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Living with chronic pain

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FROM SATURDAY'S GLOBE AND MAIL

The only time Michael DeGroote isn't in severe pain is when he is sleeping, or sitting perfectly still.

Since the wealthy philanthropist suffered a stroke five years ago, the slightest movement triggers a burning, stabbing pain on the left side of his body. Even the touch of clothing against his skin is painful.

Nothing has helped, not the 17 different medications or combinations of drugs, not hypnosis or acupuncture. His stroke damaged a part of the brain called the thalamus, a central processing site for pain, and he endured two operations in Belgium that required opening his skull to place electrodes on top of his brain. They didn't work.

Mr. DeGroote is one of an estimated five million Canadians who suffer from chronic pain, but, unlike most people, he faces no financial obstacles in seeking help. The former owner of the Hamilton Tiger-Cats and the waste-management company Laidlaw has sought out experts around North America and Europe without finding relief.

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Canadian businessman and philanthropist Michael DeGroote has suffered from chronic pain since he had a stroke five years ago and describes the feeling like living in hell. *(Deborah Baic/The Globe and Mail)*

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Hope, he has come to believe, lies in laboratories around the world, in scientists struggling to understand the biology of pain and figure out new ways to subdue it.

He is doing his part, giving $20-million to McMaster University in Hamilton to establish the Michael G. DeGroote Institute for Pain Research and Care, which seeks to find new ways to treat and manage chronic pain. The institute was one of the sponsors of a conference in Toronto this spring that brought together some of the world's top pain researchers.

Mr. DeGroote's opening address was an impassioned plea.

"To have constant, horrible pain is ..... like living in hell — in all the ways described by old-time preachers," he told the scientists.

"This is my challenge to you. Solve this agony. Find the treatments. Find the cures. I know it can be done. Fellow sufferers and their families will thank you."

For years, chronic pain was neglected by both doctors and researchers, who regarded it as a symptom of other diseases, such as arthritis.

But the past decade has seen an exponential increase in pain research, and scientists have compiled compelling evidence that chronic pain is a disease on its own, one that involves dramatic changes to the central nervous system. They are slowly gaining an understanding of what goes wrong, and an appreciation for how social and psychological factors can influence pain.

Some are looking at novel ways to reverse the changes caused by chronic pain, or zeroing in on genes which determine why some of us suffer more intensely than others. Others are charting how our natural painkilling systems work, and investigating how conscious thoughts might be used to turn them on.

All that is the good news. The bad news is that, so far at least, the new understanding of the biology of pain has not led to many new treatments. Patients are left struggling to find relief, and studies show that, among sufferers, 15 to 29 per cent have severe pain like Mr. DeGroote.

One problem is that general practitioners undergo almost no training in treating pain. The luckiest patients get into pain-management clinics without waiting months or years, and are seen by specialists who offer multiple treatments: medication, tailored exercise programs, physiotherapy, alternatives such as acupuncture and massage, and help with difficulties their pain has caused in their personal lives. Many find that even the finest care makes the pain at best bearable — it doesn't make it disappear.

But there is hope in what scientists have learned about how pain works.

Suppose you touch a hot burner on a stove. Immediately, peripheral nerves in your hands send a message to a part of the spinal cord known as the dorsal horn. In turn, the dorsal horn sends the message up to the brain, which reacts, and you instantly withdraw your hand. Pain is how your body protects and repairs itself — you tend not to use a scorched finger until it is healed.

The body also has its own natural painkilling system. It produces its own opioids and cannaboids — similar to the active ingredients in morphine and marijuana, respectively — as well as other chemicals, known as neurotransmitters, that are involved in regulating pain.

In healthy people, studies have shown that these systems are remarkably effective. When volunteers plunge their hands into icy or hot water, the system gets activated, so that when they repeat the experience a few minutes later, they find it hurts up to 40 per cent less.

So what goes wrong with chronic pain? Many researchers now believe that chronic pain rewires the central nervous system, dramatically altering it. There is no threat to the body, no hot stove burning the skin, but the peripheral nerves are still frantically firing off pain messages to the spinal cord. The body's alarm system is broken.

"The nerve can get stuck in the 'on' position," says Mary Lynch, a physician and researcher at a pain-management clinic at the Queen Elizabeth II Health Sciences Centre in Halifax.

That wiring problem can lower the pain threshold, so that water feels scalding instead of warm. To make matters worse, there is evidence that people with chronic pain don't have the natural pain control that can help mute acute sensations after, say, a real scalding.

There is no proof, however, that the systems that kick in when you bang your shin are the same ones that go haywire in chronic pain. But studies have found that healthy people who are more sensitive to pain than normal are more likely to develop chronic pain later in life, says Jeffrey Mogil, a researcher at McGill University in Montreal. Translation: The same mechanisms may indeed be involved.

So why do some patients, like Mr. DeGroote, develop chronic pain while others don't? The answer may be in their genes, says Dr. Mogil, considered one of the world's leading experts on the genetics of pain.

One kind of gene, he says, likely makes people susceptible to diseases that can lead to chronic pain, such as arthritis. Another type probably helps determine how much they will suffer.

"There are any number of sufferers of osteoarthritis who have terrible degeneration of their hands and claim not to be in any pain at all," he says. Other patients complain bitterly of pain, but there is no evidence their condition has deteriorated, he says.

Dr. Mogil wants to know why, and he is hunting for genes that make some people or animals more susceptible to pain than others. There appear to be different genes involved in different kinds of pain, he says, like tenderness to touch, or sensitivity to hot and cold. So far, scientists have found 200 genes linked to pain in mice, but that is little more than a good start, since Dr. Mogil believes there are probably thousands of them.

Our emotional response to pain also may have a genetic component. This week, John-Kar Zubieta at the University of Michigan announced that dopamine, a brain chemical that plays a role in pleasure, is also involved in pain. The more distress and fear reported by volunteers when a large needle was inserted into their jaws, the more dopamine their brains produced in parts of the brain involved in the emotional component of pain. He is now investigating whether people who produced a lot of dopamine have different genes than those who didn't.

Other researchers, such as Michael Salter at the University of Toronto, are studying chronic pain in mice, looking for physical signs of damage that would explain their suffering. He focuses on neuropathic pain, the sharp pain that results from nerve injuries.

He has found significant changes to so-called glial cells, which for years were seen as little more than the glue that helped hold the nervous system together. But glial cells help nerve cells communicate with each other. Dr. Salter and his colleagues have found that the glial cells in mice with chronic pain produce a number of substances that make their nerves behave in a hyper-excited fashion.

Compounds that could interfere with this process might provide relief from chronic pain, says Dr. Salter, who is director of the U of T's Centre for the Study of Pain. He and his colleagues have found a few things that work in mice; if they work in humans, there would be a huge demand for them, he says.

"For chronic pain, especially something called chronic neuropathic pain, there are some therapies out there, and most of them don't work very well," he says. "That is really the greatest challenge, and the greatest unmet medical need."

Scientists have known for years that brains can be tricked into controlling pain. Soldiers in battle or athletes in the middle of an important game or performance will continue despite serious injuries — their brains somehow override pain that would have them rolling on the ground in other circumstances.

The placebo effect is particularly strong in pain control. Tell patients they are getting a potent painkiller, and they will probably report less pain, even if they are getting a mild one, or a sugar pill.

A recent brain-imaging study by Dr. Zubieta at the University of Michigan showed how this may work. He injected a saltwater solution into the jaws of 14

men, which causes sustained pain. He gave them a placebo and told them it would offer them some relief. He found that parts of their brains that release natural opioids became active; in other words, the idea that they were getting painkillers caused their brains to produce real ones.

A number of techniques, including hypnosis, meditation, distraction and imagining pleasant or relaxing scenes, aim to harness the power of the brain to help control pain, and are now used at many pain-management clinics.

At Stanford University in California, Sean Mackey of the neuroimaging and pain lab has done an experiment that shows patients with chronic pain can use conscious thoughts to regulate pain. Volunteers were asked to lay on their backs in a functional magnetic resonance imager that produces pictures of their brains at work. On a computer screen, they watched the activity of a small patch in the middle front of the brain that plays a crucial role in the perception and emotional processing of pain.

The subjects were asked to try to use thoughts or ideas to control the activity in this part of their brains, which was represented on a computer screen as the image of a fire. One patient dampened the flames by thinking of snowflakes cooling her burning pain, or little people digging out the pain in her back.

Dr. Mackey found that by training their brains, patients with chronic pain can, in the short term, reduce their pain by 64 per cent. He is now following patients for a longer period, six months.

In Montreal, Dr. Mogil is studying the social context of pain. German researcher Herta Flor found that people suffering from back pain who have a solicitous spouse are more sensitive to pain; those with a partner who tries to distract them are less sensitive.

Social settings can also influence pain in mice. Even living with a group of mice in pain made healthy rodents more sensitive to pain themselves, Dr. Mogil found. He is now trying to get at the neurochemistry of sharing someone else's pain, to discover the genes and proteins that may be involved.

For all the progress scientists are making in understanding chronic pain, they haven't come up with any drugs to help millions of sufferers.

"The best drugs work in about a third of people," Dr. Mogil says. "The dirty little secret about pain research is that for all our new knowledge, ultimately, the only new thing in the clinic in the last hundred years are the anti-epileptics." It was only by accident that doctors found that drugs that reduced seizures in people with epilepsy also helped to control chronic pain, he says.

"Other than that," he says, "it is ever more clever preparations of willow bark and poppy."

Modern-day Aspirin is the synthetic version of a compound found in the bark of the white willow tree. There is evidence Hippocrates used it to treat pain, and the first mention in the medical literature dates back to 1763. Poppies provide opioids such as morphine, which was first isolated in 1804 and remains a staple in modern medicine.

But some colleagues say Dr. Mogil is being a little harsh, and note there are a few new therapies. A toxin from a poisonous snail is now being used to treat cancer pain. But it needs to be administered through a spinal tap, and is usually employed only for terminal patients.

The growing understanding about the physiology of pain, and the psychological and social factors that affect it, have led to multidisciplinary units such as the Wasser Pain Management Centre at Mount Sinai Hospital in Toronto and the pain clinic at the Queen Elizabeth II Health Sciences Centre in Halifax.

Pain specialists at these kinds of clinics make sure every combination of drugs that might work has been tried. They can also offer pain-relieving procedures, such as nerve blocks, in which numbing medications are injected near nerves.

Patients also have access to alternative or complementary treatments, such as acupuncture, and are offered new ways to mentally manage their pain. They are encouraged to make lifestyle changes — losing weight, starting to exercise — that might help.

But the waiting lists are long, from six months to five years. And Dr. Lynch, at the Halifax clinic, says patients rarely find a cure for their pain, just help either reducing it or learning to live with it.

Philip Peng, a Toronto anesthesiologist who studied to become a pain specialist after his sister developed cancer, says there is no quick fix. "The objective," he says, "is to get them back to a reasonable life from no life."

Mr. DeGroote says he has tried everything. Now 73, he lives with a full-time nurse in Bermuda, but is no longer able to enjoy long walks on the beach or his weekly tennis games. He visits Canada to see his doctors, and to spend time with his children and grandchildren.

But mostly he tries to move as little as possible, and to watch as many movies as he can. "I forget the pain when I'm watching a good movie," he says.

From 5 to 8 per cent of stroke patients develop similar, excruciating pain, usually two to three months to a year after their stroke. But only a third have direct damage to the thalamus like Mr. DeGroote.

His physician, Akbar Panju, has begun a study of stroke patients, trying to figure out why some develop what is known as central post-stroke pain and others don't. Researchers at the pain institute named for Mr. DeGroote are working on ways to study the condition in mice. Their benefactor is hoping they come up with something soon.

He is considering undergoing an operation that would involve putting electrodes directly into his brain. The procedure has helped patients suffering from Parkinson's disease and depression, and some suffering from chronic pain. In June, Mr. DeGroote wasn't ready to take the risk. He says he would have a 5-per-cent chance of dying, and doesn't like the idea of having to be awake during the surgery. But now he is more open to the idea.

Before his stroke, at the end of every summer, he would bet his grandchildren that he would water-ski at their cottage the next year, and he always won. He's hoping to win that bet again some day.

"I keep my spirits up," he says, "and I feel I'm going to beat this thing somehow."

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