

By Caroline Overington Photography Adam Knott

**R**hiannon Tracey, 22, broke her neck in a pool accident. Medically, she's a quadriplegic, and yet she walks. Irwin Vale, 23, broke his neck when a car ploughed into his electric scooter while he was on holiday in Fiji. He, too, is a quadriplegic, and yet he can take several steps using crutches. Josh Wood, 29, broke his neck trying to do an aerial snowboard jump over a road (he landed on his head), but he not only stands and walks; he runs. "From not being able to scratch my nose, I can now pretty much do everything," he says, grinning.

All three are spinal cord patients; they damaged not only their vertebrae when they had their accidents, but their central nervous systems as well. All were told that the damage was permanent, and that they would not stand or walk again. Vale's parents were told he would most likely end up in a nursing home with a chin-driven wheelchair; Tracey's mother was told that her daughter probably wouldn't be able to feed herself.

All challenged their diagnosis, sought treatment abroad and, with the investment of much time and even more money, defied prognosis. They are not alone: across the globe there are dozens of "walking quadriplegics" – people with catastrophic spinal cord injuries who technically shouldn't be able to stand but now do. This means that some of the people who currently use wheelchairs – and those who will break their necks and damage their spinal cords this week and into the future – may be able learn to stand again. But here's the thing: not everyone thinks it's worth developing these programs in Australia, and that includes many doctors.

**It was 2009 and Melbourne accountant Sharyn Bradford, 41, and her daughter Rhiannon Tracey (pictured right) were on a girls' holiday in Bali with one of Tracey's best friends. "We had been going to Bali every year since Rhiannon was a little girl," Bradford says. "We knew the place very well." They had been out on a sunset cruise and on their return decided to swim in the pool at the Jayakarta hotel. Tracey dived in and hit the bottom. "Straight away, she couldn't feel anything. From the neck down, nothing, so she started to drown," her mother recalls. Finally her friends, who at first thought she was joking, realised that it was serious and brought her to the edge of the pool. A CAT scan confirmed she had broken her neck and surgeons in Denpasar stabilised the injury, but the news was grim. "She won't walk again," they told Bradford.**

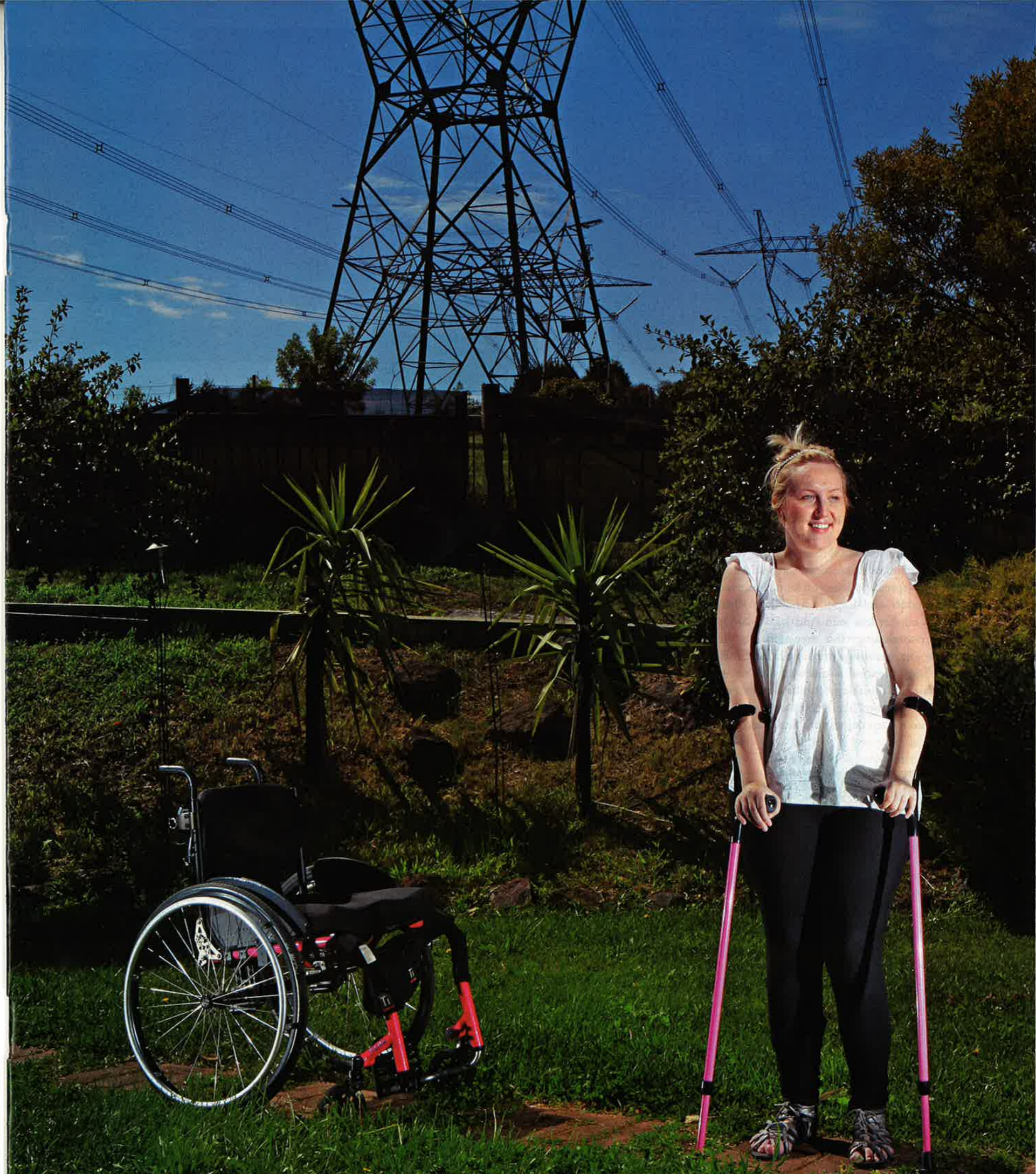
"I thought, how can you say that?" Bradford says. "Rhiannon is my only child. She was two weeks shy of her 21st birthday. I just wanted to get her home to Australia where I was sure the news would be better."

It wasn't. A week later Tracey was taken to the spinal unit at Melbourne's Austin Hospital for further operations before being transferred to the rehabilitation centre known as Royal Talbot. "Everybody was saying the same thing as they said in Bali," Bradford says. "It's not just that she's broken her neck. It's a spinal cord injury and she won't walk again. It's permanent."

Bradford had only a vague understanding of the spinal cord – a complex web of nerves and cells, along which the brain sends messages to the rest of the body. It runs down the back, protected by 24 vertebrae, the top seven of which are numbered C1 (closest to the head) through C7 (closest to the shoulders). When a

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patient breaks the bones in their neck, they might also crush or bruise the spinal cord that runs down the back, or even tear it, meaning messages from the brain can't get down the cord to the body, resulting in paralysis.

How much movement is lost depends on the height of the injury (patients with a C1, C2 fracture are likely to be quadriplegics, while those with breaks lower down the spinal cord may have good arm movement, but no leg movement). Doctors speak also of the "Asia scale", which refers to the American Spinal Injury Association scale of sensation and movement. (Asia A patients are often called "complete" quadriplegics, with no sensation below the site of the injury, while Asia E refers to an able-bodied person. Asia C, somewhere in the middle, refers to an "incomplete" injury; the patient may be able to feel temperature below the site of the injury, or patches of sensation in one or more limbs.)

Generally, the more incomplete the injury, the more favourable the potential for recovery. Tracey's injury was judged to be "C4 and C5, Asia A, complete", meaning catastrophic in terms of her likely ability to regain function. She could move nothing at all from the neck down. "They decided she was a hopeless case, so they'd leave her lying on a plinth while mechanics worked on her wheelchair," says Bradford.

"They told her to sell her car, and get rid of her skinny jeans, because she'd need long skirts to hide her catheter [spinal patients often have no control over the bladder and bowel]. And then Rhiannon started moving her left foot. And I said, surely that must mean something? But they said, no, that's a spasm. She can take drugs to control that. So Rhiannon went from the kind of girl who didn't even like taking a Panadol to taking 19 pills a day to control these spasms. She was like a zombie. And of course she went into a deep depression. She couldn't accept

— and I couldn't accept — that this was how she was going to be for the rest of her life."

So Bradford did for her daughter what many patients do these days — she turned to the internet, tapping in the words quadriplegic, walk and recovery. One of the first sites she found was for Project Walk, near San Diego in California, which bills itself as a "spinal cord recovery centre". The history of this place is well known to spinal cord patients: in 1999, an American quadriplegic, Mike Thomas, then 39, went looking for ways to recover from his spinal cord injury. His wife, Betsy, found a physical trainer named Ted Dardzinski who agreed to work on Thomas's body, which was like that of a rag doll strapped to a wheelchair. As a first step he put a pillow between Thomas's cold, white knees and told him to squeeze it. Thomas said: "I'm a quad. I don't squeeze pillows" but Dardzinski urged him on, asking Thomas to think about squeezing and to keep trying, until one of Thomas's legs jerked. Dardzinski

was excited but Thomas said, "That's a spasm." (Almost all spinal cord patients suffer uncontrolled muscle spasms, some of which are so powerful they can throw a patient from their chair.) Dardzinski — who had no formal medical training — decided that a spasm must be evidence of ability to move, and encouraged Thomas to try to "control" the spasm using both the power of his mind and a series of highly targeted exercises. Over a long time and with a great deal of repetitive exercise, Thomas did in fact regain movement in his limbs, and now walks with a stick.

Of course, the fact that Thomas started to walk after being trained by Dardzinski does not mean that Dardzinski trained Thomas to walk. And the fact that Thomas regained function after spinal cord injury says nothing about possible outcomes for other patients. Despite this, other quadriplegics were soon rolling towards Dardzinski's door, prompting he and his wife Tammy to open Project Walk. That was 12 years ago; Dardzinski no longer works there, but the centre still hums with the sound of quadriplegics at work on various exercise machines.

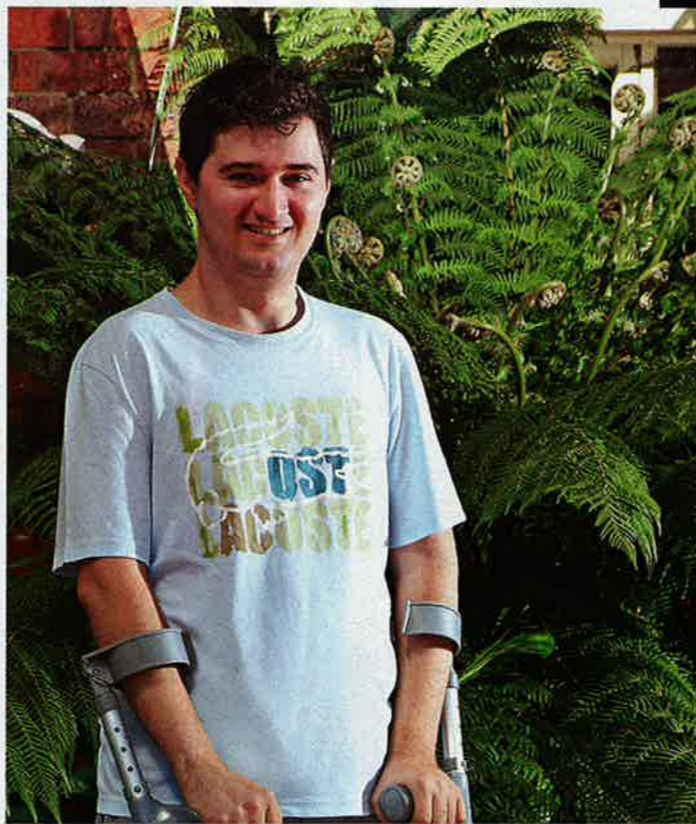
Among their number over the years have been several young Australians: Rhiannon Tracey, for example, was discharged from Royal Talbot six months after her Bali pool accident on April 29 last year and on May 9 she rolled with her mum through Project Walk's front doors. "I knew straight away it was the right place for me," Tracey says. "The atmosphere, the energy — you can't describe the positive nature of the people there. Everyone wants you to walk. They all believe you can do it."

Bradford agrees: "We were meant to stay for four weeks. At the end of it I rang my husband and said, 'Sell my car and send me the money. We are staying.'"

Eight weeks into the program, Tracey could stand in a walking frame. When *The Weekend Australian Magazine* drove to her mum's house in the Melbourne suburb of Eltham recently, she climbed unsteadily from the passenger seat of her trendy little 4WD and stood on her own two feet with no assistance. She then got into a wheelchair to go up a ramp into the house. Once inside she ditched the wheelchair and walked unsteadily, and very slowly, across the kitchen before settling into a comfy chair on the patio. "Not easy," she says, reaching for a glass of water, itself

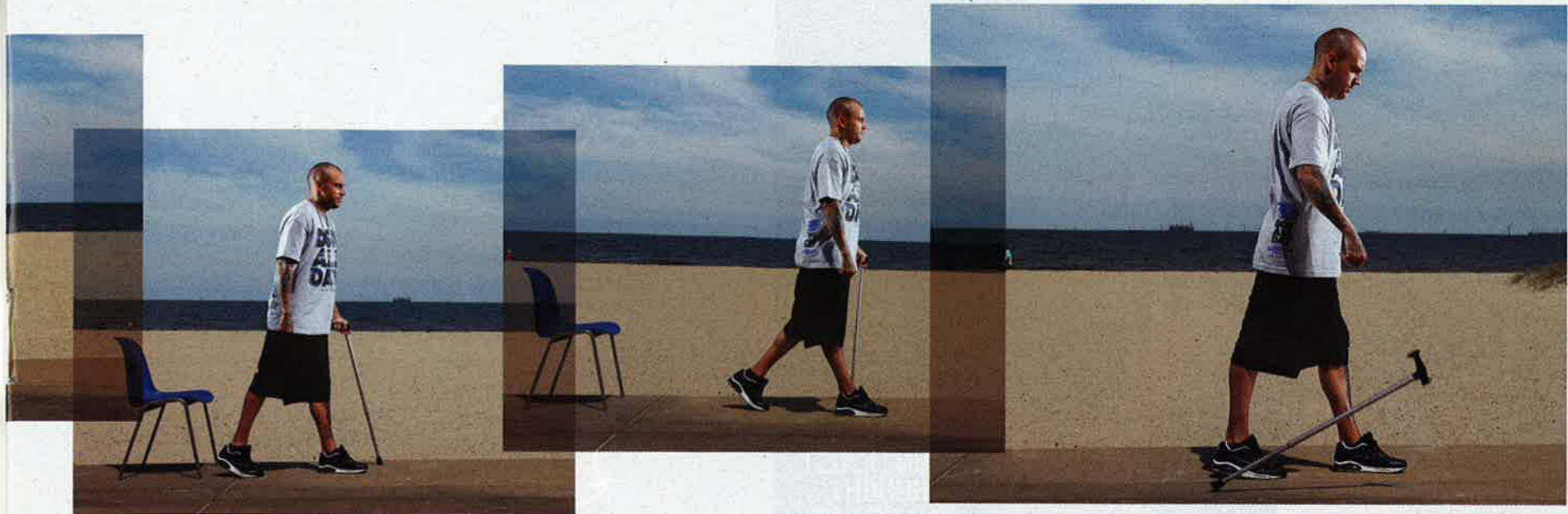


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something of a miracle. Three months ago she couldn't do that either. Tracey now has good sensation in all her limbs but struggles to feel temperature. She can also tell when she needs to go to the toilet, which many quadriplegics can't, but sometimes she still requires a catheter.

"All the treatment here [in Australia] is ... about getting people into wheelchairs and out of hospital. Nobody concentrates on whether you might be able to walk, because it will take too long and cost too much and who is going to pay for it? I wanted my life back, but there's no program for that."

At that moment the door bell rings and a voice calls out: "Hello!" It's Irwin Vale, the injured Fiji scooter rider, standing on crutches at the bottom of three porch steps. "I'm coming up," he says, and so he is, one slow step at a time. Vale's gait is far from elegant (think arthritic grandpa on a walker) and, at times, he looked to be in agony, but he insists he's not. "I look like I'm in pain, but what I'm doing is what they show you at Project Walk, which is making sure I put my foot in a place where I know it will take my weight," he says. "Once I've got one foot secure, I can bring the other one up."

Vale can't tell hot from cold, and says his sensation is "about 70 per cent" of what it was before he had his accident. He still uses a wheelchair to get around because his progress on foot is slow. "But if I'd listened to doctors, I'd be in a nursing home," he says. "The aim in Australia is to get you stable and get you out [of hospital]." Bradford adds: "And then, if you throw everything at your own recovery and you do start to walk again, like these two do, they say, 'Well, they obviously weren't as injured as we thought.' Because to say otherwise they'd have to admit that you can help quads to walk."

It's not true to say there are no similar programs in Australia. Several of the spinal units at big city hospitals are currently testing some of the methods used by Project Walk staff, and indeed there are programs, known as Walk On, in Sydney, Brisbane and (opening soon) in Perth, which have some staff who trained at Project Walk. But none of these enterprises compares in scale to the US campus, which opened in 2000.

As part of the research for this story I visited that campus last month. The foyer is decorated with photographs of triumphant quadriplegics holding their wheelchairs above their heads, and with cuttings from

newspapers of people who have made "miracle" recoveries from spinal cord injuries. Client service manager Gigi Betancourt gives me a tour of the facility. It's fitted out much like a gym, with shiny equipment, mirrors on the walls and rubber mats strewn here and there. Pop music is playing and staff, kitted out in blue polo shirts, are young, fit and smiling. There's a whiteboard on one wall with various achievements scrawled in marker pen: "On 5 September, Jen Bou Lahoud wigged the toes of her left foot!!!"

"The first thing I want to say is we don't promise anyone that if they come here, they will walk again," says Betancourt. "We do say you will get stronger. You may get better bladder control. You may get better pain management. And some clients definitely do walk. We just can't promise it for everyone."

As to what goes on at Project Walk, it's basically vigorous physical exercise – three hours a day, three or four days a week, for months – mainly of limbs below the site of a patient's injury. Given that most spinal cord patients can't move these limbs on their own, this means suspending patients in a canvas harness over a treadmill while attendants lift their feet up and down for them, or bring their knees up to their chests while they lie on mats on the floor. "What we're trying to do is get the central nervous system firing again," says Betancourt. "To get the brain sending messages, getting the client to concentrate on stepping to see if they can start doing it on their own."

It sounds like mind over matter but it's not that simple; there is some evidence that the spinal cord, like the brain, has plasticity, which may allow it to reorganise itself after injury. Project Walk is but one company that believes physical exercise, particularly of flaccid limbs, may encourage that process, leading to improved function. A foundation set up by the late Hollywood actor Christopher Reeve supports similar programs. (Shortly before his death in 2004, Reeve announced that he'd regained some function in one finger after taking part in an intense exercise program.) One of Reeve's physicians, Dr John McDonald, believes that circuits in the spinal cord can be stimulated into action. (Formerly of Washington University in St Louis, McDonald is now director of a company that markets equipment for quadriplegics trying to regain function through exercise and therefore isn't an independent source.) Dr

Susan Harkema, who is rehabilitation research director at the Kentucky Spinal Cord Injury Research Centre, appears on Reeve's website, saying she has seen "significant recovery" in quadriplegics who have started a program of vigorous exercise.

Some quadriplegics have wheeled into Project Walk and after many months of rigorous, repetitive training walked out with the aid of canes, or on walkers. Some, like Mike Thomas and Rhiannon Tracey, had been injured for only a short time before they began treatment, leading some physicians to speculate that they may have recovered on their own. (Some spinal cord patients whose spinal cord is in shock, as opposed to permanently damaged, recover sensation spontaneously.) But other patients, such as a young Australian, Barney Miller, who features on the Project Walk website, regain the ability to stand (in Miller's case, with a great deal of assistance) after 10 years in a wheelchair, with no sensation in their limbs at all.

By chance on the day of my visit there's another Australian on the floor: the snowboarder, Josh Wood, 29, of Port Melbourne. Wood's story is slightly different from that of other Australian patients in this story in that he walked, delicately, on a cane out of hospital. That he did so was remarkable since his spinal cord was crushed at C5 and he still has less than five per cent of normal function. "When I woke up in hospital a doctor said to me, 'I've seen your record. You've broken every bone in your body and now you've finally broken your neck.'" (Wood was a nightclub promoter, snowboarder and motocross rider, and is now a fashion designer.) The doctor added: "You've got a C5, C6, C7 fracture and it's complete, and you won't walk again." Recalls Wood: "I just thought, 'That's not on, that can't be.' And my Mum wouldn't accept it either." He went to Project Walk for four weeks earlier this year after hearing of Tracey's success and didn't want to leave. "In my last five minutes there [of his last day], I ran," he says. "For the first time in 11 years, I ran. I never imagined that I would run again."

Besides being essentially unproven the Project Walk program has been described as expensive, but that depends on your perspective. It costs around \$100 an hour, which is what many able-bodied people pay for a visit to any medical specialist, or indeed for a plumber. Wood hopes to return for three months next year and



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is feverishly trying to raise \$40,000, which includes flights, accommodation, some care assistance and the program’s fees. “I’ve heard people saying it’s expensive, but people who say that should spend some time in a chair themselves,” he says.

**Around 400 people will suffer a spinal cord injury** in Australia this year. Most will be men under the age of 40. Those who injure themselves in NSW have a good chance of ending up at the spinal unit at the Prince of Wales Hospital, Sydney, and in turn in the care of Dr Bonne Lee, acting director of the spinal medicine unit. Lee is aware of the politics surrounding spinal cord injury and recovery, saying: “Yes, there is growing evidence that the neurological system, like the brain, is plastic” and growing evidence that some spinal cord patients, including those with only the subtlest sensation below the site of their injury, could be trained to stand or to take some steps.

Lee is cautious about sending his patients to Project Walk, however. “There are ethical issues here,” he says. “If a patient comes in, and there is some sign, even the slightest sign, that they can get real, permanent movement back in just one of their limbs, like the ability to grasp, which can change somebody’s life, I say they should go for it. We’d throw everything at it including the kitchen sink. But there are no funds in any state hospital system in Australia for a standing or walking program for patients who aren’t ever going to be able to stand, or to walk, in a functional way.”

Patients with limited sensation below the site of their injury who travel abroad to attend programs like Project Walk may find that they blow a lot of money on a program that does not work for them, says Lee. Or, in what may be a worse outcome, that it does work, but only while they are there. “Some people may end up being able to do more, and may even stand, but they can’t stop [the program] or they will lose what they gain.”

Does this mean the program only works for as long as the patients continue to do the exercises? “Correct. Let me use this analogy: what would happen if I were to train you to run the Boston marathon? With a great deal of work, doing nothing besides training for it, you may be able to do it. And what would happen when you stopped training? You would quickly lose the ability to run the Boston marathon. You would lose the muscles you had gained, and your new abilities. It is the same with these exercise programs. It is use it or lose it.

“So a patient may be able to afford to go there for six weeks, and then their money runs out and they have to come home and, within weeks, much of the benefits are lost, because they cannot continue to train at that level. They do not have the equipment. They do not have the time. They can’t afford the trainers to stand with them and move their feet. And that is where the ethical question comes in. If you are going to offer a person a chance to stand for six weeks, but knowing that six weeks after the program is finished the bones and muscles are going to go back where they were, is that ethical?”

To that end, Lee tends to encourage his patients to concentrate on rebuilding their lives, “embracing everything life has to offer, as they did before” their accident. “As a clinician, I want my patients to be happy, and what I have found is that the people who cope better [with spinal cord injury] have a balanced life, meaning they are not focused totally on their physical selves. What I mean, I suppose, is that there is more to life than standing or walking.”

Associate Professor James Middleton of the Rehabilitation Studies Unit at the University of Sydney says flatly that Project Walk’s “Dardzinski method” (trying to get spasms under voluntary control) is “unfounded and there is no evidence to support it”. Furthermore, he says Australian spinal cord patients with reasonable sensation below the level of the injury are encouraged to try to stand and have been for some time. (Those

with very limited and no sensation are not, because it’s deemed pointless.) Middleton does not completely reject the idea that vigorous, daily exercise may enable some patients to regain some function below the level of injury but says: “Most of what we know is coming from the US. In the US, patients receive very little inpatient care. Hence they often enter into these programs without having received much therapy at all. They have a lot of potential to improve – regardless of the type of therapy you give them.”

Middleton acknowledges tension between patients who are desperate to try anything to walk again and clinicians who need to be cautious about new treatment programs. “People with spinal cord injury have a great need for hope, and commercial and capitalistic forces are picking up on this and misleading people,” he says. “They are overstating the therapeutic benefits of these interventions, sometimes because there is a lot of money and kudos to be made.”

What everyone wants – patients and doctors included – is more solid research. To that end, Professor Mary Galea of the University of Melbourne last year won a grant from the Victorian Traffic Accident Commission to study the impact of vigorous exercise and “stepping programs” on neurological recovery in spinal cord patients. The Prince of Wales is taking part (and now has a modified treadmill for patients in harnesses to try to walk on). Other hospitals have been given similar equipment to test. “It involves patients in all spinal units, in Australia and New Zealand, and it comprises different programs, including three hours a day of exercise, three times a week for 12 weeks,” Galea says. “It will identify what benefits that kind of program has over traditional therapy, and whether it ought to be funded. To find out whether it works, basically.”

Back in Eltham, Rhiannon Tracey is excited by the research but when she was offered a place in the trial, she refused it. “They said I had to stop doing Project Walk and stop doing everything else I’m doing, so they’d know whether any improvement I got was because of the program. And then they said, we can’t guarantee that you won’t be in the control group.”

Tracey, her mum, and Irwin Vale have decided to campaign energetically instead for funds to bring Project Walk to Melbourne. Vale, in particular, is frustrated at the prospect of losing function if he can’t continue to work on his gait (he’s currently paying for a physio to replicate exercises he learnt at Project Walk).

Meanwhile, Tracey has moved out of home to live with two friends (a carer comes by several times a week to assist with her personal care), and is committed to walking every day so that she doesn’t lose the skills she gained at Project Walk. “I still use the wheelchair to get to the toilet quickly, or to get around the shopping centre,” she says, “but the more I walk, the better I get.”

Josh Wood is a step ahead of her. “A mate of mine broke his leg – he wanted to borrow my wheelchair, so I gave it to him,” he says, grinning. He doesn’t even know where the wheelchair is anymore. ●

➡ To watch video of Wood, Tracey and Vale walking, go to [www.theaustralian.com.au/magazine](http://www.theaustralian.com.au/magazine)