HER MYSTERIOUS, EXCRUCIATING PAIN

HOW TO TREAT SEVERE LONG-TERM PAIN THAT HAS NO OBVIOUS CAUSE? THE QUESTION

By Christine Jackman
Some people hit the wall when they just can’t take it any more. But Amanda Spratt hit a ditch. Climbing up a steep mountain road in the French Pyrenees, halfway through the gruelling 10-day Tour de l’Aude in 2008, the champion cyclist was determined to ignore the lightning bolts of pain shooting from her lower back down her right leg, which were so excruciating that she couldn’t feel the pedal beneath her foot. For as long as the 24-year-old had been riding with the Australian Institute of Sport she’d had this gnawing demon as a passenger, and she’d learnt to put up with it. She didn’t want to be seen as being “soft” during training, she didn’t want to miss out on coming to Europe, and most of all she didn’t want to risk being taken off the program. But now the moment had come when she could take it no more, when the pain had become so overwhelming that she ran off the road and into the ditch.

Back in Australia, Spratt and the physiotherapy team at the AIS battled for months to locate the source of her pain. MRIs and nerve conductor studies on her glutes and hamstrings came back saying everything was fine. Eventually, Spratt was diagnosed as suffering Piriformis syndrome, a rare condition in which the sciatic nerve is compressed. The surgery she had to correct it was judged a complete success, but within weeks the pain was back – more searing than ever. “At first people said it was all part of the recovery but what scared me was that I could tell it was actually worse,” she says. “I could have cycled for about two hours with the pain [before the surgery] but now I could only ride about 45 minutes before it became absolutely unbearable.”

As time passed, Spratt’s condition deteriorated further. No matter how hard she worked in the gym, no matter how strong she became elsewhere, any prolonged cycling seemed to send her body into revolt. At night, her sleep was troubled, even with strong medication. By all conventional medical assessments, there was simply no physical reason for her ongoing agony. The sciatic nerve had been fixed. There was no inflammation around the site. And yet somehow she had become the pain-racked cyclist who couldn’t ride anymore.

GP’s clinics and hospital emergency departments are full of people like Amanda Spratt, seeking relief from ongoing pain that seems to have no medical basis or cause. About one in five Australians is afflicted by chronic pain – defined as daily pain that continues for three months or more after an initial injury or condition has been treated. When pain becomes persistent or never-ending like this, sufferers will inevitably go on a merry-go-round of X-rays, scans, ultrasounds and even exploratory surgery to identify the problem. Sometimes the cause is never found – by some estimates, 20 per cent of cases fit this criterion – but the “mystery” pain persists in an unrelenting form. Then the cycle continues: painkillers, depression and frustration at not being able to function normally or talk about the suffering with family and friends, whose sympathy has often worn thin. Some are sidelined by their employers – if they’re able to continue work at all. Some may even consider suicide.

Are they going mad? Is it all in their heads? Well, no. And yes. The mainstream medical community has certainly abandoned the once-popular shorthand diagnoses of “hysteria” or “hypochondria” for patients suffering chronic pain without an identifiable cause. But the answer to the second question has become far more nuanced – and exciting – following studies using magnetic resonance imaging, which allows researchers to track how the brain responds to real and imagined stimuli. These have demonstrated that pain can indeed be generated “all in your head.”

Stories are often heard about people feeling “phantom pain” in a limb that’s been amputated, but this is just one of the more bizarre manifestations of a real phenomenon in which the brain keeps telling the body to feel pain. Science is now revealing that the adult brain is not the stable, unchanging entity that generations of physicians, surgeons and healers had assumed it to be. Instead, the central nervous system (which includes the brain) boasts the remarkable ability to change and effectively “rewrite” itself. Often the trigger...
is an episode of acute pain, such as migraine, childbirth or a broken bone. If the brain responds to this trauma by rewiring itself – and the medical community is yet to agree on why it may do so in some cases but not in others – chronic pain can be the result. Behaving like a faulty alarm system, it simply refuses to be switched off once the injury or illness has passed, or becomes so sensitive that it can be tripped into agonising high alert by the slightest stimuli; the brush of a sheet on skin, the touch of your lover or child.

This ability of the brain to rewire itself is known as “neuroplasticity”, a phenomenon thrown into the public spotlight in 2007 by Canadian psychiatrist Norman Doidge's bestseller *The Brain That Changes Itself*. But if the book has a positive slant – its subtitle promises “stories of personal triumph from the frontiers of brain science” – it also shows how brains can go rogue by transmitting unnecessary pain signals.

This is why a whole new generation of scientists, doctors and therapists are taking the new understanding of neuroplasticity and asking whether it is the beginning of a revolution that can cure patients such as Amanda Spratt, when all else has failed. After all, they ask, if the brain can change itself, surely it must be possible to convince it to change back?

**On a picture-perfect morning, Professor Lorimer Moseley** – a renowned expert and author on the phenomenon of pain – was camped with friends on the Wollondilly River, south of Sydney. Walking barefoot through the scrub, he felt a “sharper prickling” around his ankle. Flicking his foot, he discounted the slight sting as the scratch of a twig, and continued down to the riverbank for his swim. The next thing he remembered was waking up in hospital. Doctors told him he was lucky to be alive – he’d been bitten by an eastern brown snake.

Six months later, Moseley was hiking in a national park near Sydney, and again felt a prickling in his leg – but this time he was soon overwhelmed by waves of agony. A companion called an ambulance, fearing he’d been bitten by a snake again, but when he examined Moseley’s leg more closely he realised he’d just been scratched by a twig. “But the thing is, it really hurt,” Moseley recalls. “I had gone pains for about a week later, just as I had for a week after the real snakebite.”

Moseley’s own misadventures neatly illustrate one of his favourite catchphrases: “Nociception” – the reception of danger signals by the nerves of the body – “is neither sufficient nor necessary for pain”. In other words, it is possible for the body to be harmed and for the brain not to generate pain, and, equally, for the body to be safe but for the brain to launch into agonising panic mode because it has misinterpreted some stimuli as an attack. “The traditional approach to pain,” Moseley says, “has been to say that chronic pain is caused by tissue damage – so to treat it, we need to fix it, cut it out or remove the nerve supply to it.”

“The other [more recent] approach is to say that we know chronic pain is not caused by chronic tissue damage, so we can’t treat it but we can teach people to manage it better. I think both approaches are indefensible on biological grounds. The better approach is to say that pain occurs because the brain is trying to protect body tissue – and then to gradually train the brain to stop trying to protect that body tissue.”

**Christine Dagg**, a 36-year-old retail executive with a penchant for extreme endurance sports, broke her thumb in a mountain biking accident in Africa in 2010. After having it set in a Tanzanian hospital, she and her husband, Wayne, flew straight back to their home town of Sydney, where she had surgery. But after days of intense pain, Dagg’s hand surgeon told her she had developed complex regional pain syndrome, or CRPS – and there were no guarantees that it would ever go away. “At times it felt like needles were being stabbed into my hand; other times, as though my hand was literally on fire – and then moments later, like it had been put in the freezer on raw ice. It was so painful, I genuinely wanted my right thumb to be cut off. I just craved a moment’s reprieve from it.”

In the scale of chronic pain severity, CRPS is about the worst you can get, according to Professor Michael Cousins, head of anaesthetics and pain management at Sydney’s Royal North Shore Hospital. He cites the case in 2008 of a young male sufferer who became so desperate that he convinced his surgeon to amputate his leg in a bid to stop the trauma.

“By the time she saw Moseley, Dagg was desperate. She’d taken extended leave and been forced to suspend her plans to fall pregnant with the couple’s first child because of the possible side-effects of the powerful drugs she was taking to manage her pain. “The medications for the pain were really wiping me out, but not really stopping it,” she says. “I was having pain block injections through my throat, into my spine, nerve stimulation, physiotherapy, weekly sessions with a psychologist. It was a slow, frustrating process with no progress, week after week, just a continuation of the pain.”

But then one day Moseley presented her with a strange contraption, and suggested she give it a try. It seemed odd, partly because it didn’t beep or whir, or involve needles or anaesthesia or a polysyllabic prescription. Instead, this “mirror box” consisted simply of a cheap mirror mounted on a light, folding board, with separate sections on either side, one for Dagg’s healthy arm and one for the afflicted arm. “I’m definitely not the sort of person who is into alternative medicine,” Dagg laughs. “If someone had told me previously about a mirror box, I would have thought, ‘That’s just too weird.’ But I was prepared to try anything by then.”

So Dagg did as she was told, removing all jewellery and putting her hands into the separate compartments. Focusing on the mirror between the compartments, she could see two “healthy” arms – one real, and one reflected – while her painful one remained hidden. “And I’ll never forget the moment I looked into that mirror and saw two ‘normal’ hands,” she says. “The pain instantly disappeared. What’s more, it absolutely felt like my ‘bad’ hand was doing all the things my healthy hand was doing.”

Although doctors and scientists have been experimenting with them for more than a century, there is not yet a consensus on why mirror boxes work when they do. And there’s the rub. For every person like Dagg, for whom “mirror therapy” has an almost miraculous effect, there are many others who do not get any sustained pain relief at all. “There are many case studies reporting fantastic results [but] only a few are undertaking empirical
Moseley says Spratt’s case is a good example of how mirror therapy can be effective in treating chronic pain conditions. "The mirror box, and Lorimer’s books, along with the work I did with the physiotherapist and psychologist at the hospital, all helped me understand why I was in pain – and ultimately, that I just didn’t need to be. It was only my brain ‘causing’ the pain, not physical damage. There was therefore no reason for it to continue."

She cheerfully admits she briefly became ‘addicted’ to her new therapy, prompting her hospital physio to confiscate it at one point. “The reality was, I couldn’t exactly walk around with a mirror box 24 hours a day,” she says, nursing her seven-week-old daughter, Sylvia. “But it was fundamental in giving me the confidence that I could stop the pain signal; that my brain could switch it off. So I just had to keep working [with other brain image therapies] to get it to switch off permanently. And in the meantime, it was great pain relief."

While still in its early stages, the research and clinical practices being developed by Moseley and his peers at Neuroscience Research Australia has attracted the support of the Australian and New Zealand College of Anaesthesists’ Faculty of Pain Medicine. “Lorimer’s work is very important,” says Associate Professor Milton Cohen, dean of the faculty. “It shows that new neural connections within the extraordinarily complex brain are not only associated with the development of chronic pain, but can also become disconnected or reconnected through therapy that alters perception. The brain is central to the experience of pain, but the brain’s plasticity – its ability to make these new connections – can also be harnessed towards alleviating, but not eliminating, pain.”

Moseley’s techniques may not work for every example of chronic pain but they illustrate the role of working “outside the square”. That is, not trying to find and fix a “broken part” but concentrating on the whole person.

Cyclist Amanda Spratt confesses she was sceptical when her Australian Institute of Sport physios invited Moseley to provide an assessment of her debilitating condition. “Lorimer was very engaging but I have to admit at the time I was thinking, how is any of this going to help me get back on my bike and back to the level I was competing at?” Spratt says. “Normally [in rehab] you’re very focused on getting back in the gym, strengthening the part of the body that’s been injured, or back on the bike.”

But Spratt was desperate. After fruitless months in rehabilitation, by early 2009 she’d fallen into a psychological and emotional spiral that Milton Cohen insists is not just a by-product of chronic pain but also a destructive contributing factor to it that must be addressed if the patient is to recover.

Moseley says Spratt’s case is a good example of how the brain can change and eventually become hyper-vigilant in its determination to protect its owner from something deemed dangerous. “The brain is like an orchestra,” he says. “The longer it plays the same tune, the better is gets at playing it and the less stimulation it needs to trigger the tune. In a chronic pain sufferer like Spratt, who has experienced pain for a long time, the

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research on it,” Moseley says.

“The best data on it suggest it is most successful for phantom limb pain... [but] it is not a panacea or magic trick that will solve the complex problem of chronic pain.” Moseley suspects mirror therapy has an impact on what is known as the “virtual body map”, a representation held in the brain of what the physical body “looks” and feels like, which can become conflicted after receiving intense or prolonged stimuli. The person suffering phantom limb pains, for example, may have a brain whose virtual body map still has that severed arm or leg “represented” in a traumatised or cramped position. In the absence of any real stimuli from that region, it may attempt to fill in the messages itself, badly. But conversely, if it receives fresh messages that the limb is healthy and mobile again – through a mirror’s reflection – it may begin to redraw its virtual body map.

“Mirror therapy alone is not really accepted practice,” says Moseley, who uses it instead as one part of a sequential therapy he has developed, called “graded motor imagery”. “But it is quickly gaining fans and scoffers. I think both camps should be open-minded about it. The ability of vision to mess with how the brain perceives our body is well established, so a mirror might be a fabulous tool to tap into that.”

Christine Dagg agrees that mirror therapy, as “magical” as it felt, was really only one part of her recovery from CRPS. “The mirror box, and Lorimer’s books, along with the work I did with the physiotherapist and psychologist at the hospital, all helped me understand why I was in pain – and ultimately, that I just didn’t need to be. It was only my brain ‘causing’ the pain, not physical damage. There was therefore no reason for it to continue.”

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brain can get so good at playing the tune that simply looking at a bike, or at someone else riding a bike, might be enough to trigger pain.

Professor Michael Cousins, head of pain management at Sydney’s Royal North Shore Hospital, agrees. “A lot of people, including a lot of doctors, still don’t recognise the fundamental difference between acute pain – which I like to call ‘good’ pain, because it warns you that you have a problem and need to get help – and chronic pain. As a result, it just isn’t on the radar, or it’s a very low priority for them. Personally, I don’t think proper pain relief should just be the primary focus of every doctor, I think it should be considered a human right.”

After assessing the struggling cyclist, Moseley discounted any physical cause for her pain. “Given where she was, and who she was, I knew she would already have seen the best the world has to offer in terms of physicians, surgeons and sports physiotherapists.” He suspected Spratt’s virtual body map might be askew, and suggested a simple test in which participants are shown slides of hands or feet in different positions and asked to identify whether they are right or left, while being timed on their responses. His hunch proved correct. “I was terrible at it!” Spratt recalls, admitting her results were the worst of the athletes who sat the test. But there was a glimmer of a breakthrough, too. “I could almost always identify the left foot correctly, but almost never the right. It kind of became obvious to me something was happening in my brain, that it was having difficulty recognising my right side.”

And so she began a whole new type of rehab. Drawing on Moseley’s “graded motor imagery” approach, a series of photos were taken of Spratt on her bike, focusing on her limbs. She began working regularly through those images, to retrain her brain to identify which of her legs was pedalling or in a different position.

Meanwhile, the closest she got to actually riding her cherished bike was repeatedly watching a video of herself winning a race, years earlier, while visualising how her body would feel as it went through those motions. “It was hard to let go of actually cycling at first,” she says. “But I understood that, because I’d had the pain for so long, my brain had got used to the idea that riding means having pain, and I had to retrain it to think differently. I still find it hard to explain that to some people now. They just don’t get how watching a video or slides can help you heal. But I have the evidence in front of me that it did work.”

Pain experts say one of their greatest challenges — given today’s obsession with silver-bullet medical cures — is to convince patients to try simple, slow therapies that use the power of the brain, I don’t know what is.”

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World Titles in Holland later in the year — and maybe even a place in the cycling team to represent Australia at the London Olympics. “Cycling is still not pain-free and it may never be pain-free,” she says matter-of-factly. “But nothing out there will hurt me as much as I used to feel. The difference now is, the whole experience has made me much smarter. Knowing what I do now has made me much more confident. And that makes me stronger mentally — and more competitive.”

If there is one thing that now unites pain specialists across Australia it’s that chronic pain should be declared a disease in its own right — and Cousins is leading the push. In 2010 he chaired the National Pain Summit, a meeting of more than 130 medical and healthcare organisations in Canberra, which called on the Federal Government to do just that. “There are anatomical changes we can point to which correlate with the degree of pain,” explains Cousins, “and there are also key psychological and environmental changes. Taken together, these all represent a separate disease entity.”

Recognising chronic pain as a disease in its own right would help liberate sufferers from the round of sometimes pointless medical investigations subsidised by the taxpayer, which are often ordered by doctors who hold to the traditional view that pain is only ever a symptom of a physical problem, says Milton Cohen. He and Cousins argue that instead, Australia urgently needs more pain clinics where sufferers can access an array of health professionals, including psychologists, occupational therapists, physiotherapists, rehabilitation counsellors and social workers. Such clinics have proven highly effective at teaching patients how to manage and reduce chronic pain. Currently, however, there is an average 184-day waiting list to get into a publicly funded service in Australia.

Meanwhile, there may be some exciting treatments on the horizon for blocking pain altogether. Several pharmaceutical companies have begun trials with drugs that inhibit a chemical dubbed “nerve growth factor”, which is believed to encourage the profusion of pain receptors around an injury. Others are experimenting with gene therapy, injecting sufferers with genes responsible for stimulating encephalin, a type of natural opiate produced by the body.

Among the more contentious treatments is the use of ketamine, a powerful anaesthetic and illicit drug being trialled for treatment of CPRS in Australia and overseas, most controversially in Germany, where doctors claim to have cured pain sufferers by putting them into induced comas for several days to “reboot” their brains. That level of drug treatment may be too daunting — or risky — for some, and it fails to persuade Lorimer Moseley, who remains committed to the gentler art of brain wrangling, surrounded by his mirror boxes and artificial limbs.

Patients, Moseley says, surprise him all the time. Like the woman with a 25-year history of debilitating lower back pain who turned up at his clinic a few years ago. He conducted a two-hour examination, explaining that her pain was unlikely to be originating in her back but that her brain was playing a “pain tune” of its own. The following week she arrived for her next session. “She looked like a different person,” he recalls. “And she just announced, ‘Well, my pain’s gone.’”

Moseley allowed himself a moment of smugness: another satisfied customer. But then she continued: “After I came to see you last week, I had an appointment with my sister’s psychic. It took me six months to get in to see her and she was brilliant.”

The patient told Moseley the psychic had discerned things about her that “she couldn’t possibly have known”. And then, as she was walking out the door at the end of the session, the psychic had pulled her aside. “She said, ‘Oh, by the way, there is nothing wrong with your back.’ And it has been fine ever since!” Moseley’s team followed the woman’s progress for the next 13 months; she never regressed, happily reporting that she remained pain-free and active.

Moseley shakes his head in wonder for a moment and I ask if experiences such as this make him doubt his own theoretical framework or practical approach. “Oh no, not at all,” he cries, breaking out of the reverie with customary ebullience. “I mean, if that isn’t evidence of the power of the brain, I don’t know what is.”