

Powering on through pain and heartbreak

An ankle operation left Melissa Sullivan in the middle of a medical nightmare, writes **PENELOPE DEBELLE**.

the incorrect spot. And something new had happened. Instead of the post-surgical pain she was used to, this operation had left her in agony. And her foot, when it was revealed, looked odd. It was a purplish colour and felt cold.

She continued to experience constant and unusual pain and every step was painful. Worse, she had no idea what was wrong or what to do.

She braved it out for a few months but the pain got worse. Finally, she visited a lawyer and asked for help. The process from then on was to establish the damage that had been done – and see what could be done to fix it.

Sullivan was dogged by bad luck. The saga of the ankle and its future was overshadowed by the world of pain she was in. She was diagnosed with three pain syndromes, one of which could have been treated if it was known about in time. The first was a serious case of Complex Regional Pain Syndrome (CRPS), pain that sets in after a fracture.

Sullivan says she was at the extreme end. “Out of zero to hundred, I was at the 95 percentile,” she says. “Nobody could tell me what the problem was.”

She also suffered deaf-ferentation, a nerve disorder that translates into hypersensitivity. A block of ice on her skin, instead of feeling cold, would read as extreme pain, “like someone shoving in a knife”.

And later, when her limb was amputated, she suffered phantom pain.

“My foot does all these weird and wacky things and the pain that the foot goes through, I feel it,” she says. “I paddle with a guy who had his legs blown off in Afghanistan

and he complained one day about an itch and it lasted five minutes and he couldn’t scratch it! He had nothing at all. They don’t know why some people suffer and some don’t but I just happened to get all three.”

She went for months without treatment and was in a wheelchair. Everything was painful. At the same time she was juggling a failing marriage and the care of two young children, both with serious medical problems.

Her daughter, Madeleine, has kidney disease while son Kaleb has Asperger’s syndrome and was fed through a gastrostomy tube for the first few years of his life.

She sold her real estate business and became a full-time carer. At one point she had both children in hospital while trying to fit in wheelchair basketball.

At her lawyer’s direction, she flew to Melbourne to have a report done by an independent specialist to appraise the extent of the physical damage and see what could be done.

He told her he could try and rebuild a foot and calf out of bones harvested from elsewhere in her body, and from donors. It was hours of surgery with a strong likelihood of failure. For the first time, amputation was mentioned.

“There is going to come a time when you are going to have to have the limb amputated,” he told her. “It is not a viable foot. Toes are curling over, your toenails are dying.”

She already knew her foot wasn’t doing well but it was hard to hear. She had watched her skin grow translucent to the point where she could see through it.

“You could see veins, it was quite weird,” she says. “And



“I feel like I’m equal to everyone else, I feel strong ... when I’m in a boat I like paddling past people who are walking their dogs or whatever because they don’t know that I’ve only got one leg

say I got a mosquito bite on my foot, or sunburn. It would take months to heal because the blood flow wasn’t right.”

Back in Adelaide she saw a surgeon who laid it on the line. The only real possibility was amputation. She saw another doctor, a vascular surgeon, and he said the same. That began a series of gruelling round of visits to specialists.

“They don’t just remove limbs; you have to go and sit through a board of medical people who all have to agree it is the right thing to do,” she says. “It’s not a matter of saying ‘can you cut my limb off?’ They won’t do it. If they can save a limb, they will save it.”

She saw a psychologist, a rehabilitation specialist, another orthopedic surgeon and a pain specialist. On July 27, 2011, three years after seeing a doctor about her ankle, her

lower limb was removed. Since then she has had 25 surgeries, many of them related to pain control. In August last year she had a second amputation above the knee.

Her stump had been too short for a prosthetic and her pain problem was exacerbated by a nerve in the stump. If she wanted to be able to walk, more of her leg had to go.

IT WAS an unimaginable ordeal and she doesn’t know how she got through it. “The last amputation was the worst for me,” she says. “I had less tears with the last amputation but from a psychological point of view it was quite difficult. And my pain management was all over the place.”

She had children relying on her and giving up wasn’t an option. Slowly, she is getting her life back. In April last year she and her children moved from Adelaide to the Gold Coast where she is part of a national elite sports development program, training in kayaking and va’a – a Tahitian outrigger canoe. Out in the water she feels strong and in the past month completed a 15-second personal best, putting her on track for the Paralympics in Rio.

“I feel like I’m equal to everyone else, I feel strong, even though I am categorised

as a paracanoeist,” she says. “I know this sounds weird but when I’m in a boat I like paddling past people who are walking their dogs or whatever because they don’t know that I’ve only got one leg.”

“They will look at the boat and they won’t know I have a disability.”

Under the care of Adelaide pain specialist, Dr Philip Cornish, she has overcome most of the complications caused by her surgeries.

She has visible under her skin, sitting almost on top of her sternum, a small, square device called a neuromodulator that inhibits her body’s neuro transmitters. Apart from an occasional jolt of CRPS pain through her non-existent foot, it has brought her pain under control.

Reaching a settlement late last year with the orthopedic specialist’s insurers has brought a measure of peace, and comfort. She has the security of being able to provide for her family. And she now has a new leg. It’s software is called I Am Batman, named by her son, and cost a cool \$106,000. All amputees should be entitled to these, she says, but hers only became possible after the settlement.

At some point she wants to paddle the 6600km Mississippi, with her children and partner Fred Tanner, her former coach. If she doesn’t make the 2016 Paralympics, the Mississippi will be on.

Her next goal is to make the Australian paracanoeing team for the Milan world titles this year. She has won world titles under the Australian Outrigging banner and is currently the fastest woman in the world in her category.

She isn’t bitter. She and Tanner are about to start a business on the Gold Coast and she says she has become more empathetic. If the surgeon walked through the door of the Adelaide restaurant where we met, she says she would speak to him.

“If he came through the door now and recognised me and came up and spoke to me, I would talk to him,” she says.

“He made a mistake. Unfortunately he made three and he changed my life, and my children’s lives as well.”



VERSATILE: Melissa Sullivan with her children Madeleine and Kaleb in 2009, top; left, playing wheelchair basketball for Adelaide Thunder; and trying out for the Rio De Janeiro Paralympics.