

# When pain persists ..

How can you cope when you know your waking hours will be filled with suffering, asks **Linda McSweeney**.

**P**ain, by definition, is a "highly unpleasant physical sensation". It can range from annoying (think ice-cream headache) to seriously distracting (bad toothache, period pain) to excruciating - (childbirth, passing a kidney stone). One thing that helps people cope with pain is the knowledge "this, too, shall pass" - that the sensation will end eventually. But one in five Australians - including children - live in chronic pain. And many of them face spending the rest of their lives in distress.

Chronic pain is classified by doctors as daily pain that lasts beyond three months. It stems from any number of ailments and injuries, with 500 chronic pain conditions listed by the International Association of the Study of Pain.

Its effects are drastic. Chronic pain can cause people to lose their jobs, their families, and even take their lives.

Australians participating in a National Drug and Alcohol Centre study into long-term use of the pharmaceutical pain relievers known as opioids report having one or more painful conditions, while prescriptions for the drug oxycodone prescriptions rose by 152 per cent between 2002 and 2008.

Australia led the world in developing, in 2010, a national framework to treat and manage pain - the National Pain Strategy - but pain is still the third most costly health problem, behind cardiovascular disease and cancer.

The economic cost of chronic pain is \$34 billion, according to Pain Australia, a non-profit organisation trying to transform the way pain is managed. There are 20 million lost workdays per year as a result of chronic pain.

"That's a very big cost to the economy but there's also an incredible amount of human suffering and it's just not recognised that this is going on," says Professor of Pain Medicine at the University of Sydney, Michael Cousins, who is also a clinician at Royal North Shore Hospital and is on the boards of Pain Australia and the Pain

Management Research Institute. "People with chronic pain tend to suffer silently because they get the message other people don't want to hear about it. They might listen once but the second time, no it's too boring. They are relentlessly losing their lives - some of them do commit suicide because they become desperate that they're losing all of their life activities while others just keep going in some sort of suspended animation.

"I see these people every day and it's absolutely, I don't know how to describe it, it's appalling."

Pain management should be a national healthcare priority and government and the community need to realise chronic pain management is an ethical issue that warrants urgent attention and funding for research, medication and access to



High price to pay: Chronic pain exacts a high toll on sufferers and the economy.





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treatment for physical and mental symptoms, Professor Cousins says.

Leader of the opioid use study, University of NSW Professor Louisa Degenhardt, says more than 40 per cent of patients in her study are unemployed and many have depression and psychological distress from ongoing pain. "Many of the stories that we're being told are just really, really awful stories of a lot of pain and a lot of unhappiness."

Former film editor Vidyamala Burch says

she spent a decade in denial of the pain she endured from two spinal injuries as a teenager and young adult before coming to the realisation there was no medical miracle to transform her life.

Alone, in agony and struggling to sit up in an intensive care bed in hospital at the age of 25, the now 54-year-old remembers feeling dreadfully alone and "feeling I was going mad", wondering how she'd get through the night before choosing to bear the pain one moment at a time.

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Burch now uses mindfulness meditation in tandem with medication for her pain and has reached a point where her life is flourishing.

"I was taught meditation when I was in hospital. I realised that my mind was a tool and I could train my mind to help me manage my body."

Burch has written a book - *Mindfulness for Health* - to inspire others in the throes of chronic pain. "I don't want anyone else to have to go through that kind of loneliness," Burch says.

A new wave of physiotherapy is also offering some hope for people whose ailments may have been misdiagnosed.

Physiotherapist Kusal Goonewardena, who provides physiotherapy to elite athletes at Melbourne University, says there has been a paradigm shift in treating chronic pain by looking at where the pain is coming from, investigating referred pain and trying to resolve problems more quickly.

"Most of these sufferers are, say for example, experiencing chronic back pain and everyone thinks 'Oh I've got a bad back' but in reality the problem is coming from somewhere else," Goonewardena says.

"It is a little bit more instantaneous. I personally had a bad shoulder for nearly nine years and I was getting treatment by top physios... but ultimately I wasn't getting a result. Using this new way of looking at a problem [called the Ridgway method] and looking at the root cause of the issue, I ended up with a result in a matter of two weeks."

"When it comes to things like chronic pain, you should never, ever give up. We've got some wonderful experts in Australia on pain itself."

Harry Katsiabianis, managing director of Taxi Link, says he had pain in his leg for years before seeking physiotherapy when he thought he had torn a calf muscle. Treatment revealed the pain was referred pain from a back problem which was promptly treated by the physiotherapist.

"I had pain in the area for a long time and it turned out it was because of my back. I was able to go for a jog with my son that night (after treatment)," Katsiabianis says.

## Don't ask me how I am

When it comes to chronic pain, most people are sympathetic up to a point. Then, well, they just want you to get on with it, writes Danny Hassall.

**C**hronic pain is contagious. I don't mean I can somehow transmit the ache of my mangled hand to another person, but I can't help but notice a look of suffering cross their face if I chance to mention it.

That's why we are gathered here at the QEII Rehabilitation centre at Sydney's Royal Prince Alfred Hospital on this blustery warm day. We are rehearsing how to respond when people ask us how we are. We've come for a three-week intensive pain management course which includes psychotherapy, physiotherapy, mindfulness training and meditation. My fellow participants include Jim\*, a sound engineer with acute RSI; Sarah, a hairdresser whose work has led to painful frozen shoulders, and Poppy, an HR manager with crippling migraines. I'm a mechanic who broke his hand at work. A long series of issues has led to chronic regional pain syndrome and a severe weakness in the affected hand. Not good if you change tyres and heave engine parts around for a living.

One of the most powerful things we've learned at the course is the difference between chronic and acute pain. When someone suffers a heart attack or are injured in a car accident, people rush to help. Friends, family, health professionals - they're all buzzing around working to fix the problem. It's empowering. You feel motivated and supported.

Chronic pain is different. Instead of being the subject of concern and empathy, it can make you something of a disappointment to all those who may have clustered around you at the beginning. You have "failed" to get better. And, frankly, this is a bit of a downer for everyone. Which brings us back to "how are you?"

Amy, a clinical psychologist, asks us to express how we feel when people ask that simple question. Sarah answers from the side of the room where she is bent over, leaning on a cushion. "It's a trigger for the pain," she says. "You can be doing your best to focus on other things and then that question brings you right back to the pain."

The best response is to ask a question back or to let your loved ones know a simple "what are you up to?" might be better.

Amy asks us to pick up a sheet of paper and hold it in front of our face.

"This is how you see the pain now. It's obscuring everything. You can't see beyond it." She has us hold our papers out at arms length so they partly obscure our

vision. Next, we place them on the table. This is what we're aiming for during this course, she reminds us. Distancing the pain from the way we live our lives while at the same time quietly acknowledging that it's there. Each of us came in here with pain obscuring every aspect of the way we saw our lives. Not only pain, but the depression and anxiety that come with the thought "what if this never gets better?"

What we are learning is to see beyond the pain but not let it consume us.

Someone's timer goes off.

This happens every five or

10 minutes, reminding

one of us to do our

stretches or have

a break from

sitting or

standing. All

of us have

run the

twin

gauntlet

of either

protecting

our

injuries too

much

(which will

hamper

improvement)

and overdoing it

(which will lead to

increased pain - which in

turn will probably lead to

that over-protective thing again.) The trick is to navigate between these two potential shipwrecks and find a medium where we challenge our abilities but don't end up worse than we started. Later, we'll troop off to the gym for more intensive therapy.

Next, it's physiotherapist Graeme, who explains not only how pain works physiologically, but how it works psychologically. One of the most valuable things I have learned on the course is to separate the ideas of "pain" and "suffering". Pain is simply that thing that your nerves, synapses and brain do. It's pretty unpleasant, but it's necessary for our survival. And there are ways of ignoring it, as Graeme says, like noise from an annoying neighbour.

Suffering, on the other hand, is all the stuff that you let pain do to you. The feelings of panic, depression and hopelessness, the damage it can do to your relationships. The mindfulness training part of the course helps reduce the suffering part of the equation. You learn to view the pain as just another feeling. Not something terrifying or threatening, but an aspect of life like any other.

At the beginning of the course, Graeme filmed us walking. The startling thing for all of us was the protective, hunched way we moved, as if bowed down by the burden of our pain. Now, as the course is finishing, we are filmed once again and the increased physical confidence we display is marked. Our pain may be there but it's not the boss any more. And we have the tools and the determination to keep it that way.

\*Participants names have been changed

