

“There is no magic solution to chronic pain. But there is hope”

It is insidious, unbearable and – most frustrating of all for the more than 3.4 million Australians affected by it – often rendered totally invisible. And because of this, there is widespread misunderstanding around chronic pain, which can leave someone like author and TV presenter Tara Moss in regular, ongoing agony that is more excruciating than childbirth. *Body+Soul* finds out what it is really like to live with chronic pain

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Tara Moss has a way with words. In fact, it is her job to be articulate: she is an accomplished author, TV presenter and host, public speaker and UNICEF ambassador, after all. But not long after suffering a hip injury in 2016, she was rendered nearly voiceless, able only to stutter a plea for help to staff in a hospital emergency ward because she was in so much pain. In the five years since, she tells *Body+Soul*, the searing aches, burns and throbs have frequently “whooped my arse”.

The initial nerve pain that niggled at Moss ultimately developed into something far more nefarious: complex regional pain syndrome (CRPS) is a condition in which the immune system malfunctions as it responds to tissue damage from trauma. The nerves misfire, sending constant pain signals to the brain. The agony is so intense that it is measured as one of the most severe on the McGill Pain Index – even putting it above the pain experienced in labour, or from having a digit amputated.

CRPS is itself classified as a rare disorder, but advocacy group PainAustralia says statistics show that more than 3.4 million Australians are living with chronic pain from various causes, such as injury, surgery, migraine, arthritis or conditions like the one Moss has. Yet because this kind of pain is invisible, the impact it has on sufferers is not widely acknowledged or understood. It is this



lack of understanding, even from within the healthcare system, that can leave sufferers feeling terrified and alone.

Professor Lorimer Moseley, a pain scientist from the University of South Australia, explains why such knowledge gaps exist. “Many people, including health professionals who don’t have an evolved understanding of pain, might look at an X-ray, for example, and say, ‘There’s nothing wrong here now, your injury has healed.’ [They’ll] assume you can’t really be in pain and just need to get on with it.” But if you’re enduring the pain on an ongoing, 24/7 basis, Moseley says, “You just can’t fight against your own mind. You have to retrain it.”

Modern pain theory advocates shifting the focus from needing to find the cure – the scan or blood test that will finally show the tissue injury that must be causing the pain and hopefully lead to its repair – to acknowledging that the brain is producing stronger and stronger pain from smaller and smaller stimuli. When it comes to chronic pain, explains Moseley, “The problem shifts from one of tissue injury, to pain – our protector – over-protecting the tissue.”

Moss admits that taming her pain is a full-time job that requires a multi-pronged approach. “I eat well, I don’t drink or smoke. I have pills I take daily and other medications I can take in emergencies. I access medical interventions, including botox for spasming muscles, and have

BY THE NUMBERS

Chronic pain is defined as daily pain that lasts longer than three months and occurs for a variety of reasons – be it an injury, surgery, arthritis or medical conditions such as endometriosis or migraine. It can also be a condition in its own right.

3.4 million Australians are affected by chronic pain

In an average year, Australians pay \$2.7 billion in out-of-pocket costs to manage their chronic pain

68% of people living with chronic pain are of working age

Of those who experience chronic pain, 43% have lived with the condition for more than five years

45% of people living with chronic pain also experience depression or anxiety

40% of early retirement is due to chronic pain

Australians who live in rural and remote areas are more likely to have chronic pain than those in major cities

People who live outside urban areas are 23% more likely to experience back pain

See painaustria.org.au for more information.



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ketamine infusions on ward in hospital. When the pain is lower on the scale, I meditate and try to practise my breathing, just like I did when I gave birth.”

Because weight-bearing is a major trigger for her, Moss has also embraced mobility aids, such as her cane (affectionately nicknamed Wolfie), a walker and a wheelchair.

Given her relationship with pain is so all-consuming, it is easy to wonder how it also impacts those closest to her. Moss tells *Body+Soul* she used to feel distressed by the fact her daughter

Sapphira, 10 (pictured left with Tara), would see her suffering so often. “As a mother, I believed it was my job to protect her,” she explains. But rather than the visibility of her vulnerability scarring her daughter, Moss now believes it developed a stronger sense of compassion in Sapphira. “Even at five years old, she’d bring me water and pat my arm soothingly. And now if she sees other kids fall over, she won’t say, ‘Get up, you’re fine!’ She’ll sit down next to them and ask if they’re OK, and if there’s anything she can do to help. Sapphira

has become sensitive to the reality that people experience pain.”

Face-to-face connections with friends can, however, be challenging. Moss explains, “By not making our public spaces accessible for everyone, we never get to see people living with pain or disability because – guess what? – they can’t leave their houses.” Pain flare-ups can also be unpredictable. “You might make plans and then have to say I’m sorry, but I can’t manage this today.”

The social isolation many people living with chronic pain experience matters – not only for their mental fitness and personal wellbeing, but also owing to the levels of pain they experience. Whether it’s loneliness, a relationship breakdown, not getting enough sleep, poor nutrition or past trauma, most people will understand that all these things can take a toll. Says Moseley, “But what we are yet to grasp is that those things may also make your pain

4 ways to support somebody living with CHRONIC PAIN

- 1 **Validate what they are feeling.** Just because you can’t see it, doesn’t mean the pain isn’t real.
- 2 **Get educated.** Not just about pain science, but about grief. The person experiencing pain may be mourning the loss of their old life.
- 3 **You can’t fix the pain, but you can minimise the suffering.** Staying socially connected to sufferers can help dial down their pain (when we are with people we love, endorphins are released).
- 4 **Keep them in the driver’s seat.** Listen to their frustrations and help them understand how to navigate healthcare systems and medication regimens, but avoid taking over, as this can be disempowering.

Tips by clinical psychologist Lynita Clark, who specialises in supporting patients living with chronic pain.

become bigger, more bothersome and more intense, too.” Still, he adds, “We are adaptable organisms. There is no magic-pill solution to chronic pain, and the journey will require patience, persistence, courage and a good coach. But there is scientifically based hope.”

It is one that Moss continues to cling on to. “I’ve come to learn that chronic pain is really neuroplasticity – brain changes – gone wrong. Now I want to use the brain’s adaptability to work in my favour, and retrain it not to be so loud and vocal about my pain.”

“The stigma associated with chronic pain is as debilitating as the daily struggle with pain.”
Read one woman’s story at

BODY+soul.com.au