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## The millions of Australians living in pain deserve better than corporate fearmongering

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MEMBERS OPINION SPECIALISTS







The 4 Corners fallout continues: the PHA and the ABC failed to give a balanced view of spinal cord stimulators and the relief they provide, says the CEO of Painaustralia.

ne of the greatest injustices of modern health discourse is that, of the one in five Australians over 25 living with chronic pain, very few are given a safe environment in which to discuss their condition.

Our society is loaded with judgement, they are told they are exaggerating, making their pain up, that their migraines are just headaches, that the stabbing pain of endometriosis day in and day out is simply "women's pain" and something they have to get used to.

They are told that it's just life, and worst of all there is a nasty streak in society that paints them as drug chasers and attention seekers, people who have improper motives for simply wanting care.

There is broad agreement that in treating chronic pain, the least invasive is the best. Multidisciplinary pain management, the gold standard for chronic pain management is not simple but, in most cases, provides significant relief and can actually see some people's pain resolve.

This includes the support of a physician (GP or specialist), psychological therapies, physiotherapy and movement-based care, pacing (pushing the body to do more just the right amount so that there is strengthening but not making the problem worse) and the best pharmacology (tablets, injections, medicine infusions etc.) for the individual.

For the vast majority of consumers, this is of huge help and makes life liveable. People can often recover with physical maintenance to the point of living well despite physical pain.

However, there is a cohort for whom non-invasive treatments do not resolve things, like mum and former fitness instructor Amanda who, in 2018 at the age of 38, had multiple vertebral fractures after a fall.

She is not exaggerating. Amanda spent months in severe pain, unable to do the basics, often unable to walk. It is hard for healthy people to imagine what it is like not to be able to crawl to the bathroom or to keep up in any way with your kids.

This was Amanda's reality, and she faced the genuine possibility of having to live out her days in a nursing home, with her husband raising their kids alone.

Amanda said that when her spinal cord stimulator was turned on for the first time it was like "someone had pulled the plug out of the bottom of the bath, the pressure and pain disappeared".

Stories like Amanda's are not uncommon; people living through the fear of not being believed about their daily pain, who through appropriate treatment find a pathway to improved health.

However, the picture painted by our national broadcaster recently was very different indeed.

On 8 April, an interview with Dr Rachel David, the CEO of Private Healthcare Australia (PHA), the peak lobbying body for Australian private health insurers, was aired as part of an episode on the ABC program 4 Corners.

That episode and media stories that have followed have displayed a surprising lack of balance and a deeply disappointing unwillingness to appropriately investigate the data and claims put forward by PHA, and the agenda behind it.

Off the back of this program, the health insurance industry was asking for devices to be recalled, claiming that spinal cord stimulators (SCS), some 40 years in the making, are of no value.

To say that to the thousands of Australians; mums, veterans and everyday people who have an implanted spinal cord stimulator that makes the invisible burden of unending, severe and persistent pain they live with bearable, is an insult to their lived experience.

In the vast majority of users these devices make their lives liveable, and importantly they can be trialled before a permanent implant procedure to give the best chance of success.

The claim of a high prevalence of people heading back into surgery after an SCS implant shows a deep and fundamental misunderstanding of the procedure itself, which is deeply unbecoming of the peak lobbying body for private insurers.

What they appear to have chosen not to say, and what the ABC failed to challenge them on, is that many surgeries are to fix lead or device placement when a person has lost weight, or their device has been moved by exercise, tasks which were near impossible for someone living with severe, chronic pain.

They make the case that every revision in surgery equals failure. If this was the case, then every pacemaker that has ever required surgical adjustment would be considered a failure, which is far from the truth.



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In addition, spinal cord stimulators, as with many medical devices require surgical update, with batteries needing replacement periodically, and pain conditions are highly complex and hard to treat. Comparing this device to a hip replacement, as the PHA has sought to do, is disingenuous and irresponsible.

While it may be cheaper for insurance companies to hope for a "set and forget" model of surgical procedures, we need to live in the real world.

Sadly, the media coverage has not featured stories like Amanda's, or any of the thousands of people who depend on these devices every day and that I see in my role.

The stories featured in media coverage that have shown some of the worst consequences when things have gone wrong are tragic and support the need for continued investment in research, and an acceleration of the planned device registry which would help to protect patients.

To be clear, no one in the pain sector is advocating for SCS devices to be used as a first-line treatment or to be implanted into those who can benefit from other treatments. Everyone with chronic pain needs access to multidisciplinary pain management to ensure the best possible outcomes.

Some will go into remission from pain. But for the few cases for whom this is not sufficient, then SCS is an option that we need to continue to provide, regulate and ensure patients have access to.

I hope that in 50 years we will look back with relief, remembering this as the time when we did not have a perfect answer to chronic pain, but when we fought hard for advancements in therapy, and did not treat effective medical interventions as an annoyance on corporate balance sheets. For now, we need to ensure that we don't condemn those suffering to having no treatment options, that would be a step back to the dark ages.

Amid unfortunate exaggeration and insurance companies' self-interest, it is the 3.4 million Australians living with chronic pain conditions who have the most to lose.

Giulia Jones is the CEO of Painaustralia and former ACT Shadow Health Minister.