldn't please them now it had gone. An M.E. stigma, past or present, was an ongoing curse.

It was like being a former Communist in the McCarthy years or having had an affair if you were running for President. Your past dictated your future.

Yet from the deep well of hurt bubbled up the joy of hope all over again. It was unquenchable like an eternal flame; like a spring which never dries out.

After these encounters with sceptics, I sought refuge from church congregations of many denominations, feeling sure that they would share in my joy. Their reactions, though, were very varied. Some allowed me to talk publicly of my healing whereas other church leaders actively discouraged it. On one occasion there was a healing service where the subject was on Jesus' miracles. Filled with my bouncy, over-brimming zeal, I asked the vicar at the end of the service if I could share my healing story at a later date.

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55. I was told that I'd have to go to court in order to have the DSS official's false notes about me removed.

He replied, “No,” admitting honestly that he had problems with believing in contemporary healings. I told him that I had too in the past but he remained silent on the matter, avoiding me thereafter.

One local church did invite me to speak, which I looked forward to as they knew me well, having witnessed me struggle to walk for a long time. As I grinned from ear to ear over the microphone, proclaiming my amazing news, I wondered afterwards if the microphone had been switched on (which it had), as the story went down like a lead balloon. A few people came up to me afterwards sharing the joy, but for the most part I might as well have said that I’d recovered from nothing more than a head cold, such was the dead reaction.

One encouraging surprise became a personal contact with the then Archbishop of Canterbury, George Carey, who received an article written by my old school friend Anna-Liza. Healing stories are a minefield for journalists, so when Anna-Liza said she was writing an article about me, simply entitled *Catherine’s Healing*, I knew I could trust her. It was first published in Canada where she still lived and copies were circulated all over the world. Around that time, Dad mentioned to me that George Carey was visiting his church in Wye one up-and-coming Sunday.

“Give him a copy of my healing article!” I screeched, thrusting a black and white photocopy into Dad’s obliging hands. After Dad handed it personally to the Archbishop, I received a heartening letter back written by Dr. Carey himself, saying he wanted to make my story more widely known.

This type of positive evangelical response was sadly in the minority from churches; my story, in fact, tended to have more impact on those who don’t profess to be Christians, giving them hope in a hopeless world.

A pattern of customary questions began to emerge from those hearing my news. The most frequently asked one was if the healing was gradual or instant. On relaying that it was instant, some people shrank back, their body language uncomfortable as if they were conversing with a woman who'd sworn she'd been kidnapped by aliens and had witnesses confirming that indeed she had been.

The caution that my Dad had initially shown seemed to sum up the feelings of others, too. An American friend of John's, studying in England, had pushed me around the British Museum in a wheelchair. On hearing about the miracle, his reaction was, "Thank you God that Catherine is free from such terrible pain, even if it's just for a short time. But how long will this continue?"

Was my healing temporary or permanent? It was obvious I no longer had M.E. but would it return one day? These were questions far beyond my futuristic knowledge, which no-one, not even a wise old sage could really answer.

* * *

As with the unexpected visit of the door-to-door salesman, I continued to expect every subsequent knock on our door to be that of a press reporter, a TV camera crew or some media messenger and couldn't understand why no-one came to record my story; this was in spite of the grapevine rapidly spreading its tendrils.

"Where are they all?" I looked around with exasperation outside our front door for a queue of vans complete with BBC logos.

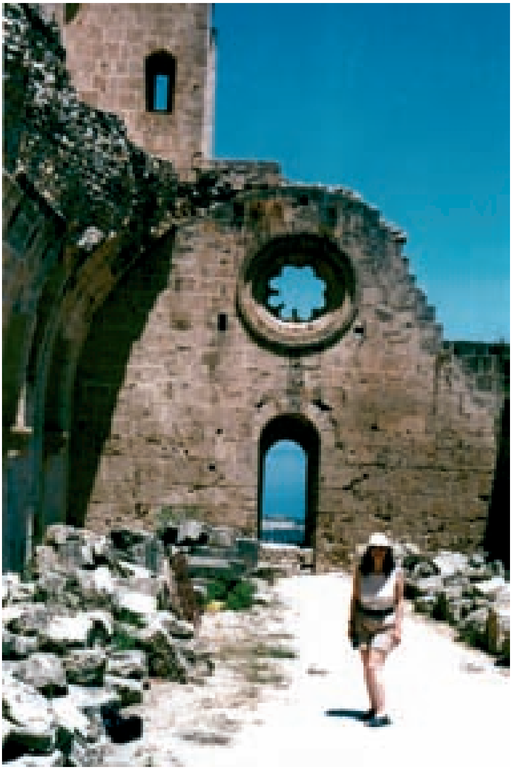
Should I phone up the tabloids and the broadsheets myself in case they hadn't heard what had happened?

And where were the dying, the sick on stretchers, those desperate to get well? Why weren't they lining up by our front door either, just as they did at Lourdes, flocking to the very place where Bernadette had her vision? Perhaps they were lining up at Peter’s house in Cranbrook, in the hope of a similar healing in his little study, although he hadn’t said that anyone was there.

I didn’t contact the media in the end because all I really wanted to do was enjoy myself. That was by far the highest priority on my list.

John and I on holiday in North Cyprus, 2008

John and I posing



Walking around
Mediterranean ruins

Working Alongside other M.E. Organisations

Further details of these M.E. groups can be found at the back of the book.

Demonstrating for a better M.E. deal, outside the Dept. of Health, London 2003. I'm far left with hat and Simon Lawrence is on the right at the front. Simon is Chairperson for the 25% M.E Group which supports the severest M.E. sufferers.
(Photo published with the kind permission of MEACH.)

Top: Linda Crowhurst

Above: Linda and Greg Crowhurst have founded Stonebird, an organisation for severe M.E. sufferers

Top: Visiting Simon Lawrence in Troon, Scotland, 2007

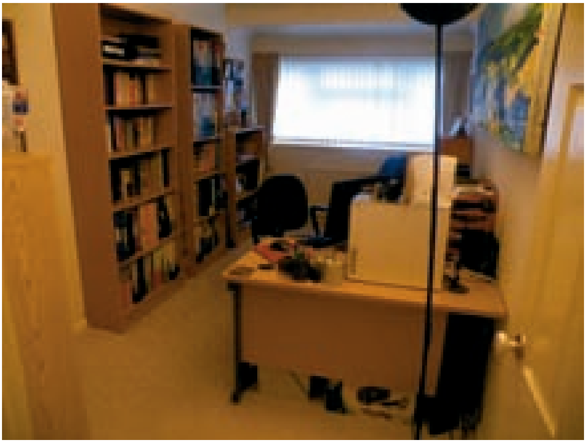
Above: Geri and David Laker. David is a trustee for the Grace Charity for M.E.. He is the carer for his wife Geri who has severe M.E.

If you feel able to, please pray for M.E. sufferers and their carers. Thank you.

The Grace Charity Office 2011

(Note John’s canvas landscape on the wall!)

The Grace Charity Office



John fundraising for the Grace Charity for M.E. at our local village fête in Langley, 2011. He drew 13 portraits in three hours!

24. Pleasure-Seeking

‘If I go to church on Sunday
Then cabaret all day Monday
Ain’t nobody’s business if I do.’ (56)

Just as John and I referred to our engagement period as the halcyon Hamtramck days, the post-healing experience was to be found in hedonistic living in halcyon Hawkhurst. I was magnetised by live music playing in historic pubs, sucking me into their whirlpool of entertainment; whenever I heard a screaming solo imitation of Rod Stewart’s *Maggie May* or some rasping blues from sultry saxophones, I dashed in like a shot.

“What would you like to drink?” inquired the bar attendants.

This invitation opened up Pandora’s Box, unpeeling what had been forbidden fruit for so long. Rum, liqueur, wine... where did I begin when still mineral water had previously been my drinking highlight ?

Sitting on a bar stool was a novel experience: I had to think long and hard about how to do that; how to climb up onto the stool, cross my legs without foot support from wheelchairs and have my weight thrown backwards to keep me balanced up there. It felt strange looking down at people instead of up at them from the wheelchair perspective.

John came willingly with me to anything enjoyable, thrilled that we were now an item together in public once again. The one thing he wasn’t too sure about was being dragged along at ten at night to go to nightclubs, when he was ready to go to bed! “Go easy on the face glitter!” he would yawn before we left, watching me pile silver and gold goo on my cheeks.

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56. *T’aint nobody’s business if I d*o by Grainger/Robbins was first recorded in 1922. The song was made famous by Billie Holiday.

But once he arrived at the stroboscopic paradise, he was glad to be there, even though it felt like gate-crashing on an 18-year-old's party (such was the age gap between us and our fellow clubbers).

Although I was 33, inside I was a teenager, not all over again but for the first time. Despite me trying to explain this to John, there were things I got up to which were acutely embarrassing for him (understandably so), especially when he'd watch me disappear into the back of bookshops, stretching up high to flick through adult books in the 'health section'. It wasn't a clinical Dr. Christiaan Barnard education this time but a more enjoyable one!

John was worried that I'd become earthy through all this pleasure-seeking but I couldn't just sing hymns all day long and live like a stereotypical nun. My body was brand new and needed to explore anything with the word 'fun' written all over it. Whenever I popped into an off-licence, knocked back a rum and coke (or two) or wore platform high shoes, I was thanking God in my heart for new muscles and an alcohol-tolerant brain. Therefore, I felt my behaviour could be justified. (Then again, why should pleasure have to be justified, as age-old philosophers might question?)

Besides dancing, the other post-healing love was swimming. Nightclubs and leisure centres quickly became my second home. It was strange seeing boards saying *You are now entering into the energy zone*. I was more used to signs pointing the way to disabled toilets. Swimming was magical as my new body twisted and glided effortlessly through the water. It felt as if I'd been swimming all my life! Whilst others mouthed their number of lengths, I cried my eyes out from just being there, my tears adding greater depth to the rippling pool.

Dad and my nephews regularly met up at the Tenterden Leisure Centre for swimming. The first time when Dad invited me to join them, I had no swimming hat or goggles, only a bright turquoise suit from yesteryear which amazingly still fitted. Determined to join in this unprecedented moment, I found a pair of John Lennon style NHS glasses (to substitute goggles) whilst a hair net made do as my cap! Plenty of disturbed looks came my way but I was oblivious to them, still floating on Cloud Nine. My family didn’t seem to care about how I looked and seemed quite happy to hang out with this nutter splashing around in the pool.

Just as I had to think about how to sit on a high bar stool, I had difficulties adjusting to the concept of happiness, wondering if it was alright to enjoy life so much? But this late-in-life pleasure was justified, again, as I thought back to my pre-healed body being only able to do armchair dancing (on a good day); of the time when my bottom sat on the sticky, beer-stained floor of my degree party, unable to shake, rattle or roll; when pubs had previously been a no-go area, not for the fights but due to the smoke, flashing jukebox lights and uncomfortable seats. Besides, people in pubs and clubs got to hear all about my healing as I continued to shout about it above funky disco beats and wanna-be Eric Claptons.

Something else I had to adjust to was the continuing change in my body, with my arms and shoulders getting bulkier whilst my thighs slimmed right down, like the build of Minnie Mouse. My skirts and trousers became too big whilst my blouses and jackets became too small. I bought figure-hugging clothes because newly found confidence had grown within, my muscles now able to bear the tightness of material. The way I started to dress also bothered John, in addition to my other behaviour but I was having too much fun! He understood in the end: it was all a shock for him too, one minute pushing his wife in a wheelchair in her baggy clothes, the next minute swinging her around the dance floor in her tight leather trousers!

I was so convinced that I'd never be seriously ill with anything ever again. Perhaps a cold or something trivial might happen but nothing chronic. I'd already had a chest infection since the healing and that was bad enough. Surely, God wouldn't be so cruel as to inflict me with anything worse than that? Chronic illness was definitely a thing of the past for me, of that I was sure.

My faith in God soared high into the sky, *truly believing that nothing was impossible for Him to do* as a result of the miracle. It was a wonderful faith to have, to be afraid of nothing, not even of a hideous, out-of-space monster from *The Alien* film landing in our sitting room. When God can work so frighteningly with the power of good, why be afraid of the power of evil? All I needed from now on was God – no-one and nothing else. He could do anything instantly and had proven that. Yet I still felt that I didn't need Him on a daily basis, only perhaps as an emergency every now and again. Nevertheless, I was very much 'in love' with Him for what He'd done for me.

"I love God so much, so very much!" I cried to my family after swimming 14 lengths in the Tenterden swimming pool.

* * *

One misty, autumnal day, when the fog wraps round you like a damp, wet shawl, a tune came into my head whilst playing the piano, its melody following me in the fragrance filled shower and later on during an amber coloured walk.

The song's lyrics were 'given' to me with such little effort, the whole thing being composed within a few days.

And Now That You Have Touched Me

And now that you have touched me
I now must believe in miracles.
How could I ever doubt you?
I was so blind to your mercy.
Your love has said it all
You knew the way I felt
And now you've healed me.

Your hand softly restoring my soul,
Restoring my mind, restoring my strength
And making me whole.
I don't always know the answer to your way
But I know you're working out my every day.

I now see the world so differently
And I'm full of thanks for what you've done for me.
I don't really deserve all of this
But you've bent down and given me your healing kiss. (57)

God's touch had caused physical changes: all the things previously branding me as permanently disabled had been altered by His power. His touch had changed my damaged brain and hurting muscles. Specific, scientific problems **must** have been corrected by the prayer: for example, low blood flow to the brain; low natural killer cells; punctuate brain lesions; raised levels of toxicity in muscles. (58)

These and much more had all been healed in a split second. God was in charge of science and resided over it, able to break scientific rules and natural phenomena.

Just as we both adjusted to the physical change, John and I had to relearn spontaneity and making instant decisions.

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57. *And Now That You Have Touched Me* by Catherine Ashenfelter, ©1997.

58. These are some of the most common findings in M.E.

Previously with M.E., every little thing had to be planned well in advance.

On a murky, drizzly December afternoon, John and I headed for Regent Street to view the Christmas lights. It was all so beautiful despite the weather and we'd only decided to go up at the last minute. Spontaneity in itself had become a beautiful thing. Being upright and on my feet all day long, instead of lying down, was as surreal an experience as sparkly old London town.

Enjoying Christmas at my parents' home was a great pleasure, a wonderful gift: tolerating the draughty Anglican church, our faces shining from Christmas merrymaking and the joyful healing; returning in the early seasonal hours to a long-awaited iced Baileys, no longer a tease; delighting in flashing tree lights instead of retreating to a room of darkness; joining in with fun and frivolity, no longer banished by pain to solitary confinement; arm in arm with John and Dad round winding country lanes, working off excess fat from the delicious meal which for the first time I could help to prepare. Yet the best thing about Christmas was the rejuvenated belief of Christ being real, of Him curing the sick today as He'd done in the past. Christmas had come to life as never before.

I knew that I had to come down to earth somehow from this extra-terrestrial lift, my continuous V.E. Day, jumping for joy in the streets as if the troops were forever Flying Home. The lark within me was flying so high that it was in danger of passing out from lack of oxygen. Yet the solution of how I'd come back down to earth evaded me: slowly, perhaps but not with a crashing tumble and the parachute failing to open up on landing. The latter, however, was to be my unchosen destiny.

The little lark fell so rapidly that it looked as if it had been shot, its beak squashed and bent from the hard ground below. The birdsong was silenced as it lay still and motionless, dazed by the suddenness of its descent.

With barely time to absorb the following series of unwelcome events, I found myself suddenly facing my worst fear of all: lying on an operating table, something which I'd always dreaded whilst having M.E.

PART FIVE:
LIFE AFTERWARDS

25. Oriental Lilies

The ride in the ambulance was bumpy and uncomfortable. Each time the driver turned a corner, my bed came away from the side and then crashed back into the cold, metal wall of the vehicle, again and again.

"Please slow down!" I remember thinking, as the woman driver pushed the accelerator pedal further to the floor. She had bright red hair, a cheerful colour to see amidst the dreary January weather.

I'd collapsed in my GP's waiting room from severe abdominal pain. It all flared up quickly after the New Year celebrations which were greeted by party poppers, animated cheers and chilled white wine. I'd felt particularly tired but initially brushed it off as 'hard living'! Shortly afterwards though, the pain started, followed by the ambulance. It was Thursday 8th January 1998, six months after the miracle. The ambulance was heading for Pembury Hospital (later referred to as Purgatory Hospital by me and John).

Whilst being wheeled in on a trolley, I thought that I'd come to the wrong place. The hospital was noticeably old fashioned, seeming more like a nursing home than a high tech casualty department. The sign on the Accident and Emergency door was just a scrap of paper selotaped on, with the letters A&E handwritten in red (which could have been in blood for all I knew). The writing wasn't neat or tidy and looked like something my six year old nephew had scrawled. I wondered if the doctors would be about five, with Fisher Price toy stethoscopes round their necks?

The pain down my left side was so bad that I couldn't turn my body: the attending nurses (who were older than five) ignored my whispered pleas of help, insisting that I climbed onto the A&E bed myself, the process of which set off howling, animal-like groans, so savage in sound that I couldn’t believe they came from my human lips.

These sorrowful moans were also ignored and the nurses continued to natter away, criticising their family members, in particular one daughter-in-law who was always tired at home and should just ‘snap out of it’.

My hands were sticky and clammy with nausea and pain so great that I was convinced I would pass out sooner or later. Despite this, no medicine was administered, not even a paracetamol because I had to ‘wait for the doctor’. After two and a half hours of silent agony, the doctor finally arrived. Her manner seemed on the flippant side, something I couldn’t weigh up in my serious state, as she refused to act on my GP’s requests for an ultrasound scan.

“I think it’s just a bad period pain,” was her diagnosis after very few questions were asked.

For some reason I became afraid that the M.E. was still with me because the healing hadn’t been ‘tested’ like this until now.

“Do you know I have a recent history of M.E?” I muttered to her.

To which she replied, “You mean C.F.S.?” (59) and visibly smirked at me. “Yes, your doctor did mention it.”

After a clash of opinions, she eventually gave in to my repeated, breathless requests for a scan. The picture on the screen showed a nine-centimetre ovarian cyst, the size of a grapefruit. The doctor blushed so much from her misdiagnosis that I could see her turning red without my glasses on. (60)

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59. C.F.S. stands for Chronic Fatigue Syndrome, an unsuitable, vague term designed to substitute the neurological disease of M.E.

60. The ovarian cyst had been present when I had M.E. but was tiny back then, not necessitating an operation at that time.

I now had to spend the night at Purgatory Hospital – hardly my choice of post-healing, hedonistic hotels, with the entertainment side just slightly down when compared to the nearby glitzy *Chez Moi* nightclub!

When a porter pushed a wheelchair towards me telling me to get in it, I was horrified.

"But my days in a wheelchair are over," I reflected. However, on clambering into it, I felt amazingly at home as he wheeled me to a ward.

Later that evening, John's smiling face greeted me like a beacon of light. He had been an important witness to my miracle, which meant more to us than ever before after this dramatic turn in events.

"I've never felt so close to you as I do now," he spoke rather sombrely, pulling up a chair. Perhaps he too realised that the timing of this was a little too near for comfort.

After hearing that an operation was imminent, to prevent possible haemorrhaging, deep-seated fears began crowding my mind.

"A general anaesthetic? That's what I've always dreaded! What happens if I still have M.E?"

Maybe it had just been a remission after all, with the M.E. lying dormant waiting to be triggered again?

"I don't want to die!" I cried to John, holding him tightly in my arms.

"You won't die – you've been healed!" he replied reassuringly, stroking my tangled hair, uncombed since early morning.

When visiting time was over, John placed a soft toy by my bedside, a Beany Baby skunk whose label named him Stinky. He'd been given to John by American friends in memory of a skunk related camping incident.

"I thought he could keep you company," were John's words on waving goodbye.

The thought was touching but the black and white creature, which drew much attention, made me feel like a real idiot. Memories started to haunt me of the teddy bear/psychiatrist episode when I was 15. The psychiatric ward at Purgatory Hospital was just a stone's throw away, so any emotional attachment that might develop with Stinky and me had to be kept well away from public scrutiny.

When the gynae ward settled down for the night, I stretched out my hand for a glass of water but found instead another shakily written, scrawled note saying *Nil by Mouth.*

"Please can I have a drink?" my parched voice whispered to the night nurse.

"You can't eat or drink for at least six hours, maybe longer," she replied emphatically.

Six hours without a crumb to eat or drop to drink? Operations were a new phenomena to me: if I still had M.E. the fast alone would have put me into a coma.

One of the few positives (or sometimes negatives) that come from being a hospital patient is who you meet in the bed next to you. To my right was Marion, whose Northern Irish accent made it unnecessary to inquire as to which part of the world she came from. As I was lying down in quiet thanks to God for my healing, Marion started offloading about friends and family members of hers who'd died in 'The Troubles'. This wasn't exactly the kind of pep talk I had in mind to prepare for my first major operation.

"At least God is faithful and won't test us beyond what we can bear," (61) my dehydrated throat croaked out loud.

"Oh, but sometimes I think He does, Catherine, I think He does!" she disagreed with great conviction.

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61. This verse comes from 1 Corinthians 10, v.13, although the word 'tested' is often translated as 'tempted'.

So with that epitome of encouragement, my mind fell into a deep sleep, dreaming of large jugs of lemonade being poured unceasingly through my open mouth.

This was my first night in hospital since meeting Sudha in London as a teenager. I was to rediscover that nights in hospital can be very lonely with few familiar faces; apprehension about the future; authorities prodding your body and writing down notes behind your back. All of this whilst you feel lousy, have interrupted sleep due to the din and bright lights, and are starving to death with your tongue hanging out like a panting dog.

Despite these woes, I still felt thankful regarding the timing of this drama.

* * *

Six a.m. was the rise-and-shine wake-up call but the wholesome whiff of brown toast and enticing coffee cruelly passed me by. Instead, I was greeted with a raging headache, so bad that it put me in a semi-conscious state. “We’ll have to give you a suppository painkiller,” the nurses explained, being unable to give me anything by mouth. When they told me to roll onto my side and put my legs in a helpful position, I realised yet again, as with other things, that this would have been impossible with M.E.

When an anaesthetist dropped by, I found myself answering, “No,” to all her questions. “Do you have asthma? Blood sugar problems? Allergies to chemicals? Do you suffer from a chronic illness?”

“Six months ago, I’d have answered ‘Yes’ to all of these,” I exclaimed with a massive grin of relief. She looked bemused whilst I only felt undeserving mercy.

The clock ticked by slowly, with my ‘slot’ being pushed back further and further. In the end, my fast lasted for sixteen hours due to emergency Caesareans going on before me. At last I was called for, the porters having an air of nervous excitement in their voices (not dissimilar to those of executioners, I suspect) as they transferred my bed onto a trolley.

“Good luck, Catherine!” called out Marion’s recognisable Irish tones whilst passing her bed.

My heart started pounding loudly, similar to 10 years previously when I broke the news to my parents that I was engaged to an American they’d never met before.

All I could think of through the winding hospital corridors was a verse from the psalms:

‘I will not die but live
and will proclaim what the LORD has done.’ (62)

My life then started to flash before me.

“This is the one to put you to sleep,” said the anaesthetist poetically, as if I was her pet dog. The hands of the big clock pointed to midday. Then... blank.

The next thing I remember was the voice of a panic-stricken theatre nurse leaning over me. “It’s slowing down! We won’t have to send her back in again!”

The hands of the clock had moved on to 4 p.m. I thought that perhaps I had died after all, as everyone standing around me was dressed in white. But there was too much stress and rushing around for it to be the joyous Pearly Gates. The nurses were worried because I was bleeding badly after the operation, thinking that it might be necessary to send me back into theatre.

But I was having one heck of a good trip as everything came floating towards me! The vocals of Joplin and Hendrix would have completed my Woodstock experience quite nicely. Gliding nurses, flying Interflora flowers, soaring needles all swirled surrealistically around in the air.

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62. Psalm 118 v.17.

Back in the ward, a bittersweet aroma of some exotic -looking pink flowers floated up my nose, filling me with peace. They were given to me by John, and I found out later that they were called Oriental lilies. (Their smell has always since reminded me to be grateful that I'm alive, so close was my brush with death if I had not been healed.)

'Be still, and know that I am God;' (63)

This was the Interflora message from my mother and sister, read aloud in meaningful tones by an older nurse.

"That's one of my favourite verses," she added. Together, she and I silently acknowledged the divine presence of those words.

All drug-induced trips, though, have their downers and the following morning I couldn't even sit up in bed, horrified by the tubes and bucket of blood by the bedside. My left hand throbbed from the cannula, attached to another tube for the drip. My throat burnt more than ever as I hadn't had a drink (except in my dreams) for 48 hours.

"Of course you can't move, love, you've had your stomach muscles cut! We'll help you up," came the kind words of a nurse who by now had stopped floating.

Forcing myself to sit up in bed, even with the help of two nurses taking both arms, needed great muscle strength on my part; again, this would have been impossible six months before. The walks up and down the corridor that they made me do, were longer than how far I could walk previously with M.E.

After several hospital nights of interrupted sleep from tearful women (many of whom were grieving from lost babies), I collapsed at home on the sofa with utter exhaustion.

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63. Psalm 46 v.10.

John ran around with his invisible pinny, making meals and meeting my special craving for milky chocolate! Lying helplessly on the sofa seemed like a déjà-vu of the M.E. days, as I stared in wonder at the depth of flowers strewn across the sitting room carpet, like a Florist's shop. We'd long run out of vases, so we kept tripping over them.

"I wouldn't have survived with the M.E.," came my solemn words to my parents whilst paying me a home visit. (64)

"No, no, you wouldn't have done," Dad said with a tear in his eye, his faint Yorkshire accent stronger than usual.

Mum said nothing but stared wide-eyed with emotion at the carpet of flowers instead. Then all three of us stared soberly at them, thankful with unspoken words that they weren't laid prematurely by my graveside.

Within a few weeks, life returned to a post-healing normality. I was tentatively pushing a shopping trolley and doing really well, or so I thought. The phone rang from local schools, pencilling me in to do supply teaching a couple of months down the line. Things were especially looking up when John and I booked an April holiday for springtime in Paris, a belated honeymoon only eight years late. The hospital nightmare seemed to be behind us.

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64. To reassure M.E. sufferers: anecdotal outcomes of anaesthetics and surgery on M.E. patients is variable. It usually depends on how severe the M.E. is. For some, a mild relapse of symptoms is experienced after the surgery, taking them longer than a healthy person to recover. Nevertheless, they do regain their previous level of pre-surgery ability. For others, they experience a permanent relapse as a result of surgery whilst some sufferers are unable to have surgery at all. As for me, I was so severe with my hypoglycaemia, dangerous reactions to chemical drugs and respiratory problems that my family, GP and I all believe that major surgery would have been difficult for me to survive.

Pleasure-seeking was the number one priority all over again. A suitcase was dragged out prematurely in February for Paris, packed with great excitement: elegant dresses, fancy suits and dusty French phrase books were all thrown in. *Chez Moi* nightclub in Tunbridge Wells warmed us up with our impending French visit, as we danced to its flashing disco lights alongside hot, sweaty bodies in the shadows of fake diamond-studded stairways.

But on our return home, John witnessed me crumple over in pain in our hallway, clutching my abdomen. It wasn't due to too much boogieing-on-down but something more sinister.

A swift trip to the GP, followed by an emergency scan, was again something not on my agenda for post-healing living. As my eyes stared at the computer, I couldn't help but burst into tears in front of the consultant as a large grey mass appeared on the screen.

"It's probably the same cyst," he said as the nearby nurse (who remembered Stinky) put her comforting arm around me.

The consultant told me that I'd had internal bleeding after the first operation which had bled into forming the second cyst.

"We'll do it right this time," he concluded rather sheepishly.

Right? Why wasn't it done right the first time? Did this mean that I was a victim of a botched operation? It sounded as if I probably was. Why was God allowing all this after the wonderful miracle? But there was no time for theological answers because I was immediately booked into the same hospital ward as before, although a different bed.

So, out of the suitcase came the satin, lace and language tapes for Paris, replaced by a hospital survival kit. Stinky wanted to come along too, much to my uneasiness. The supply teaching days were cancelled, as was our delayed French honeymoon. Was life ever going to get going again or was my healing just one big tease?

“At least I’ll get that wonderful high again, coming out of the anaesthetic,” I thought, trying hard to look forward to something.

But I didn’t get the wonderful high: instead I was as sick as a dog from the morphine and felt as if a truck had hit me. The joy of my healing was starting to evaporate and I no longer felt thankful for my close shave with death. Instead, I was depressed from the recent series of events, my abdomen raw from a soreness I never dreamt was possible and my pillow wet from tears each subsequent morning from crying in my sleep.

My tummy resembled a mashed-up dart board from the seven recent cuts: two slits from laparoscopies (camera insertions), four more slits from the first key-hole procedure and a four-inch slash from the second operation, a laparotomy, when even more stomach muscles had been sliced.

Just when I thought that my ‘new’ gynae illness was over, the two operations were only the beginning of an unceasing wave of suffering which was to follow like a deluge, passing the meagre defences I had left to stop it.

* * *

Shortly afterwards whilst lying at home in bed, a pain like a hot, iron rod started stabbing repeatedly down my left side, where the two cysts had been. It put me into a semi-conscious state and left me so sick that I refused all food and drink. We presumed it was the return of a third cyst as they can grow quickly but the symptom of blood toxicity put a different slant on the picture.

My GP was getting almost as stressed as we were and also rather confused in relation to my healing, which the whole surgery had been thrilled about. (The poor man's hair had turned grey since I'd collapsed on his surgery floor at the start of the New Year!) Another urgent hospital scan was arranged but whilst walking into the clinic, my faltering steps gave way on the plush hospital carpet as I sprawled out in a dramatic collapse. It was quite an entrance. Poor John, who'd driven me there, was beside himself and I could hear him yelling for help.

I was taken on a stretcher to the familiar, non high-tech A&E department, with the same hand scrawled note in red, selotaped to the door. It still hadn't been replaced in three months. Perhaps this was the permanent sign after all?

The diagnosis this time was Mittle Schmertz, a medical German name for painful ovulation. John and I laughed at this conclusion as a woman doesn't usually collapse when she ovulates! After three hospital nights, I was sent home with only a packet of paracetamol. Stinky wasn't impressed.

That weekend was Easter, the first Easter after my miracle, when the joy of the risen Lord should have been deep in our hearts from the recent healing. But celebration was far from our minds as I lay on my parents' sofa, feeling terrible, during a fleeting seasonal visit.

Just as John and I decided that we should leave, as my presence was hardly bringing Easter cheer, I found myself lying in a heap (once again); this time it was on my parents' floor.

A sense of stillness washed over me amidst family panic, even though my body was far from still as it shook and rocked from convulsions, interspersed with being sick on yet another nice, clean carpet.

For some of the time I was aware of conversation around me; at other moments my mind drifted into a state of nothingness.

It seemed as if death hadn’t finished its attempt to pull me over to its side.

Then, out of the blue, a struggle started with what I can only describe as my soul, the real me, struggling to get out of my body and succeeding, as it soared at a tremendous speed, going somewhere, travelling like an Express train to an unknown destination. Yet where it was heading was beautiful, a place of pastel colours: mauves, pinks and yellows. The sense of peace was indescribable although it was similar to the peace when I was healed. Was this Heaven, at last, the place I’d longed for when suffering from M.E.? I think it probably was and I didn’t want to return to troublesome earth after experiencing this new place. I loved it up there and was the happiest I’d ever been: truly happy and exhilarated! My soul most definitely was heading somewhere as I felt the speed of its travel and saw the changing colours as it sped by.

Then everything seemed to go wrong. My soul stopped travelling and instead had a quick glance down from the ceiling as I observed my very own body, completely still on the floor, neighbours bending down beside me and the worried brows of my nephews as they took refuge by the door.

“No! Don’t return! Please don’t go back! I want to stay in that place forever!” I spoke to my soul.

Then with the same speed as when it left, my spirit cascaded back into my painful, poisoned body.

After that, things are much of a blur except for the ambulance crew arriving at my parents’ house, strapping me into a chair, my eyes unable to focus or blink, just staring from shock into distant space.

“I think we’ve lost her this time, John,” my poor

Mum apparently said as I was carried outside. The passing, kindly face of an ambulance man displayed a compassionate smile; he listened sweetly to words I muttered, yet I couldn’t understand what I was saying to him, hearing instead my piercing screams from the hot iron rod of fire in my lower left abdomen, the sound magnified by the metal walls of the ambulance.

It had been quite an Easter Sunday, with what appeared to be my very own resurrection from the dead.

26. Golgotha

‘My God, my God, why have you forsaken me?
Why are you so far from saving me,
so far from the words of my groaning?
O my God, I cry out by day, but you do not answer,
by night, and am not silent.’ (65)

Through my failing vision, my eyes picked out the anxious face of my brother Paul, who’d driven family members to the hospital. I remember thinking that it might be the last time I saw him.

I hadn’t been taken to Pembury this time, but to a hospital in Ashford as it was the closest one to my parents’ home. In the A&E department, John dwelt more than ever on my healing, even telling the attending doctor all about it.

“We don’t understand what’s going on. My wife had a wonderful healing miracle last year… ” he started to recount.

“No, stop it! Don’t tell him!” I ordered, in between having convulsions. For the first time since its event, I felt ashamed of being linked to a miracle. Talking about my healing seemed stupid and embarrassing, given my current situation.

“Go on, I’d like to hear about it. I’m interested in those kind of stories,” the young doctor replied in his soft, Australasian accent.

So John proceeded to tell him about the miracle with great enthusiasm, whilst the antipodean doctor pierced a cannula unfeelingly into my arm.

It seemed as if nothing could stop the power of my healing story: not impending death and not even the suppressing shouts of the miracle recipient. Someone, somewhere, would carry the can proclaiming its wonder.

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65. Psalm 22 v1-2.

After several days of hearing yet more groaning women in cheerless wards (my own groans included), the tests conducted revealed nothing conclusive. This was in spite of my out-of-body experience!!! A few things did show up that hinted at possible infection but weren't definite enough for a diagnosis.

'Do not be far from me,
For trouble is near
And there is no-one to help.' (66)

With no diagnosis, I became a vulnerable target of mere opinion, of which there is plenty around in hospitals. It was after one of many fainting episodes that a registrar asked me, "What are your plans?"

Plans? Well, hardly to go on a world cruise. My plans were to try and stay upright without choking on my vomit during a faint. But that reply wasn't good enough.

"We need your bed!" instructed the ward Führer.

I daren't tell her that I was still recovering from the shock of an out-of-body experience.

Meanwhile, the hot, piercing abdominal pain where my operations had been continued in between collapses all over the ward, sometimes into people's saving arms and other times onto the hard, cold, bleach scented floor.

'Forlorn her nights and days go by;
Her life used up in weeping.' (67)

Where was God in all this, the God who'd healed me? Why wasn't He intervening a second time? He was like a hero who'd saved me from drowning in the sea, only to throw me back into the deep, floundering waters.

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66. Psalm 22 v 11.

67. *The Odyssey,* Homer, Book XI, 195-6, from *World Masterpieces,* Third Edition, Vol. 1, © 1973 W.W. Norton & Company Inc. NYC.

Knowing that God had rescued me before and still could rescue me made me hate Him for refusing to do it a second time.

“Why didn’t you just let me die, God, instead of saving my life? I hate you! I hate you so much!” I wailed to Him from the depths of my hospital bed, with language under my breath that turned the air a shade of sea blue.

I even began to wish that I hadn’t been healed. John suggested that perhaps I’d been called to a life of suffering. The miracle no longer gave me hope, adding only to the mounting division between me and the Miracle Maker.

> ‘The men who were guarding Jesus began mocking and beating him.’ (68)

The lady doctor started off being sweet in her smart attire and stylish handbag but turned ferociously on me like a Rottweiler being accidentally prodded from its sleep. “Can't you give me some antibiotics? A nurse thinks it sounds like an infection,” I suggested mildly because the doctor seemed a bit clueless as to what the matter might be. Her response wasn’t what I expected.

“I don’t like to be told what to do!” she growled at me in front of medical staff surrounding my bed.

The spirit of her fringed animal print clothing then possessed her very own soul as she commenced on a physical assault, unseen by the others. She performed an internal examination but unlike other doctors I’d had performing similar tasks, she forcefully punched my womb many times over with her fists, the greater my cries the greater her punches.

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68. Luke 22 v.63.

There was no apology, whereas other doctors had always responded with a sincere “Sorry,” if they’d hurt me unintentionally. Their examinations had been gentle. Hers was a sexual assault.

She left me wounded and sobbing for pain relief. Who could I report her to? If I did, no-one would believe me anyway. They didn’t seem to believe I was even ill, let alone believe in a sexual assault from a female consultant.

(The incident left me withdrawn from intimate physical touch for months afterwards, so deep was the grievous memory.)

“I get on with her rather well,” commented a patient at the far end of the ward.

Why then, did the staff have it in for me? Was it my healing story, which I started talking about all over again, handing out Anna-Liza’s article to convince myself as much as convince others? Was it my history of M.E. and the literature of lies so prevalent about it in medical circles? Or was it the presence of Stinky, who amazingly kept popping up by my bedside to keep me company?

Then, the knives were drawn in a final conclusion, far sharper than a surgeon’s tools.

“We all think it’s your M.E!” raised a young nurse’s voice judgementally. She only looked in her early twenties, so was hardly a voice of experience.

The nurse then proceeded to force me out of bed, pulling me up by the arms, refusing my request to bring a bedpan.

“There’s no reason why you can’t walk to the toilet!” she reprimanded.

“You’d better believe my wife if she says she can’t do something. She really means it,” interjected John, looking very concerned.

He was ignored as she pulled me onto my feet, then unexpectedly let me go whilst her face dissolved into remorse as she watched me drop to the floor, bang my head, swiftly followed by my persecuted tears. Another nurse eventually got a bedpan.

Oh, the hurt of being disbelieved – one of the greatest crimes in all humanity, when the vulnerable are abused by those meant to help them; when the weak have no power to fight back against the authorities who've misused their position through bullying.

What if I still had M.E? The thought of this in light of sceptical medical attitudes horrified me. It would be nothing less than torture for sufferers, on every level (69). It was torturous enough for me without the illness.

'He lies now even so, with aching heart, and longs for your return… ' (70)

John was finding this particular year, 1998, to be worse than all the M.E. years as my carer: the unpredictability of each day when the thought of a 999 call was never too far away; trips in and out of casualty, presuming the problem was all over only for it to flare up again; all this made his stress levels at an all-time high. With the M.E. it had been predictable: if I went out for the day, we knew I'd have extra pain and exhaustion for several days afterwards. We could plan with the M.E. This so far unnamed condition, triggered by two operations, was a constant apprehension.

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69. To reassure M.E. sufferers: some patients have received first-class care on the NHS with sympathetic and even knowledgeable staff. Others have dreadful experiences. It seems to depend on the individuals treating the patient and what they believe about the illness. The Grace Charity for M.E. has compiled a hospital booklet aimed at educating hospital staff should a sufferer need to go into hospital, attempting to reduce bad experiences for the patient. (For more details of the booklet, *www.thegracecharityforme.org*).

70. *The Odyssey* Homer, Book XI, 208, 209. See Note 67 for details.

John's working day sometimes involved a phone call from my family whilst he was teaching, asking him to come quickly to hospital or to take me to hospital. The end of his day often finished with blotting out his strain through a stack of rented videos piled up by the television. On one occasion, a nurse thought that *he* was the patient as he lay down beside me at A&E due to exhaustion. Watching John so tired made me realise how carers can be overlooked in emergencies, when they're dashing round here, there and everywhere, phoning round with news to anxious relatives, whilst trying to think practically in a panicky crisis.

* * *

As the hospital in Ashford couldn't fix me, I was eventually sent back to Pembury. By then, I'd rather outstayed my welcome; therefore, the insults continued.

"You should be like the lady opposite – she's a Miss Positive. Can you be a Miss Positive today? You're a pretty girl with a lovely husband. You must get on with your life!" a nurse chipped in with her tuppence worth. She then refused to give me painkillers drawn up by the consultant. "It's best if you can do without your painkillers," came out her unbelievable words, even though I was meant to have them.

"There's nothing wrong with you! Your blood pressure's fine, your temperature's fine and your tests show nothing conclusive!"

It went from bad to worse.

"You need bullying. Some patients can do with bullying and you're one of them," hissed the puff adder taunts of the ward sister. "I've dealt with people like you before who are depressed!"

But I wasn't really depressed. My complaints about her to the registrar were dismissed as he continued to mock me further, recommending that I saw a psychologist to help with my ‘pain perception’.

John said that he instinctively grabbed Stinky on his way to Purgatory Hospital (who was becoming a bad omen, it seemed), followed by a sack of my previous Get Well cards. We told people to stop sending any more as we’d use the ones they’d sent before instead.

“Ooh, look at all the cards you’ve got so quickly! Aren’t you popular!” commented a passing nurse.

“No, not really. They’re the same ones as I had last time I was in here,” I moaned. “I’m always here and no-one knows why.”

John’s faith and belief in my healing wasn’t shaken but his logic was. Why wasn’t God intervening for His own sake, so His miracle through me wouldn’t be undermined? John prayed that I’d be well again, for God’s sake literally, not for ours, so that glory would point to Him again. As John’s right foot slammed down on the accelerator back and forth on the A21, he began to wonder if the new wave of suffering was something that we’d done, our fault? Had we sinned? Was it that second rum and coke I had back in January or was it John enjoying himself too much on the *Chez Moi* dance floor in his jazzy waistcoat? No answers came, of course, only an unsettling crisis of confusion.

The confusion continued amongst those who’d heard of the healing. “Sorry to hear about Catherine’s M.E. relapse. She was doing so well!” neighbours offered their condolences.

“BUT THIS ISN’T M.E. IT’S SOMETHING ELSE!” John would always take time to explain passionately, their muddled thinking angering him.

Yet to some people it didn’t matter what caused this second bout of illness. If I was ill again, it undermined the miracle, full stop, making them less challenged to believe it in the first place.

My GP had a different view on the matter compared to that of the hospitals'. "I think you've got a mini peritonitis. I bet they've moved the position of the ovary when they operated, so your released eggs are grazing against the peritoneum."

* * *

3rd July 1998 rolled round, the first anniversary of my healing miracle. But it was a sad day as I clutched my abdomen which had been in constant pain for sometime. "They've ruined my healing!" I lamented to John on a day that should have had us dancing in the streets, celebrating a special occasion.

I even went back to Jen, hoping for a second miracle but it didn't come this time. We met in the same study where the Divine Healer had met with us before, surrounded by the same books, the same furniture, with me even sitting on the same low chair.

"What I remember before when we met in here was your attitude of acceptance, Catherine, how you accepted your suffering of M.E. and hadn't come for healing. It was a lovely attitude you had. Perhaps you're meant to have the same attitude again of this new problem, of acceptance," Jen suggested gently, knowing that was not what I came to hear.

After concluding with a prayer, I went away the same as before – in constant abdominal pain.

It was all becoming too much. I thought back to Irish Marion's comment at the start of my hospital trips, when she said that God takes us beyond what we can bear. Now, months later, I concurred with her. But she left out the best bit of that verse which promises that God will find a way out for us so that we can bear the suffering.

For me, that 'way out' started in accepting my new illness all over again, that for some reason I couldn't begin to understand, God might have a reason and plan in allowing this affliction even after his mighty healing miracle. This acceptance of suffering *after* a miracle was far harder than accepting it before. I tried to find strength again through the sufferings of Christ just as I had in the desperate M.E. days. I learned the same lessons as before, lessons I thought that I'd never have to relive.

After the healing, I thought that I'd never need God 24/7 because I had my own physical strength back. But I needed Him now just as much, if not more than ever.

I call out to you but I don't hear you answer me
You say that you care but your love I just do not see.
Where have you gone God? Oh, where have you gone?
You seem so far away, is that now where you'll stay?
I feel you've let me down, you're watching me go through this pain
And I'm asking you for help, crying out to you again and again.
Where have you gone God? Oh, where have you gone?
You seem so far away, is that now where you'll stay?

Then I think of the cross and picture your swollen eyes,
amongst your own anguish I hear my desperate cries.
Reflections of my suffering I now see in your own,
for the first time I realise I'm at last not alone.
I've found where you are God, I've found where you are,
you're here with me in my pain, 'cause you suffered just the same.
It is now I sense your comfort, it is now I feel you near me
And finally with you I now find empathy.

I stretch out my hand towards you, take this pain I cannot bear.
As you lift my burden from me, I see your love and care.
I've found where you are God, I've found where you are,
you're here with me in my pain,'cause you've suffered just the same.
Take over from me, Lord, you've been through more than me,
I know you understand now, please come and heal me. (71)

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71. From the song *Where have you gone God*? Catherine Ashenfelter ©1998. (I wrote this *after* the miraculous healing of 1997.)

Other ‘ways out’ that God provided for me, besides acceptance, was falling (sometimes literally) into the arms of praying Christians whilst at hospital. One doctor had travelled all the way from Ghana to be used as a great encouragement for me and John. We even had him round for dinner during a better phase.

‘But now a breeze came up for us astern -
a canvas-bellying landbreeze, hale shipmate
sent by the singing nymph with sun-bright hair;’ (72)

The many emergency trips in 1998 still hadn’t provided answers as to what had gone wrong after the second operation. Whilst God was seemingly distant to our prayers, he was actually working busily behind the scenes, shipping in yet another consultant to a different hospital at the Conquest in Hastings. This new surgeon proved to be the ‘breeze’ we’d all been waiting for, to get things progressing and moving in the right direction.

When the cyst grew back a third time, necessitating another operation, the sent surgeon discovered evidence of inflammation whilst cutting me open. Adhesions (73) had formed on my womb and peritoneum from the Purgatory operations, indicating that I did have peritonitis at some stage during those emergency hospital trips. Yet I’d been told instead at Pembury to see a psychologist for my ‘pain perception’.

It came to light in subsequent communication with Pembury that errors of both judgement and surgical performance were admitted during the two operations under their care. I looked into suing them but refrained as the whole thing would re-live my trauma.

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72. *The Odyssey* by Homer, Book X1, 6-8. See Note 67 for details.

73. Adhesions are fibrous tissue which join internal surfaces together that should be separate, formed as a result of severe inflammation.

Meanwhile, my abdomen became free from pain after the Conquest surgeon cut the adhesions. The cyst would never grow back again because he had removed the left ovary and tube. The hospital stay was yet another time of lengthy thirst, fenced in by tubes with a longing desire for that first-allowed suck on an ice cube.

* * *

Once the emergency trips slowed down, it dawned on us that the M.E. hadn’t returned despite ample opportunity for it to do so. All those drugs, antibiotics and anaesthetics that were pumped repeatedly through my body, hadn’t triggered a relapse. In fact, my muscles seemed stronger than ever as my legs jogged round the village sports field and my arms pushed back pool water in a newly built Cranbrook sports centre.

The resurrected Lazarus blood started flowing through my veins all over again but this time the Purgatory experience had transformed my perspective. Yes, the miracle had been special. Yes, the Miracle Maker was special but I was no more special than anyone else for receiving the miracle. How wrong I had been in thinking that I’d be spared any serious illness ever again, receiving some kind of favourable protection compared to others. 1998, the year after the miracle, had almost cost me my life.

God is sometimes compared to a potter, shaping our lives as the potter would mould pots and jars. But instead of using gentle clay tools, I felt that God had used a sledgehammer with me.

After six emergency hospital trips in eight months, I no longer felt guilty about being healed. I was on the same level as those who’d never had a miracle, prone to suffering as they were.

“You were intent on being famous after your healing, wanting to go on television, write a book and be a pop star," John summarised bluntly during a quiet moment at home. He seemed relieved that I'd been humbled, although upset as to how severe the humbling had been.

There was nothing wrong with being famous, going on tele, writing a book and being like Norah Jones at the piano but maybe that's not what God wanted with the new life He'd given me. Or maybe it was but my attitude had to be refined first before all that took place.

My hatred towards God melted slowly like cheese on toast as I learnt to trust Him tentatively again, the hard lumps of hurt slowly turning into runny rivers of confidence. I pressed my hand deeper into His as time progressed, loving Him once more, not trying to suss out His logic but revering Him as the One in charge. He'd proved this role through my miracle and finding His strength in suffering.

My relationship with John also had to be rebuilt all over again, a second time, as the post-healing months of fun and games were just a distant memory.

I'd been traumatised in a positive way by the miracle followed by negative trauma afterwards. For several months I had nightmares of nurses and doctors circling my bed, their faces contorted and twisted like the demons in the Vatican's Last Judgement fresco. They were mocking and taunting my illness, pulling me onto a boat and attempting to ferry me along with Dante's damned to Purgatory.

When the New Year saw the back of 1998, it was a welcome relief. Goodbye to a year of painful cannulas, grey cardboard sick bowls and A&E departments. It had been the worst year of my life and as Homer would add (of the Simpson cartoon, not Classical variety)… so far!

But a beautiful thing was happening as a Phoenix of good health rose again from Purgatory ashes, still freeing me from the curse of M.E. The M.E. didn't even return when my GP put me temporarily back on the Pill at her suggestion, to give the other ovary a rest. This was a further indication of complete healing from the disease because the Pill had triggered a relapse immediately after my marriage.

When the rosy-fingered dawn arrived faithfully, morning by morning across the Wealden sky, it carried with it hope and peace. The chorus of songbirds were possibly even the same ones who greeted me in former healing celebration.

The calm brought much needed serenity for John and me. An uneventful day, which might be boring for some, was bliss for us.

27. Dancing Boots

The grandiose apparition of The Louvre stood proudly, boasting its rococo style over the glassy courtyard pyramids. It looked arrogant in the daytime but romantic at night from softer lighting, attracting myriads of sweethearts who flocked there at sunset. Finally, John and I had made it to Paris.

As we ran, hand in hand, through the maze of Louvre corridors, cramming as much in to see as possible, the whole experience seemed very dream-like on passing world-famous art; sculptures and paintings we'd previously studied in text books were suddenly only inches away from us. After almost 20 years of M.E. followed by the dreadful Purgatory year, I was content to just look at The Louvre ceiling with its gold-plated splendour, let alone absorb famous art as well. Sipping a couple of caffé lattes on a courtyard balcony fringed with marble statues, was such extreme pleasure that it almost hurt. (The price of the coffees, however, did hurt!) If I'd have known back then that we would return to Paris several more times in the future, that pleasure would have hurt even more.

During this more 'settled' period, John and I seemed to be forever at Gatwick Airport, jetting off to some exotic place or other. My pre-nuptial name of JET (Catherine **J**ane **E**lizabeth **T**urner) which John christened me with during our engagement, was an apt description as our planes touched down in North Africa, the Mediterranean and the good old US of A.

My continuingly healed, strong legs pounded up the spiral, stone staircases of towering ribats, whilst my emotions were durable enough to resist the provocations of Arab traders when searching for henna in a local market. My energies continued from country to country with festive Greek and Turkish dancing, the rhythms of which enticed John to join in with nifty footwork. In our much used suitcases, a pair of long-legged black stretch boots accompanied us on holiday (which I purchased after the healing), hitting the dance floors of many a global nightclub.

Travel certainly does broaden the mind. For John and me, the healing stories from several Catholic countries added weight to my own experience. Little corner shrines set back in niches were a dime a dozen up quaint cobble-stoned backstreets, opposite bars and cafés, over shop doorways and family homes; the sacred mixing with the secular. Two places in particular stuck in our minds as special places for healing: Siena Cathedral, Italy, hidden in a labyrinth of narrow streets and the church of Ta' Pinu set in an open plain on the tiny Mediterranean island of Gozo.

In Siena, we were stopped in our tourist tracks by a collection of brightly coloured crash helmets, filling a side chapel of the Cathedral. A guide explained to us that they were a symbolic thank you to Mary from motorbike riders who'd survived horrific road accidents. In a different side chapel in another country, Gozo, it wasn't crash helmets but baby clothes, photos and letters which crowded the space, again as a thank you to Mary for saving the lives of many sick young children. These healing stories were meaningful to both me and John in a way that they wouldn't have been before our own personal encounter with the Divine. We were a little concerned about the focus of thank yous being on Mary rather than on Christ but perhaps Mary had been praying for these desperate people just as Jen had prayed for me? I certainly thanked Jen for her prayer so why shouldn't Mary be thanked by those who asked her to pray for them? Thanked but not worshipped is probably the issue. (Only Jesus should be worshipped, not Mary and I'm sure Mary would agree with that.)

* * *

One embarrassing thing which occurred time after time at airport securities was my setting off the bleeps of walk-through metal detectors. Taking off hair slides, bracelets, belts and even my glasses made no difference, making the cautious staff very perplexed. “Try taking off your shoes or your earrings,” they suggested, whilst holding up an already tired and exasperated queue of travellers behind me. Once security was satisfied that I wasn’t armed with illegal weapons or posing as a terrorist, they let me through in bewilderment, the cause of the ringing alarm bells unknown.

Back in Kent, similar things happened at shops with anti-theft screening. I’d set the bloomin’ things off each time I went in and out of shops whilst heads turned judgementally in my direction.

“It’s something in your bag,” commented a salesman at a music shop in Tunbridge Wells.

“No, it’s just me! I tend to set them off!”

“It’s you?” he replied, his jaw dropping to the ground.

One time, I counted that I set off anti-theft alarms eight times in a single morning, curtailing my shopping trip to Tunbridge Wells due to unjust humiliation.

I do wonder if the healing had left some kind of electrical charge around me, because I didn’t set shop alarms off before the miracle, even in my metal wheelchair! (It only occurred for a few years after the healing. I don’t tend to set alarms off at all anymore, so perhaps I’m less holy now.)

Other than holidays abroad, further happy memories with John are a lot closer to home, as we participated in local pub jam nites in our halcyon village of Hawkhurst. The faces of the organisers first greeted me with terror, their long, frizzy hair and leather gear being a world apart from our clean-cut Donny and Marie Osmond image. Yet behind their tough exterior they were mild little pussycats, encouraging me and John enormously with our singing and music. The jam nites were much harder to perform than you might think with unrehearsed harmonies, chords and rhythms all improvised to please an unpredictable audience. Walking back home under a velvet, starry sky, heady from rum and cokes and the buzz of blues ringing in our ears, are some of my all-time happiest memories. (We were sometimes greeted by a chorus of croaky frogs singing near our flat, too! They weren't the pub musicians.)

Returning to work after a lengthy 'sabbatical' of seven years was both exciting and disappointing. Working again was a dream that I thought would never come true, so when leaving at eight in the morning, briefcase in hand, prim and proper in a suit to embark on supply teaching, the euphoric smile couldn't be wiped from my face. Standing all day in heels, thinking on my feet and running up and down a hockey pitch whilst simultaneously blowing a whistle, was still hard to take in as I stared at my dusty wheelchair back home.

Brushing shoulders with work colleagues all over again was refreshing; it enriched a previously isolated M.E. experience. Some colleagues were lovely and supportive but a downside was discovering how horrible some could be. It seemed ironic that I'd dreamed for so long about returning to work from my bed of pain only to be bullied by so-called 'professional' adults.

Listening to the negative staff room gossip made me determined to never forget the positive experience that had come from my suffering and healing. Despite my efforts, I never felt a part of the healthy, career-minded world, my heart still lying with the sick, vulnerable and disabled.

"Why don't you write a book?" suggested an old architect friend of mine from Art College days, as I lamented over the sick and healthy divide in this country.

The thought had never occurred to me until his suggestion. After mentioning the idea to John and contemplating it myself, I soon found my fingers hammering out a synopsis on our manual typewriter, a former wedding gift from my parents. Around 15 publishers were sent the synopsis plus a few chapters in progress. Not one publisher, however, wanted to take up the book: apparently I wasn't famous enough. Some Christian publishers weren't even moved by my miracle, throwing Anna-Liza's article on my healing into their office paper shredder. Yet the more I wrote the book, the more I felt it was a purpose, focusing on it with a fixation like Handel's writing of *The Messiah,* when he locked himself behind doors for several days until its completion. I didn't lock myself behind anywhere whilst writing the book but was locked in by the peace and quiet of Wealden countryside around our flat, vital for creative flow.

Over the years in writing this book, our sitting room filled gradually with souvenirs from our world travels: painted Greek vases, Islamic prayer beads and sparkling Florentine wood blocks of the Virgin Mary, reminding me of some of the countries my black dancing boots had touched down on, making their mark.

Yet despite world travel, writing a book and working again, I still wanted to do something specific for M.E. truth, so that my years of suffering wouldn't be in vain. As my grateful gaze lingered over Maltese glass and Tunisian copper, inspiring happy holiday memories, I couldn't quite decide what that M.E. something could be.

28. The Gift Withheld

‘Ah, if you knew what peace there is in an accepted sorrow!’
(74)

More than anything in the world, more than good health and my healing, was my desire to have a baby. It was an innate desire, a biological and emotional urge so strong that it chose me rather than me choosing motherhood; a deep yearning passed down since the creation of Mother Earth; a longing which might best be described simply as ‘natural’.

John, too, felt the same way about fatherhood. One reason he studied at great expense for his Masters degree in the States was to provide a more financial security for a future family. He chose me to be the mother of his children as well as being his wife, discussing children at length during our engagement period.

The post-marital return of M.E. had stopped any hope of pregnancy, but since my healing the window of baby opportunity opened up all over again, causing a wave of breathless excitement to consume us in our dream possibly coming true.

At the age of 37, armed with one ovary and free from constant gynae problems, we decided to ‘give it a go’. We must have been good fertility machines because I got pregnant straightaway. The lark was ascending all over again as we were reeling from elative shock.

As soon as the second blue line appeared on the pregnancy test, we told the world our news, reminiscent of when we told the world about my healing. The first person who I told (besides John!) was Mum, eager to present her with a grandchild after 12 years of marriage. She replied that my Dad would have been pleased.

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74. Madame Guyon (1648-1717). She was a Catholic mystic.

(My father had passed away a couple of years previously from a heart attack. I was upset that I couldn't share my good news with him.)

John, of course, got on the phone to the States. I've never seen him so happy about anything. The miracle had been an eerie, spooky kind of joy, such was its supernatural drama; babies though, are nothing but goo-goo happiness.

"We'll bring the baby to see you in the Autumn," his voice sped over the transatlantic phone line to his Mom.

"Hang on, I might not be very well after the birth," I yelled out, concerned at the thought of flying to America only weeks after the exhausting event.

Early October was the baby's due date, a favourite time of the year for me when cadmium yellow leaves contrast with cobalt blue sky. Congratulations cards greeted us as parents-to-be, our minds racing with preparations for eight months time. Our tiny flat was hardly big enough for the both of us, let alone a new addition to the family.

Should we move before or after the birth?

What should I eat to make the baby healthy?

What do babies eat once they're born?

I knew little about Farleys Rusks and horrible muck in baby jam jars. Would I really have to taste it first and say "Yum, yum!" before feeding the closed mouth in front of me?

John and I had both been the youngest in our families, so had no experience of passing round babies or helping brothers and sisters to get dressed. We both knew more about looking after baby guinea-pigs.

It wasn't long before the subject of names came up, a topic drawn out further by the purchase of a dictionary of first names, complete with a drooling baby on the front cover. Our made-up names of Naylin and Mavrick for our future children, devised when we were art students, no longer had the same appeal.

"Max," John said emphatically after flicking through the book.

"Max Ashenfelter?" I pulled a face in disgust. "Sounds like someone from a Woody Allen film!"

But John was so taken with the name Max (for its congeniality rather than its meaning of greatness), that his enthusiasm won me over. We just hoped, with that name, that it was going to be a boy.

Emotionally I loved being pregnant. Nurturing the tiny embryo, entirely dependent on its mother, was immensely fulfilling. I spent my time studying pregnancy books and parenting magazines, fascinated by how quickly the organs were developed in the baby. I loved going into Mothercare, running my hands over Winnie-the-Pooh romper suits and smiling at the sweetest little booties imaginable. It was a relief to see that pregnancy clothes could be attractive to show off the bump, and not just be hideous sacks.

Physically I hated being pregnant, not in anticipation of getting bigger but due to constant nausea and frequent vomiting. The slightest smell of fried food made me dive for fresh air and the fatigue at times was so overwhelming that I nodded off whilst driving! I was alarmed at how many pregnancy symptoms I had so quickly: around nine of them arrived in the first week followed by my tummy looking three months pregnant when I was only six weeks. My body seemed to have gone into an exaggerated overdrive of being pregnant.

"It's a good sign to feel sick. That means that your HCG levels are working," friends told me.

"It's a good sign to be big so quickly. That means the baby is developing well," reassured my GP.

Despite my concerns, everything, apparently, was a good sign.

Then, out of the blue, I had some breakthrough bleeding one afternoon, coinciding with sharp abdominal pains. I tried not to worry, having read in my plethora of pregnancy literature that both weren’t uncommon in early pregnancy.

But that same night I woke up with a sudden urge to go to the loo, whereupon a torrent of blood gushed forth onto the black and white lino floor. It just kept coming and coming.

By this time John was wide awake from my wailing lament and probably the neighbours were too. After clearing up, John and I huddled together on the sitting-room sofa for the rest of the long, numbing night, wondering why we were the victims of such a tragedy.

At six weeks, I’d miscarried.

The physical pain was surprisingly severe, with prescription painkillers barely touching the cramps. Emotionally I was a wreck, whilst John was deeply troubled too as we attempted to comfort one another. The abstract statue of us intertwining was reminiscent of the engagement days in Hamtramck, when we cuddled together from the cold; this time it was due to grief.

The freakish looking embryo, no bigger than a pea-size, had encapsulated our hearts. I looked at a medical drawing of a six-week-old embryo which looked like a monster, with tiny stumps of arm and leg buds. Yet I loved this ugly creature, possibly more than anyone else in the world.

It was true grieving like the loss of a family member. The recent death of my father helped me travel down this new, unfamiliar path of miscarriage. I found it irreverent that our child had probably disappeared down the toilet, without a physical memory or gravestone to mark its short life.

So I wrote the following poem:

My Heartache

Some see you as a cold statistic
Unfeeling, uncaring
Just a clump of cells
"It happens to one in four," I'm constantly reminded

Others even tell me to be grateful
As you must have had something wrong with you
"It's nature's way," they nod their heads
"Just try again!"

I will try again...
Try to convey that the earth lost a soul,
A person, a human being....
MY BABY

Grief is necessary to mourn your death
A very real death
Yet not marked by a tomb or gravestone
But only by my heartache (75)

John and I were still recovering from the shock of me getting pregnant so quickly, let alone the shock of losing the baby so suddenly.

It was awkward for people to know what to say, although I welcomed a hug and a heartfelt "Sorry". It was more difficult for John because the attention focused largely on me, yet he needed comforting too. Some people, however, said upsetting things, thinking that they were actually consoling me. The worst were accusations implying that it was my fault, that I must have done something to harm it such as carrying shopping bags or going swimming. The guilt made me feel like a child murderer.

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75. *My Heartache* Catherine Ashenfelter © 2001.

Whilst cutting out a red paper heart for Max, writing a goodbye message and tying it up in a long, crimson stained ribbon, some lyrics came into my head. Just like my healing song, the melody was completed at our upright piano.

A Song for Max

The Lord gave then He took away
Ask no questions but just accept
The Lord gave then He took away
Ask no questions but just accept

Such joy, such joy
In a short time you gave us Max
Such joy, such joy
In a short time you gave us Max

And the will keeps on rising
To start afresh, all over again
And the will keeps on rising
To start afresh, all over again (76)

As primroses and daffodils lit up the dreary, wet March landscape, our hopes were equally lit up by the spring life bursting around us in the woods and fields. Start afresh we certainly did and a couple of months later I was pregnant all over again. New hope, new morning sickness, new everything as fresh as the early morning dew. This time we told no-one.

But tragedy struck us a second time.

Then a third.

Then a fourth.

In fact a total of ten times over, in the space of eight post-healing years.

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76. *A Song for Max* Catherine Ashenfelter © 2001.

Just as I'd been in the minority for receiving a miracle, I was now in the minority of 'unexplained early recurrent miscarriage'.

* * *

We kept trying and never gave up because the M.E. healing had strengthened our belief in the impossible.

I gave each baby a name, a grateful message for the hope they'd given us, with ten red paper hearts wrapped up and put away in the back of a drawer and also in the back of my scarred, harrowed memories. Out of sight but never completely out of mind.

They were like beautiful visitors spending precious time with us, touching our lives with unimaginable hope, bringing us closer together through their lives and deaths. They were our children although none lived for more than seven weeks in my womb. Yet they were all loved and so very wanted.

So began my search for why I kept miscarrying. Endless trips to the Conquest Hospital for blood tests galore; further surgery three times over, both major and minor to improve fertility chances; even John's specimens had to be checked, which turned out to be OK, much to his relief!

I was always at the Conquest for investigation, always. It reminded me of my search for an M.E. cure, leaving no stone unturned. Despite the tests, very little came to light. One test revealed low progesterone, so hormones were pumped into me, even via self-injection which bruised my thighs so much that I could hardly walk. Sadly, the treatment prescribed gave me bad side-effects and had to be stopped.

I changed my diet, altered my lifestyle and basically stopped everything as some had suggested this might work. But the babies kept dying. Trying for children felt like leading lambs to a slaughter house, as if we were choosing their short lives by continuing to try for them.

The emotional side came to a head one freezing November afternoon, on what seemed like the first day of winter. I was stuck to a bench in Regents Park, London, after seeing a private consultant at a miscarriage clinic in Harley Street.

The eyes of the fertility consultant blinked £ signs as he rattled off test after test that he felt needed doing, whilst his ringing mobile phone was always answered in case it led to another cheque. Despite my booked appointment, I took second place to his phone, apparently. He didn't listen carefully to what I said, writing it down incorrectly; he shouted at me for inquiring about test prices and I left emotionally and financially poorer. In fact, I handed over to him a cheque worth six weeks of my wages, feeling too upset to complain about him.

One of the blood tests he took did reveal a possible problem, that of high Natural Killer Cells (77), which may have been responsible for attacking the little embryos. But I couldn't really afford to keep going back to see him for treatment and my NHS consultant refused to prescribe the treatment he wanted.

Sitting in Regents Park after his appointment, I couldn't help but stare at the round, blubber faced babies being pushed in their prams by fulfilled, nurturing mothers. As the sun set in late afternoon, its shadows penetrated deeply into my fragile heart, ripped to pieces ten times over and put back with increasing frailty.

I couldn't take this baby stuff anymore. It was sending me over the edge.

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77. M.E. sufferers tend to have low Natural Killer Cells so my high testing could be evidence for the healing miracle.

Unlike the Pembury year when I hated God for allowing so much suffering in my post-healing life, I found the M.E. miracle to be one of the few things which comforted me.

If God could heal me so miraculously, He could easily give me and John a child. So, there must be a reason why He's withholding this precious gift.

In fact, if it wasn't for the miracle, I don't think I could have held up. The healing shone brighter for me in the darkness of miscarriage grief.

Watching Mums push their babies and the ensuing envy which that triggered in me, made me realise how disabled people must envy my healing. Someone in a wheelchair would long for my mobility whilst I longed to be as pregnant as an overweight walrus. The secret was to find peace in this emotional storm, as I used to when my legs and arms burnt from scalding M.E. pain.

How could I find peace when baby pictures were everywhere – in magazines, in supermarkets where entire aisles were dedicated to them? Even in church, whilst attempting to find this peace, there were often christenings with beautifully presented children in lacy gowns looking more adorable than ever.

The answer as always was to be found in God, forcing myself to journey into His heart, longing for that peace I was unable to find within.

> 'And earth has nothing I desire besides you.
> My flesh and my heart may fail,
> but God is the strength of my heart
> and my portion forever.' (78)

My heart was certainly failing but with God as my primary desire, my focus shifted towards Him and away from slobbering, cute, bald-headed babies.

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78. Psalm 73 v.25, 26.

‘...those who seek the Lord lack no good thing.’ (79)

Children, of course, are gifts and I couldn’t demand a gift from their Giver.

Yet again, it made me thankful for the gifts the Giver **had** given me: marriage, health and the ability to work again.

The acceptance side was a constant struggle, though. Although John and I had accepted that we’d never have children when I had severe M.E., our recent little babies were a ray of unexpected sunshine, blotted out almost as quickly by dark rain clouds. The emotional roller coaster of back and forth joy with despair, stretched us further than rubber, as we bounced back dazed and hurt. As soon as I announced to John that I was pregnant all over again, he would purposefully and understandably suppress his joy as a defence mechanism.

“I’m trying not to think about it,” he’d reply.

I felt such a failure to him when things didn’t work out. He eventually came to a place of acceptance when he didn’t mind if we had children or not, just as he’d accepted my wheelchair with difficulty in the past. We didn’t really talk much about children in the end; we knew how the other felt and could see it in each others’ faces. The older we got, the more difficult it was to accept the situation.

* * *

Jen kindly prayed for us, the lady who was instrumental in my healing. This was the second time I’d been back to Jen since the M.E. miracle. The first return was to ask her prayers for the gynae problems; the answer for that came through an operation. But this time after her prayers, I continued to miscarry.

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79. Psalm 34 v.10.

Acceptance again, like accepting the sticks, then the wheelchair, then the stares from others at my wheelchair; acceptance of post-healing distress, that I wasn't immune from further suffering and now acceptance in our mid-forties that we'd probably never be parents. Acceptance – the hardest lesson of all, an act of the will yet not denying or suppressing the sorrow but rather finding the peace of Christ within that sorrow.

With M.E., I'd found strength from Christmas cards picturing the Madonna and Child, giving a nurturing, protective spirit. But this time, the same beautiful Florentine paintings on mantelpiece and Christmas ribbon alienated me from the message of hope they brought.

There's never a good time to have a miscarriage but I think one of the worst times must be Christmas, when there's so much pressure on you to be happy, with the focus so strongly on children. At seven weeks we lost a baby whom I named Grace. (Apparently, the inner parts of her eyes and ears were formed, with indentations for fingers and toes. Clinically, she was a foetus, advancing from an embryo). We lost her during Christmas week when I had my first pre-booked scan, which was meant to be an exciting time of confirming the baby's heartbeat. Instead, the scan confirmed our baby's death. The fertility outpatients' clinic was filling up with pregnant women whose children were playing with toys, amidst flashing Christmas tree lights and tinsel wonder. After my sorrowful scan, I was directed to an 'early pregnancy clinic', where the torn, faded poster of a tearful, painted Russian doll was becoming a familiar sight to me in the cold, bare waiting room bereft of seasonal joy.

If I wasn't grieving enough, I found myself sitting next to a woman in her thirties whom I presumed had also had a miscarriage. She hadn't: in fact she was still pregnant but about to have an abortion. Her reason for this was that the baby wouldn’t fit into her plans.

“I can’t go through with the pregnancy. I’ve got my life to lead now and am going back to college soon. I’ve told my other children at home why I’m doing it and they understand.”

I have never felt so many emotions all at once: anger, hurt, envy, injustice and sheer disbelief that a hospital would ‘care’ for us in our varying states by placing us next to one another.

Once home, my physical pregnancy symptoms continued as the hormones took a while to balance out, with even the pregnancy test being positive for a couple of weeks after the miscarriage, which is normal apparently. Still having morning sickness, food cravings and a slight bump whilst I was grieving for a child no longer inside me, was heart-rending.

The anti-life attitude in Western society didn’t help this acceptance process. Posters in women’s toilets labelling pregnancy as a ‘mistake’ and promoting the Morning After Pill, ruined not only an evening out at the cinema but also undermined all of our tiny babies. (No baby is ever a mistake – unplanned maybe, but not a mistake.) Media headlines were dominated by the idea of crossing human and animal embryos, an idea previously found only in science-fiction stories. Incredibly, it was eventually passed as legal. Once again, this undermined the short lives of our children, as if their only ‘use’ might be for experiments.

On a more local level, a doctor was persistent with me to take an amniocentesis test, to see if the baby I was carrying had Down’s syndrome. He pressurised me three times to have the test, despite my firm rejection of it each time. He told me that Down’s syndrome children would be hard work as part of a family: in other words, if the test proved positive, he wanted me to have an abortion. I found his attitude to those with Down's syndrome to be undermining, as he sought to control my life (and John's); it also showed how vulnerable pregnant women can be in the face of medical opinion. I was reminded by an event just after my 1997 miracle, when a young man with Down's syndrome had understood my healing, shouting "Hallelujah Catherine!". He realised that I no longer needed my walking sticks and this realisation touched me very much.

I thought erroneously that immersing myself in Primary School teaching might help, being surrounded by other people's children. It did help at first but so much focus was on 'the family' at that age with many of the children having new babies at home. Frequently, I had to cover for other staff whose lessons included pictures of babies but the worst was helping children make Mother's Day cards and poems, which was the straw breaking this camel's heart as well as back.

When shopping, I went the long way round a supermarket to get a bag of sugar, thus avoiding the short cut through the baby aisle; pulled the curtains on Mother's Day so as not to see children out with their families; avoided church services with christenings so as not to get upset. Meanwhile, more and more of my friends were having babies and it was hard for them too; they didn't want to upset me with their bundles of joy.

I realised that acceptance meant more than just knowing you won't get something you badly want; the process went beyond that. I had to enter into the joy of other parents, to be happy for them and go beyond my sorrow. This didn't mean denying our own children or the pain their deaths had brought us but it was going into a deeper place of acceptance. To be pleased genuinely for others through an act of the will was what I had to do, just as I wanted those with disabilities to be pleased for me and my healing. So I started grinning from ear to ear at children in public, really trying hard to be pleased about the joy they brought to their parents. The children looked scared at my grinning whilst the parents became overly protective of them, in case I was some kind of nutter. Entering into other people’s joy did help me a little bit but it was and still is, very hard.

This mature attitude of acceptance was also shown by my mother when she continued to thank God for my miracle despite her own horrendous physical suffering. She had developed just about chronic everything including arthritis, diabetes, cellulitis, respiratory problems in addition to heart and renal failure. Her life had become a daily physical torment as well as the emotional torment chronic illness can bring. I’m sure she longed for a miracle like mine, yet through God’s grace she developed a beautiful outlook of thanks, not envy, towards my healing.

* * *

There was one last baby avenue for me and John to try, that of adoption. We weren’t opposed to bringing up other people’s children; in some ways it would be easier than having to endure nine months of pregnancy and the uncertainty when giving birth. Naively, we thought it would be easy to adopt because there are so many orphaned children in the world. Living in Kent seemed one of the best places for this because orphaned, asylum-seeking children frequently made the local headlines. The colour of a child’s skin didn’t matter to us because we liked all children... black, yellow, red – we didn’t care. The price of overseas adoption, though, horrified us, averaging around £15,000 per child. (The USA and USSR were the most expensive at £25,000 per Yankee Doodle and Muscovite. Thai children were the cheapest at only £9,000 because it took ages to actually get them, apparently.) In addition, if you were turned down by the panel of judges you wouldn’t get any of your money back. Quite simply, John and I couldn’t afford it: we didn’t even own our home at the time but rented. If the red tape had been less (there was a 21-point procedure for Inter-Country Adoption) and cheaper, we’d have adopted several children I’m sure.

Domestic adoption was free but babies were a rarity: you’d be more likely to get an older child with emotional difficulties than a goo-goo, dribbling clean slate. Gone were the days when you could choose a baby from a Children’s Home or drive to a hospital and pick up a baby delivered only hours beforehand. (I know of couples who have done both of these in England, when there were plenty of babies around before legalised abortion.) One evening, John and I plucked up the courage to attend an adoption meeting run by Kent County Council. The battle-weary faces of couples in the room showed how tired others were of the ‘whole baby thing’ as well as us. If we were to proceed, we would have a two-year encounter with Social Services afterwards. At the end of the evening, one thing was clear: Social Services were not there to primarily support your marriage but rather to do business with you. Unbelievably, we were told that we would have to stop trying for children before applying for adoption. If a pregnancy occurred once the application had begun, the adoption process would be halted. If a miscarriage happened during the application, the process would still be stopped. I found this scenario to be emotionally traumatic, especially if I miscarried again and the adoption process was simultaneously stopped. That would be like losing two children at once. I thought about keeping a pregnancy quiet from them whilst also going ahead with the process but Social Services required regular medicals from our GPs, so I wouldn't be able to keep a pregnancy quiet for long.

Seeing as I got pregnant so easily, I felt it wasn't right for us to stop trying for children. John respected my decision but I think he was perhaps more keen to go ahead with the domestic adoption than me. The interviews, though, would have to be conducted over our holiday time, not during evenings or weekends and would be intense and frequent, when Social Services would virtually live in our home (their words). We didn't feel right about this approach. In addition, holidays meant a lot to me and John, especially as we couldn't holiday together when I had M.E. After the first adoption evening, John and I had exactly the same thing on our minds as we drove home: that was to dive straight to the fridge for an ice cold bottle of Baileys which we fought over amidst laughter and relief that a stressful evening was over with.

Perhaps we'd never become parents, thereby missing out on so much... the dressing up as Father Christmas, tiptoeing in quietly with a sack of presents; our tea-towel and tinsel child at a school Nativity play; homemade cards saying 'I love you Mummy and Daddy' for Mother's and Father's Day; teaching our children how to pray and teaching them generally; the first boyfriend or girlfriend and the relief or horrors that would bring. Just as the fruit of our marriage with M.E. was a different marital fruit compared to the norm, perhaps God had something else in mind for us as a couple, something else for us to nurture and watch grow? Perhaps this was the work I was searching for after my healing, a special purpose unique to us both?

After our wedding day, my Dad commented that he'd never seen so much fruit on the trees in the autumn of 1989. The apples in his garden were so heavy in number that the branches were bending over; this coincided with the ‘fruit’ theme of our wedding because children were so much a part of our future plans. (80)

One night, shortly after the adoption evening, John and I were both wide awake in bed although neither of us knew that at the time. I wasn’t feeling very well, but also wasn’t thinking particularly about my miscarriages nor especially grieving for them, yet out of the blue a vision appeared by the left side of our bed next to me. It was a crowd of young people whom I presumed to be angels. Their heights were all varied and their faces were youthful. In fact, their faces seemed perfect in form and feature, making me believe them to be visitors from another place or time. Their countenance was of a bright, white light. I blinked to see if this picture was in my mind or perhaps part of a dream: it wasn’t, because my eyes were wide open and these ‘beings’ were standing in front of me. Suddenly, they started to sing and the music I heard was the most uplifting I’ve ever experienced. The notes jumped all over the place, up and down scales, yet still kept in harmony. As I listened more carefully, I realised what they were singing was humanly impossible: the musical scales didn’t exist in human terms. Yet I was hearing it, so it did exist. The harmonies were incredible, fused and blended together with impossible notes. The speed of their singing was nothing like the dirges of some hymns sung in church.

The following morning, I was so filled with angel gusto that I tentatively mentioned my vision to John, half-expecting him to label me as stark-raving bonkers or ask me how much Baileys I’d had to drink lately. But as I relayed the experience to him, I was obviously deeply overcome by something I had indeed witnessed.

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80. In 2011, aged 47, I was diagnosed with ‘possible’ Obstetric Antiphospholipid Antibodies. This meant that my blood may have thickened in pregnancy, cutting off blood supply to the embryos. The treatment is usually aspirin.

“Were they children?” he asked in detail.

“Not really, just youthful-looking... I suppose one or two may have been children.”

“How many were there? Were there about ten?”

His particular interest for detail began to make me nervous.

“I don’t know... just a small crowd, perhaps eight, nine, maybe ten. I didn’t count them. Why do you ask?”

“At around the time you were awake, I felt really strongly that I should ask our children to pray for you.”

Never have I had such an emotional lump stick in my throat.

29. The Grace Charity For M.E.

The bright yellow shirt of the interviewer across the desk made sure I was ready and alert. That, combined with his dazzling white teeth which sparkled from anticipatory excitement, made my pulse race a little higher. “Remember, you’ve over three million people listening to you,” were his last words before the radio recording.

It was 2001 and I was a guest on Radio 2’s *Good Morning Sunday* show, interviewed by former *Crackerjack* presenter Don Maclean. The interview came about so bizarrely: I’d been listening to the programme regularly on Sunday mornings but became increasingly irritated by the atheistic guests who proudly declared their lack of faith on this quasi-religious show.

“Just turn it off, if it bothers you,” John used to say as I writhed in bed from liberal, politically correct, daren’t upset our multi-faith and humanist society comments. But on reaching for the off switch, a thought popped into my head which my now deceased Yorkshire father used to say.

“Do it thee sen!” (This, when translated to Southern-speak, means “Do it yourself!”)

That was it! “Why don’t I go on myself and talk about my healing miracle?”

John didn’t bat an eyelid about the idea; after all, he’d seen me wait by the phone for days, seriously thinking that Elton John would phone me up to discuss some songs of mine that I’d sent him on a tape. Elton never phoned me, much to my amazement.

This time I was still undeterred even though main guests of the show were world-wide celebrities, such as Sir Tim Rice, Prime Ministers, Muhammed Ali’s daughter and... Catherine Ashenfelter?

With Yorkshire blood flowing through my veins more strongly than ever, I hammered out a letter, enclosed an article on my healing story and sent it accidentally to the wrong name and address. I wrote *Don Macleod* not *Don Maclean;* Don Macleod was a presenter on Radio 3 and the programme's address was in Manchester, not London. Despite this, it still got to the correct person! Not long afterwards an envelope arrived in the post with a BBC logo on the outside, inviting me to come on the show. No-one, including me, could really believe it nor believe how easy it had been to become one of their guests!

Before the show I'd been asked to suggest some records to play in the programme, bringing about a Desert Island Discs flavour. Tentatively I handed them a CD of my own music, asking if they would play a piano and vocals track about my healing. A sound technician, the producer and Don Maclean all made judgemental eye contact as they listened to my song being test played. Then each of them nodded, turned to me and gave a thumbs up! (Elton John never did phone me about my music but this was even better.)

The interview lasted for almost an hour, its contents edited down to half that. I was asked about the miracle, why I thought I was healed (for which I'll never know), what M.E. is and the prejudice surrounding the disease. It was a tough but enjoyable interview and also an emotional one, with my voice breaking from time to time, interspersed with laughter. My focus though, at all times, was to speak up for the severe sufferers; for those who are bedridden and who can't speak at all. I became their voice that day which was a huge privilege and one that I hope I did justice to.

After the interview, I was hurried out for the next guest to take my place. She was Mary Chapin Carpenter (a famous musician whom I'd never heard of although John had); I shook her applauded hand and then made my way to Trafalgar Square for some much needed pigeon reflection. The radio adrenaline rush had made me hyper.

When the interview was aired I thought that my music career was signed, sealed and delivered with my fame secured, especially as listeners wrote into the show asking for my song recordings. I was elevated to the main guest slot for the interview and stayed on the show's internet 'Best Bits' for over one year. My interview was chosen to stay up for longer than those of Topol and BB King!

"National newspapers will be contacting you; they're really interested in your story!" enthused the show's producer. "We all thought you came across so well!"

But no broadsheets or tabloids did ever contact me, neither did record companies or TV guest shows. Instead, a heavy sack of mail was sent my way, heavy from the sheer amount of emails and letters but also heavy from hearts breaking over M.E., describing how the disease had destroyed the lives of both sufferers and those closest to them.

The post kept coming and coming, months after the interview, from people inspired by the miracle. Over one hundred written letters were passed on to me, quadruple the usual amount for the show.

My fame as a media star was painfully short-lived, however. When a programme for 2001 highlights of *Good Morning Sunday* interviews came on air, mine was completely omitted!

"Well, they are famous darling, whereas you're not!" John was laughing as he watched my face crumple in disbelief when I didn't get a mention in the whole of two hours!

I tried to get back on the show, especially when Aled Jones was the new host with a new producer, but my emails were sometimes deleted before being read. No matter how hard I tried or prayed, I couldn’t get back on the radio. Obviously, fame wasn’t going to get to my head because I no longer had any.

Meanwhile, the continuing heart-breaking letters that kept trickling in, pointed me slowly in a direction to try and help those who were corresponding. What had resulted from the programme was my new role as a servant, serving those who still suffered from M.E. At first, I thought that might be to establish a medical clinic, especially when I was put in contact with a retired immunologist after the show who seemed interested. But the clinic idea fell through and the hopes of many sufferers were unfairly dashed.

It became obvious that this work had to be based on prayer rather than medicine; prayer, after all, was the reason for the miracle and subsequent ‘calling’. So John and I started a different slant by going into sufferers’ homes and praying for them, or praying for them at a distance if they were too unwell for visits. Before long, over 30 people were interested in supporting us by praying for names of sufferers from a distance.

After several discussions over the name of the work, we settled for The Grace Charity For M.E. My nephews and niece chipped in with their opinions on the name which was helpful from their teenage points of view. Grace was the most important word in the name because it was by the grace of God that the work had started.

Trustees and patrons’ names on headed notepaper made the charity increasingly official. The first pennies were raised through the sale of Christmas cards I designed, which proved to be the most fulfilling application of my art degree to date. The incoming cash necessitated a bank account which eventually attracted cheques from fundraisers: coffee mornings, grants and donations made sure that the bank balance was regularly topped up. When the charity became overwhelming for the two of us to handle, people came along to help share the load. The focus of the charity was always to try and help the individual M.E. sufferer, rather than boasting membership numbers like some bigger charities do.

John’s growing interest in the charity was a welcome relief; I was going to do it anyway, as my conviction was so great. Therefore, having him counsel and pray with sufferers over the phone and for him to eventually become Treasurer was a real joy, bringing a renewed sense of direction and purpose in our marriage.

I thought (wrongly again), that it would be easy to get back into the media when the charity became registered. But radio, television, local papers and even local churches all at one time showed no enthusiasm for our work.

“What about Radio Kent?” suggested someone we knew, who’d heard that we’d only tried national radio stations.

“Radio Kent? *Does anyone even listen to Radio Kent?*” came my disparaging response.

My previous radio contemporaries were famous people such as Lord and Lady Doodle-y-Flip and celebrities promoting their latest autobiographies. Radio Kent merely interviewed Joe Public about improving local bus services and clearing up dog mess from pavements. Was I meant to lower myself and go on such a show?

Well, getting onto Radio Kent was actually very difficult! Once again, my emails and written correspondence were completely ignored. I became so humiliated at the thought of not even getting on to Radio Kent that I eventually became determined to go on! I kept phoning an office number until it was picked up and a date was put down in their diary! The female presenter announced that she wanted John to come on too, for a live interview. Suddenly I was dreading it. The two of us would sound just like Basil and Sybil Fawlty together, bickering live on air. Maybe it wasn't such a good idea after all. That's another fine mess I'd probably got us into.

On a chilly May morning, whilst it was still dark, we rose from our sleepy beds at 5 a.m. to travel to Tunbridge Wells for a live interview at 7.15 a.m. Two heavy, navy doors opened wide for us on pressing the outside buzzer and speaking our names. Once inside, we were both so nervous and still half asleep that we had to guzzle down coffee just to stay awake, which of course made us even more jittery!

"Do you remember what you said?" I asked John back in the car as we searched Kent for a morning croissant after the interview.

"No, not a word. Do you?"

"No, nothing. I can't remember anything either of us said. It's too early in the morning!"

Thankfully, what we said was fine and we didn't sound like Basil and Sybil (much!). We listened to the 15-minute interview at home on the *Listen Again* section after a wonderful breakfast of croissants and caffé lattes discovered in Cranbrook. That evening, John and I went for a romantic walk in a nearby wood, carpeted with never-ending bluebells, framed by the vibrant yellow of rapeseed. We then realised that the interview on that long day had been the best thing we'd ever done together as a couple, even if it was only Radio Kent!

Interviews, especially live ones, can be quite draining. Just as my media adrenalin was settling down, the local press was stirring up. When the *Kent Messenger* printed an unassuming article about the charity from a phone interview, I thought the media blitz was over. A live radio chat and one article wasn't bad going in the space of a week. The newspaper, however, was scouted by local television who picked up on the article. This resulted in South East News contacting me to comment on M.E. diagnosis (or rather lack of it) in the UK. They would come to our home and bring the camera with them. THE TELEVISION! Yes, Mum, I was gonna be on the box, the tube, the big screen! Quick, where's my make-up?

Timing can be so strange. For years I'd wanted to be on the tele to talk about my healing but now it was too inconvenient. John and I had to look urgently for a new place to live as our landlord had not long sold the home we were living in. This also meant a new home had to be found for the charity. Legally, we had to get out within two weeks with nowhere lined up to go.

"I can't faff around anymore with all this media stuff. We're going to be on the streets in a couple of weeks if we don't find a home soon!" was my concern.

But an opportunity like this was too good to miss, surely, with a reporter tracking *me* down?! The pain and torment of M.E. patients came into my mind and I could feel their desire for me to convey their distress.

The crew stayed quite a while in our home, going from room to room to get the best lighting and asked me challenging, scientific questions. As the competent blonde journalist and the heavily laden cameraman left side by side, I breathed a sigh of relief. Finally, I could get on and look for somewhere to live.

Then, the phone rang. I rushed to pick it up, thinking it might be the chance of a new home but it wasn't. It was Radio Kent... again.

"Can you do an interview on our breakfast show tomorrow morning?" raced the excited words of a well-educated sounding man.

"Tomorrow? Well, no, not really. I've promised to visit my mother who's not well," came my convenient excuse.

"Oh, go on, please! We've never had such a roll with

M.E. in the news as we have now!” he persisted, quite impassioned.

“Well, I really do have things to get on with, like finding a place to live! Anyway, I’ve already been on Radio Kent a week ago and I’ve just had a TV crew in the house. Will I get paid for this interview?”

“I’m afraid not,” he retorted rather sheepishly. “Go on, please! Think of all the M.E. people you will help!”

His last words struck a humiliating chord with me. Of course I should do this interview and promote the charity as much as possible. What a turnaround, when a radio producer was begging me to go on his show! Only a few weeks before, I was begging all of them!

This was to be the first live phone interview I’d ever done and yet again, it was to be conducted at an unearthly time of 7 a.m., just after the news slot. When the phone rang the next morning connecting me to the show, I was sitting in my fluffy slippers and silky, beige pyjamas, a glass of water by my side and a finger in my left ear to block out John’s bathroom sounds of brushing and rinsing his teeth as he was getting ready for work.

I strained to hear the last bits of news headlines; then came my name, representing ‘The Grace Charity for M.E.’ The host threw me with his tabloid style presentation, imagining him to have a mass of medallions round an open-necked shirt, revealing a thick forest of black chest hair. I don’t know if he really looked like that or not.

The interview lasted around ten minutes and it was gruelling. The line was rather faint, which didn’t help. I was asked to comment on a girl’s medical case, when she’d been referred to the wrong consultant for M.E. I knew nothing about this girl’s health history and strained my ears to listen carefully to the presenter’s words. It was like a ten minute exam, only worse than that because thousands of people were tuned in!

It couldn’t have been too bad an interview, though, as snippets of it were repeated throughout the day on their news headlines!

“Charity worker says there is gross ignorance in the NHS on M.E!”

Personally, I thought everybody knew that already.

I still managed to see my mother as planned that day and later that week the phone did ring with the offer of a new home, just in the nick of legal time.

I learnt that media exposure is all about happening at the right time, which is not necessarily my timing. Many times, I had been turned down for speaking engagements and had often had articles returned to me unpublished. Yet some very fruitful times were to come, when my talks would go ahead and articles would be published.

Some of the best speaking engagements were very local, at John’s school, in front of hoards of sixth form and Year 11 pupils. I was asked on at least 15 occasions to address them about my healing miracle, attempting to bring to life their RS syllabus on Science and Miracles. The experience was so fulfilling that I often turned down paid work elsewhere in order to keep these pre-booked, unpaid talks. My conviction to speak about my healing at any given opportunity was so strong.

In spite of my fulfilment with the media and public speaking, I also learnt that it wasn’t always good to be in the papers. On one occasion, the ‘miracle’ bit of my story was completely omitted, the journalist writing that I’d merely ‘recovered’. To me, that trivialised M.E., implying that it simply went away of its own accord. Another time I blurted out, “But I never said that!” on reading a published article I’d submitted. Words were sometimes added or extracted just to make a good story, not necessarily to report the truth.

Although John and I sadly had no children, the Grace

Charity was starting to become our surrogate family. It was unique to us both. We nurtured it and watched it grow. We always put it first when making decisions, ensuring it would flourish and not shrivel up. Even its birth was painful with the initial rejection of charity status, followed by sweat and tears for it to come into existence.

As Christmas cards flooded in from M.E. sufferers we'd never met, thanking us for the charity work, their glitter not only sparkled on the frost-filled Victorian pictures but also healed our own broken hearts, as our nurturing desires were finally put to use. Helping the sick wasn't the kind of family that we'd imagined or even wanted but then again our new life together was entirely God's, for Him to use as He wished. Touching these people's lives, many of them strangers, defending the rights of the oppressed and protecting the vulnerable, became after a while strangely fulfilling.

"Perhaps our children are praying for us in this work," I turned to John, as we looked in awe at all the cards. He smiled and said that he liked that idea.

30. Everything Beautiful in its Time

‘Remember those in prison as if you were their fellow-prisoners, **and those who are ill-treated as if you yourselves were suffering.**’ (81)

It’s a cloudy, muggy Thursday morning in early July 2008, 11 years to the very day since my healing miracle. Thursdays seem to be anniversaries of drama in my life, both good and bad. John and I got engaged on a Michigan Thursday; my Dad dropped dead on a Canterbury Thursday and I was healed on a Cranbrook Thursday. *Top of the Pops*, my favourite childhood TV show, is no longer on a Thursday or on any day of the week as it’s been taken off altogether. Kate Bush, however, is still screeching away, probably on any day of the week and is still making great songs, well into her forties. We’ve bought her latest album which has the song *Bertie* about her young son, accompanied by a graceful sounding Renaissance guitar.

‘*Here comes the sunshine*
Here comes that son of mine
Here comes the everything
Here’s a song and a song for him

You bring me so much joy
And then you bring me
More joy’ (82)

A surge of sorrow suddenly comes over me as the lyrics resemble those I wrote for Max, the first baby we lost. Then I wilfully try to enter into the songwriter’s delight about her own child, as her euphoric music overflows and touches me with her infectious joy.

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81. Hebrews 13 verse 3 (bold font mine).
82. *Bertie* from the album *Aerial* Kate Bush, © 2005 EMI Records.

Something which has become traditional whilst celebrating my healing anniversary has been the purchase of Oriental lilies, always symbolic of my miracle. Just a whiff of their distinct scent immediately takes me back to Pembury Hospital and waking up from major surgery. The aniseed-like fragrance endorses my thankful heart that I was healed only months before the onslaught of seven general anaesthetics.

To mark the reverence of this special day, I also light some scented tea candles, to brighten up the English summer gloom outside.

But on this 11th anniversary, I feel rather sad as I've been suffering from a bowel problem which has left me debilitated and despairing. It's been undiagnosed and untreated for over three years now (83). How I wish that I felt better for celebrating such a happy occasion. As I tearfully pour myself a large mug of filter coffee, grateful for its introduction from John into my morning ritual, I check the post. One envelope has a daunting post mark of 'Charing Crematorium' which makes me rather nervous. On opening it up though, my teary morning transforms into unexpected joy as a cheque for almost £500, payable to The Grace Charity for M.E., is tucked inside a letter. The money was a collection made at the request of Graham Cray, the Bishop of Maidstone, after he spoke at a service at the Crematorium. My eyes continue to cry but this time not from sadness but from spirited happiness. The timing of this unannounced cheque couldn't have been better, on my healing anniversary and at the start of the day. The Grace Charity was going to flourish no matter how I felt.

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83. Later on, I was diagnosed with colitis and Small Intestine Bacterial Overgrowth. The cause could have been medicine and/or a bug picked up from abroad. I wonder if I was 'left' for so long by doctors regarding treatment and diagnosis due to my history of M.E., which some may have been prejudiced against?

My Colombian coffee, sitting invitingly on the kitchen table, is half drunk and I can’t help but think of ‘the half-full, half-empty’ cliché. Reflecting over the 11 post-healing years, I have to admit that those times seem to have been half-empty rather than half-full! My life, since the miracle, has consisted of endless hospital trips, operations and miscarriages. The suffering has been so constant that I start to write out a list of ‘sad and unfortunate events’, in contrast to the wonderful list of M.E. symptoms healed 11 years ago to this day.

The following events have happened since my healing miracle 1997-2008

1. 18 admissions to hospital (not outpatients), 11 of them emergency admissions (mainly gynaecological problems)
2. 7 operations under general anaesthetics (mostly gynae)
3. 10 early miscarriages
4. Roughly 40 routine outpatients appointments to hospital (in addition to the 18 admissions above!).
5. 24 courses of antibiotics (gynae, chest infections, gastrointestinal)
6. 6 local anaesthetics
7. Heavy sedation
8. 13 bouts of bronchitis (from rental accommodation which was damp. I now have a mould sensitivity.)
9. 10 viral infections
10. 2½ years of constant abdominal pain from adhesions (this was due to two botched operations)
12. Monthly period pains resulting from the above operations which went wrong. The pain causes monthly collapse and I have to be drugged on prescription painkillers
12. Chronic lower back weakness and back pain due to abdominal weakness from all the gynae operations!
13. 3½ years of chronic diarrhoea possibly due to so many antibiotics, which has left me debilitated, dehydrated and sometimes suicidal

14. My father's sudden death
15. Light sensitivity as a result of damaged eyes from using interactive white boards in schools

In addition, John's sister died prematurely; John has been poisoned by fumes at work for 2½ years; we have been persecuted by landlords and forced to leave our home; we have both encountered serious bullying at work.

Although it makes sombre reading, I'm actually grateful that I've survived it all!!!

That survival has only been due to God's miraculous intervention. I then glance at the list of M.E. symptoms He healed me from so amazingly on 3rd July 1997 (84) and realise that I have a choice whether to focus on the good healing list or the bad post-healing list.

The symptoms which had gone column, after Jen's prayer on 3rd July 1997

1. Crippling pain, both muscular and neuropathic, in my legs and arms
2. Intermittent muscle paralysis
3. All over muscle weakness and tenderness
4. Pins and needles
5. Numbness
6. Poor balance
7. Poor co-ordination
8. Joint pain
9. Muscle twitches (fasciculations) on legs and arms
10. Toxic sensation in my blood
11. Acute noise and light sensitivity
12. Slow, sometimes slurred speech
13. Poor concentration when reading, writing, talking, listening and thinking
14. Poor short-term memory, e.g. forgetting what I'd just read

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84. See Chapter 20, In the Twinkling of an Eye.

15. Physical fatigue after the simplest of tasks e.g. brushing my teeth
16. Mental fatigue after the simplest of tasks e.g. a short phone conversation
17. Severe low blood sugar problems (hypoglycaemia)
18. Faintness when being upright (in addition to faintness from hypoglycaemia)
19. Asthma, especially chemical and dust sensitivities
20. Breathlessness after the simplest of physical and mental tasks
21. Intolerance to sugary foods, food preservatives and additives
22. Sickness allergy to certain foods, e.g. shellfish
23. Intolerance to alcohol
24. Severely bad side effects from routine medicines
25. Severely bad side effects from local anaesthetics
26. Intolerance of hot and cold temperature
27. Sensation of ‘brain fog’ when I failed to think clearly
28. Daily insomnia
29. Reactive exhaustion from busy surroundings e.g. traffic, crowds etc.
30. Excessive hair loss
31. Daily throat inflammations
32. Irritable bowel syndrome
33. Inability to perspire
34. Essential daytime sleeping
35. Inability to cope with much stress
36. Being overly anxious
37. Inability to overcome common viruses
38. Problems with swallowing
39. Muscle stiffness
40. Clumsiness
41. Poor oxygen intake, being unable to be near candles or a log fire
42. Poor neuromuscular skills, being unable to work a computer mouse
43. Dysphasia (choosing the incorrect word in speech)

Which list do I focus on? The healing list or the bad ‘post-healing’ list?

Whilst I mustn’t deny all the recent suffering, my mind does naturally drift onto focusing on one of the lists.

Another tradition which has crept into the celebration of this special day, has been to drag out my dusty wheelchair and sit in it for a while, reliving my past in an effort to be grateful for the continued transformation. As I sit in it, feet on footrests, stick in hand, I don’t feel any M.E. symptoms at all because I’m just sitting in a wheelchair. So I take some elastic bands and put them round my wrists and ankles, purposefully constricting blood flow which shortly brings about the familiar M.E. burning pain in my muscles. I attempt to get up and walk with my stick but find it difficult to shuffle out of the wheelchair and stand, due to my weak and painful legs. My body goes into spasms, unable to walk in a straight line, pushing heavily on the stick for support and grabbing a nearby door handle to save me from falling over. Meanwhile, the elastic bands get tighter and the burning pain becomes unbearable, as if my muscles and blood are on fire, with my mind delving into another dimension of going ‘beyond myself’ because my strength can’t deal with this continuous torture. God help me, please help me. I can’t endure another moment of this scalding pain.

I decide to take off the elastic bands. Immediately a welcome, warm rush of blood flows through my limbs, making me sigh from relief. I realise that I have the freedom to take off those rubber bands and make the M.E. pain go away; others aren’t so fortunate and have to endure it with no earthly, only heavenly, end in sight.

The tea candles around me burn brighter, their fragrance stronger.

I continue to think back 11 years ago, when achieving a mere fraction of what I’d done this morning would have been impossible. Running up and down stairs, stretching up for a box of cereal, lifting the kettle... the list is endless of what I'm still able to do, with muscles and brain remaining as good as the day of the healing. Calf muscles, triceps, biceps and all the muscles of my legs and arms have never relapsed since the special prayer. Even having 'just toast' for a late breakfast is remarkable, instead of cramming bacon and eggs down my throat before eight in the morning, to prevent a hypo attack by ten o'clock.

In a few hours, I plan to shop at the Co-op, then drive to Maidstone and be John's trophy wife for his department's art show, standing in high heels for several hours (me, not John), followed by a meal at one of the better restaurants there. Tomorrow, I've agreed to supply teach all day in forecast hot weather at a local primary school, including teaching athletics. So I'd better practise my long jump technique!

The pastel coloured Oriental lilies open wider to give out their heavy, healing scented aroma.

11 years on, the M.E. still hasn't returned, although a few of the symptoms on the healing list have returned. Their cause, though, has not been M.E. but due to other reasons, often from manmade mistakes. My breathing, at times, isn't as good as it was after the miracle, not due to M.E. but to so many chest infections from living in damp rental accommodation. Another example of a healed symptom which has returned is that of electric white light sensitivity, due to using interactive whiteboards at school. It affects me a bit like snow blindness. (Other teachers have also reported health problems from using them.) The few symptoms which have returned from the healed list have served to confuse people and to throw doubt on my miracle. Yet I can still go jogging and swimming regularly and gaze at flashing Christmas tree lights without my eyes hurting.

I used to think that the M.E. would never return because God had conquered that particular illness. My thinking has since changed because none of us know the mind of God so I suppose that the M.E. could come back one day. It's had ample opportunities to come back in the past 11 years, though, with hundreds of circumstances which could have triggered relapses; but so far it never has.

Some people find it strange that I still talk about my healing with zest despite suffering so much since. Even people who took me out in my wheelchair question my ongoing enthusiasm for miracle wonder, as they remind me of my post-healing trials and tribulations. Each new health problem which comes my way pushes the miracle further back into their distant, hazy memories as it holds less significance for them.

Yet my miracle means so much to me, almost everything in fact, and more so since further torment: it glows brighter with inspirational light as darker events filter in.

When my muscles became instantly pain-free, skin became rosier, speech fluent, memory sharper, eating and drinking became normal, then I don't easily forget this! When I couldn't pick up even a heavy mug of tea and suddenly went to carrying a crate of heavy car tools over my head (as John witnessed), then that is worth celebrating! When every faculty was suddenly restored and an illness classified as permanent with no medical cure, suddenly disappeared in a split second, then I'm bound to still think about that morning, noon and night! It was a miracle, for goodness' sake, one which I still talk about at every given opportunity; one which was as dramatic as the blind given their sight, the dumb given their speech and the lame leaping for joy! It happened. It is a fact of history and further suffering will never undermine its power.

The event still touches people today, just as I was touched as a child by two-thousand-year-old healing stories bellowed into the vaults of ancient Brook church.

I'm privileged that my miracle was immediate because few healings appear to be as dramatic as mine. Most tend to be gradual healings from the moment of a prayer, which is still wonderful and undisputed but mine was scary. Jen's own miracle was just as awesome, apparently; also, Dorothy Kerin, the founder of Burrswood, experienced a miracle which made those around her bedside 'so frightened' (85). (Not that I'm a Jen Larcombe or Dorothy Kerin, who are quite remarkable people.)

No-one writes a book unless they have something to say and I presume that the descriptions of struggles and deliverance in my book speak for themselves. If I was to summarise what I've 'learnt' the most through it all, I would have to say it is to see my need of God 24/7. Suffering can certainly do that.

Every day now, I try to feel the agony of other M.E. sufferers to the point whereby it feels like me suffering, as if it's my tormented body and soul. I realise that I can't help sufferers unless I relive the M.E. nightmare and remind myself of what they're going through.

John once told me that I was called to a life of suffering, even after the healing. I don't think that is entirely true, as I've had too much vitality and good health for that! But I do think that the suffering since M.E. has been important so that I still can relate to those in need. If the feelings of pain and loss were always a long time ago and a distant memory, then I couldn't get alongside those who still endure such things.

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85. *The Living Touch* by Dorothy Kerin, printed by K&SC (Printers Ltd.). First published 1914, reprinted 1987, available from Burrswood (a centre of Christian spiritual healing and medicine), Groombridge, Tunbridge Wells, Kent.

My spiritual experiences have helped me to focus amidst post-healing darkness. As I think back to the dramatic, instant miracle of Biblical magnitude, the vision of angels that may have been our children, the blissful peace when my soul soared to Paradise during an ‘out-of-body’ experience, then I am thankful! When I hear of other people’s M.E. returning after they claim to have been healed, yet mine so far hasn’t returned, then I’m grateful. As I think back to all my health problems since the miracle and of God’s mercy in delivering me from them, then that brings a joyful smile to my face! The smile broadens at the thought of being united, forever, with our many children in Heaven.

Despite my wonderful gift of a physical healing, I do believe that the best gift of all to receive is the peace of Christ: not a human peace but His supernatural peace. This gift is available to all of us, right now, free of charge. I’ve experienced good health without His peace and poor health with His peace and out of the two, His peace is the more precious gift.

I look down at the kitchen table, observing the two lists once again: the list of symptoms I was healed from and the list of post-healing suffering. I decide to dwell on the healing list, realising that I will always have much to be thankful for.

The kitchen is filled with heady fragrances from flowers, candles and filter coffee, the aroma carrying memories of gratitude.

My brightly coloured coffee mug begins to look half-full rather than half-empty, although its contents have turned ice cold. I turn to make a fresh pot and watch the mug fill not just to the brim but until it overflows.

Postscript The few symptoms which returned from the ‘healing list’ have thankfully gone away again, from a variety of methods... operations, homoeopathy but mostly from prayer alone.

Afterword

I’ve just finished reading Catherine’s brilliant account of her healing, that day back in July 1997; it brought so many memories flooding back. Getting myself dressed up for the important meeting I was supposed to be attending that day and wondering if ‘The Girl with M.E.’ was going to come after all. Time was ticking by, I knew I couldn’t wait for her much longer; perhaps she just didn’t feel up to coming out after all?

Then, on my way to the car – already late – the doorbell rang. There she was, wobbling on her seat-stick, white-faced and sweating with the sheer effort of standing there. I sat her down (before she fell down) and explained I had to leave. I felt such a heel but to be honest I never felt less like praying in my life! She looked so ill she sent my faith levels down to rock bottom! I remember praying a few mechanical words (just to keep her happy), and thinking all the time, ‘This prayer isn’t going anywhere. I’m not doing it right at all!” So I said a quick ‘Amen’ and thankfully left her to her cup of tea.

I can still remember the shock and sheer astonishment that I felt when I heard she was healed! Catherine’s story has taught me a huge lesson; we can get so caught up with ‘how’ we pray – what we say, how long we go on for, how many biblical promises we should claim and if we should wage Spiritual Warfare – that we take our eyes off Jesus Himself and forget He is the one who does the healing, not our fancy methods or powerful words! If healing prayer depended on the faith of the pray-er Catherine would not have been healed! That day she and I simply took her pain and weakness to Jesus and quietly (and quickly) asked for His help – and then left the rest to Him!

Jennifer Rees-Larcombe, 8th Nov. 2011, Hadlow, Kent

The Final Word

Right. Now that I've finished reading Catherine's book, as presumably you the reader have also, several things immediately spring to mind:

1. That I would appear to be somewhat of a dedicated, creative, sensitive jerk.
2. That everything Catherine has written in this book is true as witnessed by me.
3. That carers of the long-term disabled need support, too, and lots of it. Give yourself a break, an hour, a day, or even a week or two. You'll both be much better off for it, trust me.
4. That God knows, and God alone knows, what he is doing and why or how. Neither of us were saints when Catherine was healed, and we jolly well aren't saints now. Anyone who claims to have a handle on God's ways and activities is either deluded or lying.
5. Er, although in contradiction to (4) above, however, I've learned that God's love for us is unfathomable.
6. We've both suffered, but as Catherine has concluded in the last chapter, that it is the ***Peace of Christ*** that is the most important thing in life to have; everything else fades almost into irrelevance.
7. I think I'd better change the family motto.

John Ashenfelter, 21st Feb. 2009, Cranbrook, Kent

M.E. Support Groups

The Grace Charity for M.E.
Popin
20 Dickens Close
Langley
Maidstone
Kent ME17 1TB

Email: *info@thegracecharityforme.org*
Website: *www.thegracecharityforme.org*

For severe M.E., it's good to become a member of the 25% M.E. Group

25% M.E. Group
21 Church Street
Troon
Ayrshire
KA10 6HT

Tel: 01292 318611
Email: *enquiry@25megroup.org*
Website: *www.25megroup.org*

Also, Stonebird provide good support for severe M.E. sufferers and their carers
www.stonebird.co.uk

Tymes Trust focuses on assisting M.E. sufferers of school age

Tymes Trust (The Young M.E. Sufferers Trust)
P.O. Box 4347
Stock
Ingatestone CM4 9TE

Tel: 0845 003 9002
Website: *www.tymestrust.org*