

BEATING
SCOLIOSIS





BEFORE



AFTER

GOING STRAIGHT

X-rays of Margarette's spine before and after her treatment. The screws and metal blocks

(right) used to straighten her spine were inserted in two operations that took 13 hours to perform

as she was. It was the beginning of a two-year journey that has rewritten our lives; upended the mother-daughter relationship, made us recipients of the best surgical skills the 21st century can offer, given us an unlikely link to England's last Plantagenet king — and taught me about the tango. It also gave me an entirely unexpected insight into my family's own medical history.

That evening I phoned my mother, holding a copy of Grace's x-ray in my hand so I could try to describe her spine. She said, with a gasp of recognition: "Oh! Your father had that."

My father had been dead for eight years then. I didn't know he'd had a twisted spine: I'd probably never seen him without a shirt. I didn't know then that most cases of scoliosis occur randomly and that we were unusual in being able to trace a familial link. Neither did I make the logical connection right away, that if Grace had inherited this devastating condition from him, then someone else also had it — me.

There was a smattering of frost on the ground as we arrived at Stanmore in early December. Grace had been diagnosed just before her GCSEs but I had asked that the operation be postponed so she could sit her exams and settle into sixth form. No point rehearsing the sheer sense of fear as she was wheeled off to theatre for the six-hour operation — any parent can imagine how that feels.

The object of a spinal fusion is to bring the vertebrae into a straight line, then fuse them

together, effectively creating a single bone. It is high-stakes work, millimetres from the spinal cord. The surgeon removes the discs and cartilage between the vertebrae to be fused together and packs the space between them with "morselised graft" — in Grace's case, the ground-up remains of her ninth rib. The whole thing is pinned together with titanium screws.

We had been told the first few days would be miserable. They were. Grace was too weak to cry: tears simply leaked out of her eyes. She was attached to a morphine pump to control the pain from the surgery and a thick plastic tube drained fluid out of her chest.

After a week, she was allowed to sit up. "Stand back," a nurse told me cheerily. "They always throw up when we get them upright." Once she could stand, her torso was wrapped in plaster bandages which, once hardened, would form a mould to make the thermoplastic brace — a rigid corset — she would have to wear for the next three months, 23 hours a day.

Grace burst into tears — again — when the brace arrived and her plaintive cries of "No! I hate this!" were only drowned out by the cries of the girl in the next bed who had been operated on to remove a cancerous tumour that was eating away at her spine, whose brace had arrived at the same time.

For the first few weeks at home, Grace could barely do anything for herself. I moved her into my bedroom (she could not get up the windy stairs to her attic room). I climbed into the shower with her to wash her hair. I sat for hours beside her as she was sleeping.

Aislinn, my older daughter, came home from university for Christmas, and Stuart, my husband, who had wearied of London life and moved to Devon the year before, paid frequent visits. We were blessed with lovely neighbours and friends. But for much of the next few months there was just the two of us.

Grace was determined that spinal surgery would not stop her celebrating New Year's Eve, so after lengthy negotiation I agreed she could go to a party. For one hour. In her brace. So I spent midnight that year sitting in my car outside a house in Belsize Park, fielding calls from Grace pleading for "five more minutes" and listening to the rain patter down on the car's roof as the New Year came in.

The girls and I had been watching *Fawlty Towers* and other classic comedies. I'd never seen *Friends*, so when Grace suggested we watch that too, I said fine: by the time I realised there were 10 series, a total of 236 episodes, it was too late to back out. It was cold outside, so we put the fire on, wrapped ourselves in blankets and lay on the sofa in front of the TV, laughing, for hours on end. Slowly, Grace began to recover her strength.

I don't mean it was easy — there were times when she was down and resented my fretting over missing school and forcing her to focus on Chinese history when she was exhausted — but over those weeks and months, a relationship that had always been close became even stronger. And just as well: before long, Grace was the one looking after me.

I began to get a debilitating pain around my ribcage last January, while Grace was still in the early stages of recovery. I thought I must have pulled a muscle, but the pain persisted. I was too busy working and trying to look after Grace to do anything about it. My mother also needed attention. She was recovering from cancer so I was forever driving the 12 miles across London from my house to hers.

So it was late spring before I went to my GP. A spinal x-ray showed I had a gentle S-shaped double curve. Thinking there must be some link to Grace, but not imagining it was serious — I'd always attributed my lifelong back pain to too many hours spent over the computer keyboard — I thought I should talk to Sean Molloy, the orthopaedic consultant who had been in charge of her case. I could not be directly referred on the NHS (that would involve seeing another consultant

first) so I made an appointment at his private clinic. I had read somewhere that mild scoliosis can be helped by special exercises and I thought he would recommend a decent physio.

Molloy, 45, is an extraordinary man: not just a world-class surgeon but a trained chiropractor, and engineer. Aged 17, he was one of the youngest tennis players to be selected for the Davis Cup. Call it denial, but it never occurred to me that I might need surgery. I was more afraid he might think I was suffering from Munchausen syndrome; that having seen my daughter through a medical drama I now wanted my moment in the limelight.

So a white noise seemed to buzz in my head as, after an MRI scan, Mr Molloy explained that my case was more advanced and difficult than Grace's. What had started as an adolescent idiopathic (unexplained) curvature like hers had stiffened with age and the pressure it exerted was crushing my vertebral discs — the bottom two were damaged beyond repair. In a case like mine, the gravitational force that bears down on everyone, compacting the spine

I'D ATTRIBUTED MY LIFELONG BACK PAIN TO HOURS SPENT AT THE COMPUTER

replace the crushed discs, would be a huge ordeal, needing a long period of recovery. I would lose all flexibility in my spine where the vertebrae were to be fused.

The massive emotional shock was compounded by the practicalities that were running through my head. I had been living with the after-effects of Grace having half this much surgery — and she was still recovering. Who would look after me? Who would look after my mother? Who would look after Grace? So I told him no, I couldn't go ahead. "Fine," he said kindly as I left. "See how you get on with the pain, and

STILL LIFE

Left: with dance teacher Alexandra Wood (right), relearning how to balance, and to walk straight — the surgery had altered Margarete's centre of gravity. Right: the physician Sean Molloy, who performed the operations



time News at Ten came on every night I was wan and exhausted, trying to ease the discomfort in my back with a hot-water bottle or a glass of red wine.

I hadn't slept more than two hours at a stretch in years. Pain was the first sensation I experienced when waking. I had learnt to live with it, but once a solution was on offer — and not even a guaranteed solution, as Mr Molloy stressed that this was a risky procedure that could leave me disabled in a different way — I could not ignore it any more.

But again, I asked that the operation be delayed. Having missed so many months of school, Grace was way behind and I needed the autumn to try to help her get back on track for her A-level exams.

As I was packing to go into hospital in the first week of February, it was confirmed that the skeleton found buried beneath a car park in Leicester was Richard III. When Grace was having her operation I'd had trouble trying to explain scoliosis. With the story all over the TV and pictures of the curvy-spined remains in every paper, people were constantly ringing to say: "Oh, now I understand what you've got..."

In Richard III's day, the only "treatment" available was a form of traction a bit like being tortured on the rack: today, he would have an



as we get older, caused the spine to rotate where one curve meets another and the pain around my ribs was the first sign that my spine was buckling, forcing my ribcage diagonally down on my right side. If not checked, the likelihood was that the process would continue, slowly crushing my lung cavity.

The surgery needed to correct the deformity, drilling metal screws into my spine from base of shoulder-blade level to my pelvis, followed by a second operation to access the spine from the front of the body and insert metal cages to

when you're ready, come back to me." Two weeks later, I was back in his clinic. I kept telling myself surgery was impractical, impossible, but I could not suppress the thought that just kept bubbling up: this amazing man could fix me. For what I had never told anyone, never even really admitted to myself, was that pain, my ever-present friend, was beginning to dominate my life. On the face of it, I was reasonably fit. I walked to and from the office, three miles each way, and swam two or three times a week. But by the

operation similar to mine, very possibly at the hands of Mr Molloy. I was one of the first patients to benefit from the O-arm imaging system, a £600,000 piece of cutting-edge medical technology installed at the Clementine Churchill Hospital last year (a second machine has since been bought for use in the NHS at the Royal National Orthopaedic Hospital).

Molloy was the first physician to use the system in the UK. Where once surgeons had to stop-start operations to take x-rays to help them estimate where the screws they ➤➤➤

were putting into the spine were going, the O-arm — which, as its name suggests, is a circular scanner that surrounds the patient — can take up to 400 images in 13 seconds and turn them into 3-D simulacra that are then linked to a navigation system known as the Stealth Station, which enhances the accuracy of the procedure. Just look at my x-ray to see the precise way every screw is positioned. “It’s a GPS for the spine,” says Molloy. “We take a ‘spin’ of the patient, which means we can know where the surgical instruments are at all times and insert screws in a much safer way.”

In my case, Molloy chipped away the bony protrusions that had grown on my vertebrae and used the resulting bone fragments to grind up and pack between the vertebrae he intended to straighten. He drilled a “pilot hole” in each of these, inserted screws into the bone, then, using a tool he designed himself, fixed each screw to a metal rod delineating the new line of my spine. Titanium bolts were fixed into my pelvis. The whole procedure took 8½ hours.

In a second — 4½-hour — operation two days later, he made an incision in the abdomen and approached the spine from the front of my body to insert metal blocks to replace the damaged discs and to reinforce the fusion from my third lumbar vertebra to my pelvis to strengthen it, “like building the foundations of a house”.

It goes without saying that such surgery needs phenomenal powers of concentration and a steely nerve. Tennis, one of the last gladiatorial sports, is an oddly good training: “It’s important to have experienced a stressful situation, so that if anything goes wrong in surgery you can bring your own pulse rate down and think in a very calculated way about the next step,” he says. “I once played a Davis Cup match that lasted five hours, but I do operations that last nine hours... They take as long as they take and you have to have the stamina for it.”

My concerns about how I would cope were solved in an afternoon. I invited my girlfriends for Sunday tea, made lots of cakes and gave them each a glass of fizz: “Guess, what! I need you to look after me,” I told them. Half an hour later I had someone signed up on the calendar every day for two months.

I will be forever grateful for their help. My cousin, an intensive-care nurse, collected me from hospital and stayed for the first few, crucial days. I was on morphine, so I don’t remember much

about the early weeks now, except that I had to wear compression stockings to ward off deep-vein thrombosis and — as I couldn’t bend — could not shower without someone to take them off and on for me.

Being dependent was a surprisingly enriching experience: a school friend I usually rarely saw washed my hair. Others brought box sets, or books, or home-made soup. One who was determined to honour her place in the sock-changing rota, despite having broken her collarbone, brought her husband. He was on a day off from working with a charity for the disabled and, having to help both of us, complained loudly of his busman’s holiday.



The researchers have discovered a mutant gene they call Druk after the “Thunder Dragon” of Bhutanese mythology. When they introduce it into the fish (below), the results are dramatic. The mutant mimics adolescent onset scoliosis in humans, in which there is a dramatic curve in the spinal column. The markers for Druk and other genes will be passed back to Texas Scottish Rite, where Wise hopes to identify parallel markers in the human genome ■

COULD THE TIDE BE TURNING?

Researchers in America are just coming to the end of a five-year study of 2,000 families with scoliosis to try to identify the genetic basis of the condition.

Dr Carol Wise, the director of molecular genetics at the Texas Scottish Rite Children’s Hospital, says the most likely candidate so far is LBX1, a gene on the 10th chromosome; though whether it impacts on the development of bones, muscles or neurons is not yet known.

“There’s every reason to believe that gene is causal, but there’s more work to do,” says Wise. “We know it is responsible for early pattern formation, so it’s responsible for proper muscle growth and proper nerve growth. What we’re up against next is understanding what it does later in development.”

Wise is collaborating with a group at the University of Washington School of Medicine in St Louis, Missouri, which is experimenting on zebrafish, chosen because the young develop outside the mother and, as they mature, their skin is translucent, so it is easy to see the spine.

When your spine is moved, your centre of gravity changes, so I had to learn to walk again, or at least to balance in a new way. That meant walking, walking, walking, around streets I’d known for years but suddenly felt unfamiliar. My surgery straightened my lower back but left my upper curve, as fixing that would have left me rigid from the neck down. So I was still a tad off kilter but determined to end up standing straight.

No matter how long I spent in front of the mirror trying to balance my shoulders, I couldn’t get it right, so I enlisted the help of Alexandra Wood, a dance teacher who is also one of Britain’s leading tango dancers. Wood had classical training but when she discovered the Argentinian dance everything she’d learnt was turned on its head: “Suddenly you’re wearing 4in heels and you have to change the way your body moves. That’s helped me help you realign, as I had to do that for myself,” she said.

But my biggest inspiration has been Grace — because just as I was the only one who knew how it really was for her once the visitors had gone, so she’s the one who knows how it has been for me. She comforted me through the bad times, gave me practical advice, and made me watch Friends, all over again.

We are both an inch taller. In two weeks’ time, I will drop her at Leeds University, where she starts the next phase of her life. Her surgery has left her with a huge scar that arcs around her body. She says it makes her feel like a Bond girl.

Me? I’ve just painted my toenails, something I’d almost given up hope of doing again. I’m not ready to take on Daniel Craig yet, but I’m getting there ■