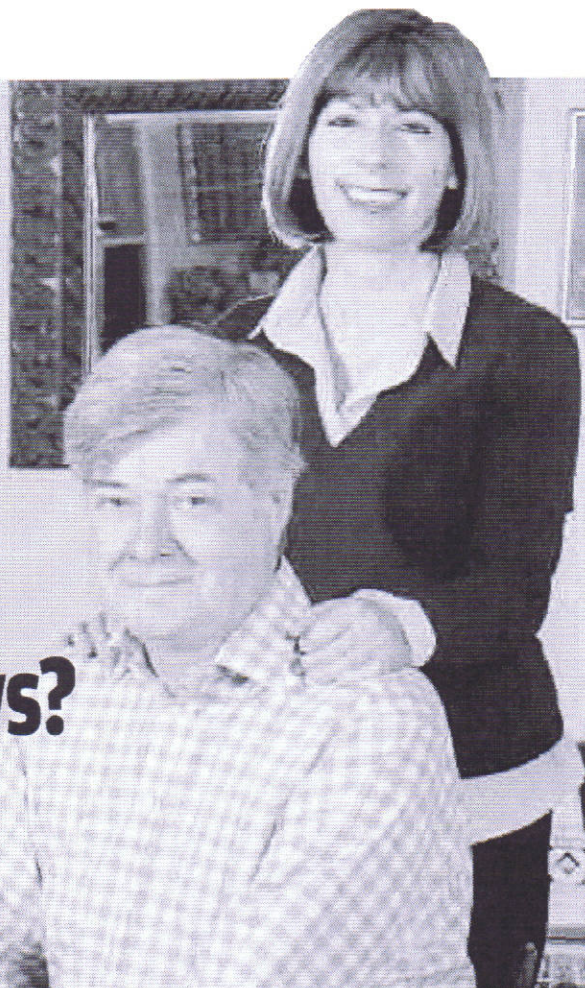


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Page: 38
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**It was just a cold –
but 24 hours later
I was paralysed,
in agony and sure
I was going to die.
The really bad news?
The same could
happen to YOU!**



Long struggle: Robin says he could not have made a recovery without his wife Suzi

By JILL PARSONS

ROBIN SHEPPARD remembers precisely when he took his last unaided steps. Visiting his elderly father in the run-up to Christmas three-and-a-half years ago, he'd decided to go to bed early because he was feeling under the weather.

He walked up stairs, assuming all he needed was a good night's sleep. Yet within 24 hours he had collapsed and was flat on his back on the landing, paralysed and in excruciating pain.

'I was terrified,' he recalls. 'I was in agony and couldn't breathe properly. I tried to use my mobile to call my wife, Suzi, who was visiting her

own father, but I couldn't lift the phone.

'In panic, I shouted out to my father, but he is a bit deaf and had the television on at full volume. He was so engrossed that he didn't hear me.

'After what felt like for ever, although it was probably closer to an hour, a neighbour who'd popped in for a chat with my dad heard my weak cries, took one look at me and called an

ambulance.' What Robin didn't know then is that the neighbour's visit saved his life, and that he faced a monumental battle back to health. In fact, his doctors doubted he'd ever walk again – and all because of a cough.

Robin, 53, had Guillain-Barre Syndrome, a cat-

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astrophic condition which can be triggered by something as innocuous as a cold or stomach upset. Even the flu jab can cause it.

And anyone, it seems, can fall victim to it: young and old, healthy and sick, men and women are all at risk. Doctors are still unclear as to what makes a common illness progress to a life-threatening condition, or why some fall victim and not others.

But there's no doubt about its terrifying consequences.

Guillain-Barre causes the body's immune system to turn on itself, specifically to attack the lining of the nerves, known as the myelin sheath,

which carries signals to the muscles. With the nerves unable to transmit signals effectively the muscles no longer respond to the brain's commands.

The arms and legs, where the nerve signals have to travel the furthest, are the first to be affected, but the condition can also spread to the stomach, spine, lungs and face. In extreme cases, without urgent medical help and in the grip of total paralysis, it can kill.

Robin's struggle with the illness, and his long haul to recovery, have been vividly brought to life in his remarkable book, *A Solitary Confinement*. It offers a salutary lesson for anyone who insists on carrying on as normal, despite feeling unwell.

With hindsight, Robin can now see that he ignored warning signs.

'I'd developed a hacking, dry cough a week beforehand,' he recalls. 'It would not go away and I was definitely lacking in energy.'

But the wealthy hotelier, who was running the exclusive members club Home House in London (as well as launching Ty-nant mineral water in his spare time), was far too busy to let his symptoms get in the way.

He'd always been fit and healthy — he'd not long given up playing rugby, and kept in shape with golf and cycling — and assumed he'd just throw off whatever ailment it was.

Then, the day before his collapse, the father-of-two noticed tingling in his fingers. A few years earlier he'd been diagnosed with psoriatic arthritis, which causes pain and stiffness in the joints, particularly in fingers and toes. He put the new symptom down to this.

'On the drive from London for what was supposed to be a flying visit to my father's house in Bath, I was really woozy and had to stop and get out of the car for some fresh air. I drove the rest of the way at a snail's pace and somehow made it, but I didn't feel at all well, so went to bed to sleep it off.'

The next day, he thought he'd try to go to work, 'but it was very clear I couldn't carry on'.

'My legs were like jelly, and I was in agony from pain that seemed to be spreading from my spine. Four hours later I got up to use the bathroom, fell down on the landing and couldn't get

up. My arms, my legs, my head — nothing would move. I knew I was in big trouble.

'When the ambulance arrived, I remember seeing the worry on the paramedics' faces, although they were incredibly calm and soothing as they carried me down the stairs and topped me up with bursts of oxygen.'

H

E CONTINUES: 'By then I was barely conscious, but I was determined to keep awake. I felt if I shut my eyes I might never wake up.'

'I tried to keep talking, but my breathing was becoming weaker and my voice fainter as I felt the paralysis creeping through my neck, chest, throat and tongue. It was terrifying.'

Robin was taken to intensive care at the Royal United Hospital in Bath.

'In A&E, I was told quite breezily that my breathing was about to give out and I shouldn't be alarmed. I was gulping and gasping for air. I could feel my eyes starting to roll in their sockets and I had a vague picture of staff running towards me in slow motion.'

'It felt like I was falling and drowning. I saw white light flying past me. I was convinced I was going to die. Then I wondered if I was dead; then I wondered if I could be dead when I was still thinking.'

When Robin's wife, Suzi, arrived at the hospital a few hours later, she was told there was a real chance he might not survive — the doctors thought his organs would fail.

'It was incredibly shocking,' says Suzi, who is in her early 50s. 'Robin had been pretty much his normal self when I last saw him, yet when I arrived at the hospital he was paralysed, wired up to everything and unconscious. They were not sure he would make it.'

Robin's fate was determined by a piece of good luck. Suzi heard the doctors debating what was wrong with her husband — polio seemed to be the most likely diagnosis.

But then someone also mentioned Guillain-Barre, and that he'd need early treatment with immunoglobulin

— antibodies used to boost the immune system's response — if it was to make a difference.

When Suzi heard this, and after making sure it would do Robin no harm, she pressed for the treatment to be given to him 'just in case'. The couple later learned that Robin wouldn't have recovered to the extent he did if he'd



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not had the medication in time.

After 24 hours, Robin's condition improved. It became clear that he had developed the more severe type of Guillain-Barre Syndrome, where the nerves themselves as well as the myelin sheaths had been damaged. This increased both the levels of pain and the damage to his nervous system.

While Robin himself is stoic about this, Suzi says it meant he was 'in an enormous amount of pain all the time'.

'Every tiny movement was excruciating; it was also incredibly painful to be touched. But with no reflexes, he had no means of showing it.'

The doctors said it was the worst case they had seen, out of hundreds

over the years. Around 1,000 people develop the syndrome each year in the UK, and all need hospitalisation. Eighty per cent will experience a milder, more localised form, from which they will fully recover.

Three days after he was admitted, Robin recovered consciousness. At that point, he was still paralysed and attached to a ventilator. He was told that as his deterioration was so rapid and his symptoms so severe, he could expect a long haul when it came to recovery.

There was no way of knowing how badly damaged his nervous system was, and to what extent it would recover. 'I was told I would eventually be able to breathe on my own, and talk, but there was no guarantee I would walk again. I'd also suffer constant tiredness and probably pain.'

'In a way I was glad to know, as it definitely revved up my fighting spirit and made me determined to get better. But there was no doubt about the terrible state I was in; I saw it reflected in the horror on the faces of my family, particularly my sons and stepchildren, who burst into tears when they saw me.'

'My eyes were gummed together through dehydration and I could prise one of them open only a fraction. Because I couldn't move my head, this eye stared up at the ceiling most of the time. Friends and family had to loom over me so I could see them.'

'I couldn't move my body at all — all I could do was flap my mouth open and shut like a freshly caught fish gulping for air. I had tubes and machinery everywhere, and it felt like I'd been stapled to the bed.'

'My room was a constant hive of activity, from the intensive-care nurses replacing catheters and keeping me clean, to medical students gawping, to physios trying to get any small movement in my body, as well as a slew of doctors.'

'My sense of hearing seemed to go

into overdrive to compensate for all the other lost sensations and the noise was overwhelming.

'Eventually, you begin the process of clawing bits of yourself back. In my case, the beginnings of the bounce-back came after 16 days of extreme pain and total immobility, all in a haze of painkilling drugs.'

'I spent hours looking at the light fittings from different angles or imagining myself on a walk in the country or looking at a wonderful view — things I'd loved in my previous life. It might sound strange, but I was never bored.'

'I did, however, feel trapped. I could do nothing for myself. I was being fed through a tube and the unbearable itch in my nose would go on for hours, because I couldn't even tell anyone to scratch it.'

'Meanwhile every nerve felt raw and jangling, and every sound deafening.'

'This lack of control was quite scary and hard to come to terms with. But there was little I could do to show the fear I felt, both about my current state and what the future might hold, because I couldn't speak. I still had a degree of facial movement, and could

raise an eyebrow, or grimace, or mouth things to let them know that I understood.'

'I was also fortunate that Suzi spent most of her time by my side, being practical and focused.'

'To be honest, I don't know if I would have reacted the same if the situation had been reversed. I'm not sure I'd be so resolute and organised in the face of such a devastating condition. Suzi brought sanity and laughter to my situation, as well as caring for me; she was amazing.'

After a month Robin was able to breathe unaided for short spells, which indicated enough improvement to move him out of intensive care and into a neurological ward.

During his five months there, he spent several hours every day undertaking painful, slow and exhausting physiotherapy to stimulate the nervous system.

Eight weeks after he was admitted, he managed to sit on the edge of his bed for three seconds.

'I felt like I'd climbed the Elger,' he says. 'A week later, I could pull myself into a sitting position and hold it for 30 seconds before flopping back onto the bed.'

'Once I could sit up, propped up by a couple of pillows, the next target was to get myself



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into a wheelchair, using a hoist. I'd been there about four months by the time I mastered it — my legs didn't function at all and my arms looked like wasted twigs.'

While Robin praises the nurses and the care he received, he is critical of the nine-to-five culture that, if it weren't for his ability to pay extra, would have limited his access to physiotherapy.

'There are no drugs for Guillain-Barre, just physio and time, and I would literally inch towards progress each day. First sitting up, then learning to stand, then walking with a Zimmer frame — and I needed help, not just Monday to Friday but every day.

'Six months without extra physiotherapy at the weekend would have seriously set me back. I could pay, and they were happy to help on that basis, but it is not right.'

Even with the extra help, it was far from easy. Ten weeks after he was admitted and having gained just enough control to sit up with help and breathe unaided for extended periods, Robin was told by a consultant he'd never walk again. This, says Suzi was a huge knockback.

'The consultant just bluntly delivered the news,' she says. 'I was very upset, although I tried not to show it in front of Robin because I could see how much it had already distressed him.'

BUT Robin was to prove that doctor wrong. After six months, he was transferred to the Wolfson Rehabilitation Centre in Roehampton for three months of specialist treatment.

There, he gradually learned to stand without help and then took his first faltering steps, using specialist harnesses to support his emaciated body (he'd lost 4st in hospital), while he struggled to place one foot in front of the other.

It has been a tough journey. While, more than three years on, Robin has recovered enough to return to work, he cannot drive and uses a walking stick. He continues his physiotherapy several times a week, but his fine motor skills in his hands and feet are unlikely to return.

His writing is now spidery and difficult to read, so he uses voice recognition software to type. His voice, too, is weaker than it was.

Inevitably, his attitude to life has changed.

'I am very grateful to be here. I could be paralysed, or have died. I say thank you a lot more and am much more relaxed. I'm naturally a workaholic, but I have learned to delegate.

'I have moments of feeling depressed, even angry, about what happened — but I try not to let such notions dominate, as I have much to be grateful for. I am reasonably independent, mentally alert and can get a normal pair of trousers on by myself.

'But I've probably got as much of my abilities back as I ever will. That means accepting that I'll spend the rest of my life in someone else's body, and that can be hard to take.'

If there is a lesson to be learned from his experience, Robin says it's to listen to your body. 'I now realise that I was running on empty, but like a lot of men I ignored the signs and hoped they would pass. If only I'd listened and slowed down sooner.'

■ *A SOLITARY Confinement by Robin Sheppard is published by Ecademy Press (£10.99). All proceeds go to the GBS Society for research.*