

'I live this life in pain'

Canadians with chronic pain struggling to find help, hope.



Lous Heshusius does exercise to relieve pain after waking from sleep in Sooke, B.C. July 27, 2011. Heshusius has suffered from chronic pain since surviving a near fatal car crash in 1996.

Sometimes, when the pain drugs don't reach her, Lous Heshusius lies on the floor as still as a corpse. "Please," she'll whisper to herself, "Please, let it pass."

She says there have been moments when she's imagined taking a knife and cutting through the muscles and tissues in her shoulder and neck, just to ease the unbearable tightness.

It has been 15 years since the car crash that nearly killed her. Fifteen years and more than 30,000 hours of pain — stabbing, burning pain so intense at times she cannot think or speak. The kind of pain that paralyzes, says the woman from Sooke, B.C. "It's like going into another world."

She has no memory of the impact, no memory of being broadsided by a car travelling 90 kilometres an hour as she pulled away from a stop sign on a country road north of Toronto in September of 1996. No memory of her car being rammed across the intersection and flipping into a ditch.

When police found her unconscious and slumped in the mangled front seat, her face bloodied from the shattered glass of the windshield she hit when her seat belt came undone, they thought she was dead.



Doctors at the hospital told her the force of the impact was so intense that her neck could have been broken; death could have been instant.

"Such a painless journey it would have been," Heshusius wrote in her published memoir of a life lived in pain.

"Straight to paradise."

Instead, the accident sent Heshusius into a world she could not have prepared for, a state experienced by millions of Canadians every day — one of unrelenting, incapacitating and life-altering pain.

One in five Canadians — roughly six million people — is living with chronic pain of some kind, sometimes as a result of trauma or illness, and sometimes for no obvious reason at all. Over the next two decades, that figure is expected to grow to one in three as the population ages. Aging brings pain, from arthritis, from complications of diabetes, from stroke and heart disease.

Cardiac surgery, surgery for breast cancer, caesarean sections, hip replacements and even gallbladder removal and hernia repairs — all can cause persistent pain. Depending on the operation and how it's performed, 10 to 50 per cent of patients will be left with burning, electric-shock-like pain, sometimes years after incisions heal. Thoracotomies — where the chest is cut and the ribs pried open to gain access to the heart and lungs — carry one of the greatest risks.

While modern medicine can help people survive serious illness, sometimes it's at the cost of great pain. Nerve damage from some chemotherapy drugs can lead to one of the most profound pain conditions known — chemotherapy-induced peripheral neuropathy, a condition that can cause numbness, tingling and pain that starts in the hands and feet and can slowly creep up the arms and legs. Doctors have no way to predict who will get it.

All in all, chronic pain — back pain, head pain, neck pain, abdominal pain, joint pain, pelvic pain, pain from fibromyalgia, pain from irritable bowel syndrome and any pain that persists beyond six months or the "normal" recovery time — costs Canada an estimated \$6 billion a year in direct health-care costs, as well as an estimated \$37 billion a year in lost productivity. That's more than cancer, heart disease and HIV combined.

Yet chronic pain is one of the most invisible, under-treated and disbelieved afflictions in Canada — a country that is, ironically, home to some of the world's leaders in pain research.

Pain is virtually ignored in discussions about health reform. Wait times for treatment at publicly funded pain clinics in Canada average one to three years. The chronic pain clinic at Vancouver's St. Paul's Hospital has a 3 1/2-year wait list of about 1,300 patients. In Calgary and Ottawa, the wait time to see a



pain doctor can be a year or longer. At the Alan Edwards Pain Management Unit at the Montreal General Hospital, the waiting list is 700 names long.

For children in pain, the situation is equally bleak: Only a handful of centres with specialized pain programs for children and adolescents exist in Canada. Most don't run anywhere close to full time.

Doctors who treat patients living in pain say that any wait for care beyond six months is medically unacceptable, because early intervention can keep lives from turning into train wrecks. Uncontrolled pain can cost people their jobs, careers, homes, marriages, friends and sense of identity. People, including young mothers — and the burden of pain is greater for women than for men — lose the ability to take care of their families. Constant severe pain deadens personalities. Looking in the mirror, Heshusius said she sometimes hardly recognizes herself. "Who is she?" she wonders.

Pain is demoralizing and isolating. It can destroy people financially. People unable to work lose their benefits; they lose fights with insurance companies and workers' compensation.

The instinct is to retreat, to curl up and wait for the torment to stop. People living with chronic pain are twice as likely to suffer major depression as people living without pain.

They are also twice as likely to kill themselves.

Yet despite the burden of suffering, pain is poorly treated in Canada. Sometimes it is not treated at all.

"You can do a lot with what's available now, but most people don't get it," says Dr. Catherine Bushnell, Canada Research Chair in clinical pain and president of the Canadian Pain Society.

Experts blame the meagre training health professionals receive on assessing and managing pain (a survey of 10 major Canadian universities found that veterinary medicine students receive, on average, 87 hours of mandatory training in pain, versus 16 hours, on average, for medical students); inadequate funding for research (just one-quarter of one per cent of all federal dollars for health research in Canada go to pain); a health system that doesn't compensate doctors for the time it takes to provide meaningful pain care ("we take up too much time," pain patients say over and over again), stigmatization and attitudes toward people with pain and a strong reluctance to prescribe opioids for chronic non-cancer pain.

So patients struggle to find doctors to help them, leaving the burden of care to fall on over-stretched pain clinics and the small number of community doctors willing to help. People with pain describe being treated like street addicts when they land in emergency rooms in a pain attack so severe they can barely put one foot in front of the other.



Chronic pain patients, "are often given the message, 'you're imagining it. It can't be that bad. You need to get over it. There's nothing we can do'," says Dr. Mark Ware, director of clinical research at the Alan Edwards Pain Management Unit.

"These kinds of things stick in a patient's mind. They are horrible things to hear when you're facing a long-term diagnosis of a chronic pain syndrome."

The problem is that pain is invisible. There's no blood test to measure it. People look normal, and when there's no broken bone or tumour, no slipped disc or joint arthritis, no "organic" problem or obvious "pathology," the tendency is to dismiss it, to label people as fakers or malingerers, to accuse them of seeking "secondary gains" such as disability benefits or insurance compensation.

News stories about people who "cheat" the system; the little tolerance society has for people who complain of pain — all play into the idea that chronic pain "is a bit of a muse," says Dean Tripp, associate professor of psychology, anesthesiology and urology at Queen's University in Kingston, Ont.

Research shows just how misguided that thinking is.

Pain kills. People with chronic pain die two to five years earlier than those without pain. Poorly treated chronic pain can cause lasting changes in the peripheral nerves, spinal cord and brain so that, essentially, the body forgets how to stop hurting long after the point where normal healing should have occurred.

The pain system becomes so wound up, explains Dr. Michael Negraeff, an anesthesiologist and pain specialist at Vancouver General Hospital, that normal touch hurts, "and regular pain becomes huge pain."

One Toronto woman, who spoke with Postmedia News and asked not to be identified, has suffered electric-shock-like pain across her chest since undergoing a quadruple bypass in 2003. She suffers from neuropathy, or nerve pain. Her surgeon used an older procedure for bypass that carries a 10 to 15 per cent risk of neuropathy, rather than an alternative technique that carries a far lower risk. She woke from surgery with excruciating pain.

"There was this enormous pressure to be tough," she says — to hold out taking the pain drugs until she could no longer stand the pain, even though the evidence is mounting — including data from Canada — that the worse the pain control after cardiac surgery, the more likely people are to still be in pain six, 12 and even 24 months later. Had she been encouraged to take enough medicine to stay on top of the pain it might never have developed into chronic pain.

She soon couldn't bear to have anything touch her chest, not even silk. She says it felt as if a swath of her chest was on fire. Through friends, she met theatrical costume designers who spent days designing a



bodice-like wire brace that hangs down from her shoulders and straps to her hips, to keep her clothes away from her skin. Getting dressed still takes hours. Even now, "every time I put something on or take it off, it's a wave of pain," she says.

Judy Kohut's pain starts in the middle of her back, and then snakes up, into her neck and head. The Edmonton woman has spinal stenosis, scoliosis, fibromyalgia and nerve pain. If you saw her seated in a restaurant she would look perfectly normal, until she stood. She's bent at the waist, and shuffles, dragging one leg. In 2003, she started to feel intense pain in her back, but she was working in a communications job she loved and refused to pay attention to it, until the day she flew home from Ottawa, lifted her luggage off the turnstile, set it on the floor and couldn't stand up again. Her body had seized up completely. At the hospital she had the first of three back surgeries to deal with the worst of the ravaged discs. She's had surgery to replace both knees and her left hip since. She used to be five-foot-10 and is now five-foot-seven at most. On the worst days, which are most days, she describes her pain as nine on a scale of 10, even with powerful medications. Her total body is in spasm.

"It's extremely difficult to put one foot in front of the other."

She says her best days are a 7. The excruciating lower back pain is still there, as well as that feeling, as if someone were sticking a hot knife under the shoulder blade. But the fibromyalgia isn't so hot and burning and prickly, and she has some feeling in her feet.

Once highly independent, Kohut now can't walk unaided; she needs help getting in and out of the bath. She can't do her own hair because she can't raise her arms; she can't do her own shopping because most days she can't even carry a purse. She says she feels like a prisoner in her own skin.

She runs a support group for people living with chronic pain and one of the things that rubs raw the most are the comments, "Well, you don't look handicapped."

"What does that mean, handicapped?" Kohut asks. "What is someone who is handicapped supposed to look like?"

She says society needs to stop turning away from people in pain. "Turn toward us. Reach out and give us hope."

She reads a lot; she journals, she searches for information.

"I try to keep my head busy with something, so that I'm not only thinking about the pain surrounding my body."

Prayer, massage, meditation and deep breathing. Physiotherapy and acupuncture and electrical spinal stimulation. Anti-convulsants to slow down the communication between pain nerves to keep them from



firing uncontrollably. Narcotics and nerve blocks and Botox and cortisone injections. People with pain — at least those who can afford it or with insurance to pay for it — try one therapy after another. Some help; some make the pain worse. Some people spend thousands of dollars only to realize, "This isn't working."

One 49-year-old man tried massage, acupuncture, nerve blocks and drugs injected into the epidural space in his spine. Nothing worked for his neck and back pain. He has finally found relief with medicinal marijuana. He has a federal licence to possess it, but he has to use it as if he were a criminal, keeping it a secret from his children, his neighbours and the parents of the young children he coaches in a minor league sport.

"I can't allow these people to find out I'm using pot for my pain," he says. But the drug works for him. It gives him energy to do his exercises in the morning; it gives him an appetite.

It sometimes distracts him from thinking about his pain.

There is no cure for chronic pain and none is in sight. The best doctors can hope for with medications alone is about a 30 per cent reduction in pain levels.

For some patients, the drugs don't even do that much, says Dr. Lori Montgomery, medical director of the Calgary Chronic Pain Centre. As well, the side effects — nausea, dry mouth, overwhelming fatigue, weight gain, foggy thinking and memory problems — can be intolerable.

That's why pain experts say that treatment requires a multi-pronged approach that includes access to psychologists, rehab specialists, physiotherapists, occupational therapists — services that, in most parts of the country, aren't publicly funded.

Pain researchers, doctors and patient groups across Canada want a national pain strategy that would officially recognize chronic pain as a disease in its own right — not merely a symptom of something else. They urge better co-ordination of resources, more investment in training doctors in pain, better assessment, prevention and pain treatment across the country in hospitals, long-term care facilities and nursing homes, more multi-disciplinary pain clinics and improved community-level care to help people manage their pain and gain control over their lives.

"The primary-care level doesn't know how to deal with pain. So the sophisticated tertiary clinics end up with all of them. Many of these patients need simple blocks, simple interventions, they don't need the special things we offer," says Dr. Yoram Shir, director of the Alan Edwards Pain Management Unit.

"If we invested more to take care of these patients it could lead to huge benefits for the country."

Every one of us is at risk of chronic pain, Shir says. The public, he says, must demand change.



"People need to demand and insist on the right to be treated properly — not to wait in the ER for three days, not to wait a year-and-a-half to see me here, because my waiting list is 700 patients long," he says. "These are among the most horrible diseases that human kind knows."

Lous Heshusius says what's needed is a sea change in society's mindset about pain.

"There is so much in society that works against pain relief, against us getting help — structural problems, political problems, funding problems."

We live in a society that says only that which can be seen and measured is true and valid and real, she says, "and I think that is doing us in."

"It's why insurance companies can get away with pretending we don't have pain. It's why my neighbour has no clue I live in pain, because when I go out of the house, they can't 'see' anything. If I said, 'I have cancer,' they know. But they can't understand pain."

She says she can't count the times she has heard, "But you look fine." Or, "Can't you take some pain pills for that?"

"People have no idea what kind of lives we live," she says.

Her old one ended in a split-second's distraction.

Her first memory of the crash is of coming to as paramedics strapped her to a stretcher.

"It was a fantastic experience — I felt like I was in sunlight, there was this very wonderful light feeling, with a lot of beautiful faces in front of me, except the faces turned out to be very worried paramedics," says the Dutch-born Heshusius, who was a tenured, full professor of education at Toronto's York University before her accident, a job she says she loved.

The crash mangled her neck and vertebrae. Fifteen years later, she still suffers sharp, shooting pain that travels from the base of her skull, up into her head, and then through her neck into her left shoulder and arm.

"It feels as if the tissue and the muscles are too tight," she says. "It's like a trap and I want to take a knife and cut through it to create space."

The pain is usually at its worst in the morning. When the pain is intense, when it lives "somewhere between 11 and infinity" on a scale of 10, as she describes it in her book, "It just grabs your attention so totally that you cannot really move. It's extraordinarily hard to find the language for it. You just move into another sphere."



During the worst years, "those horrible, dark, dark days" between 1999 and the end of 2003, she says she thought of suicide every day. She says she tried to talk to six health-care professionals. The response was, essentially: "We don't want to go there."

"I'm still angry with that. I'm still furious."

Were it not for her two daughters, she would not be alive today, she says. ("There is no question about it.") One of her girls once told her she would give up her arms if it meant freeing her mother from her world of pain.

They were her salvation. So, too, were the hundreds of pages of jotted notes she kept that would later form her book, *Inside Chronic Pain: An Intimate and Critical Account*.

Over the years, she has seen 22 doctors and specialists, from the "truly caring to the clearly uncaring." Prolotherapy, an alternative treatment that involves injections into the ligaments and tendons, has taken about 50 per cent of the pain away, but it's still there. It moves in and out and she says she never knows when a major pain attack will hit. She's landed in emergency rooms twice.

When the pain gets intense, "it's almost like leaving this world." Her mind and her brain and the pain are like one consciousness, she says. She goes into the pain, and she focuses on it, and if "I can stay focused on that spot and stay in it," she wrote in her book, "I can keep from going crazy."

Heshusius can't teach anymore, or take long trips. She often spends hours looking out at the ocean from her yard.

"I've always been a bit of a solitary person, which serves me well, now that I live this life in pain," she says.

"Because you find yourself alone a great deal."

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‘You mean this isn’t going to go away?’

Car accident set teacher-turned-author down painful path



Cathryn Morgan wrote an award winning children's book and is a former teacher in Ottawa who lives with pain daily. Cat was injured in a car crash in 2004. She suffers from severe neck pain, muscle spasms, headaches and fatigue and sees seven specialists (including a neurologist, pain specialist, psychologist and physiotherapist) to help control her pain. She was photographed at her home in Ottawa Wednesday July 13, 2011.

After the accident, Cathryn (Cat) Morgan’s neck felt as if it had been smashed down between her shoulders.

Even now, seven years later, it feels as if her neck is on an angle, as if she’s always looking left — the way her head was turned at the moment of impact. Her left shoulder usually feels as if it’s up around her ear, and she still has that “shoved down” feeling of her neck into her body — that “turtle in the shell” feeling.

Morgan was on her way to her brother’s anniversary dinner when she was hit by another car in a parking lot thoroughfare. Her head went back hard against the headrest, then there was a jarring jolt when she hit the speed bump.

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Today the former Ottawa elementary school teacher suffers from neck pain, back pain and dizziness that comes and goes, as well as severe headaches; at times, she says, it feels as if fireworks are exploding in her head.

At first, she tried teaching part-time, because she thought that focusing on what she loved doing would help carry her through the torment, but by the end of each day, "I would crash." The moment she realized, "I can't do this anymore," was huge, and it was devastating. "I wanted to work so badly."

Morgan has neuropathic pain and chronic myofascial pain, or CMP — a condition that affects the muscles and the sheath of tissue that surrounds them. Every day, her muscles feel as if she has run a marathon.

She was originally treated for whiplash. When she was diagnosed seven months after the accident with chronic pain, she was stunned. "You mean this isn't going to go away?" she remembers saying.

She relies on eight health professionals to help keep her functioning. Without them, "it would be like being put in a glass jar and having the lid screwed on tight."

This year she published *GrrrOUCH!* Pain is like a grouchy bear, an award-winning children's book about physical and emotional pain that resonates with adults, too. It took her two years to write 572 words, because she couldn't bear to sit at her computer for more than 30-minute stretches at a time.

Her treatments include physiotherapy; massage therapy and prolotherapy — a painful, alternative treatment that involves a series of injections into the ligaments into the neck, back and buttocks. "With chronic pain treatments, you go into the pain and through the pain and out the other side," she says.

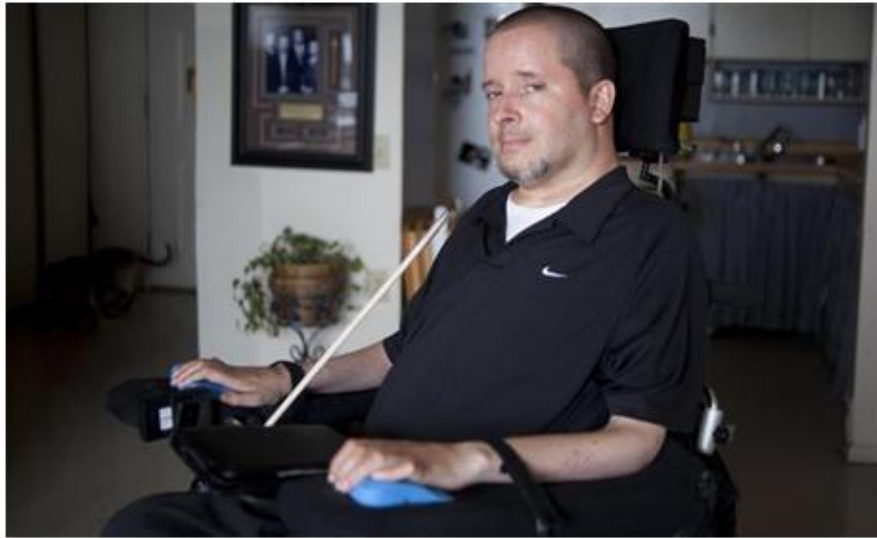
She focuses on pacing, meditation, exercise and putting things in priority. Family and friends have helped keep her moving forward. She works hard to make the box that contains her life bigger, she says, and to "celebrate every day."

The paperwork from her car insurance company describes the date of her car accident as a "date of loss" — as if she could go to a lost and found and dig out her old life. That date, she wrote this summer, is the "Great Divide between past and present" — the thing that separates "before and after, then and now."



The burden of no proof

Because there is no objective way to measure chronic pain, people who suffer from it often struggle to convince others that their pain is real.



Kurt Gengenbach is a C4 quadriplegic that suffers from chronic pain. Gengenbach is photographed in his Toronto, Ont., home, July 27, 2011.

Three months after breaking the fourth cervical vertebra in his neck in a freak hockey accident at the age of 17, Kurt Gengenbach began experiencing a new and spectacular kind of torment.

He started feeling pain in his left pectoral muscle - a constant burning, pins-and-needles sensation that slowly spread to his right shoulder, across his chest, down into his abdomen and finally through his legs and into his feet.

Gengenbach is a quadriplegic. He cannot move his arms or his legs. But he can feel pain. His ankles feel as if they're bound in thick, bonecrushing casts. A Kleenex against his bare shoulder can feel like a blowtorch. The skin on his chest is so hypersensitive he can't breathe deeply to relax when the pain hits, the way his therapist told him to, because expanding his chest makes his skin stretch, and it's torture. "Basically I'm paralysed by pain," he says.



The tragic irony - that a body that can't even move is still racked by continuing pain - is compounded, Gengenbach says, by the fact that sometimes people don't believe him.

Some of his attendants know that just moving his arm or touching him can be painful. "Others think, 'It can't hurt him that much,' and they just kind of throw me around," the Toronto resident says. "They don't believe it."

Canadian researchers are trying to stamp out once and for all the skepticism faced by many who suffer severe, persistent pain. The revolution in research Canadians are helping to lead is aimed at showing just how real pain is.

Researchers are using hightech imaging to show the human brain in the act of processing pain.

They're discovering how unrelenting, day-in and day-out pain can change the brain's anatomy (pain shrinks the brain in some areas) and how those abnormal changes can be reversed with successful treatment. They're discovering just how often poorly treated pain after surgery morphs into chronic pain that can last for years.

In Quebec, 3,500 patients are being followed in what is believed to be the largest registry of chronic-pain patients in the world - a massive undertaking that could unlock answers to one of the most universal of all human experiences, including what factors predispose us to chronic pain, and what perpetuates it.

The goal across this research spectrum is to reduce suffering and banish the idea that pain that doesn't respond to treatment - or that seems wholly out of sync with any physical finding - isn't genuine.

"There is a huge social change that is happening," says Dr. Fernando Cervero, director of the Alan Edwards Centre for Research on Pain at McGill University, one of the world's leading pain research centres. "We are in a way leading, but also society is leading it. People are saying, 'Why do we have to live with pain?' "

Scientists have long been searching for an objective way to measure pain - using heart rate, blood pressure, temperature changes, muscle tension, and skin sweating. These physiological "markers" can work for short, sharp pain, but not chronic pain.

Now, researchers are taking the first steps toward developing a tool to detect pain based on patterns of human brain activity. The most recent experiments involve functional MRIs. Normal MRIs take pictures of the structure of the brain; fMRIs take a series of pictures showing what activity is going on.

In a study reported last month, Stanford University School of Medicine researchers put people inside the brain-scanning machines, applied a heat probe to their arms, then looked at the brain patterns with and without heat.



The brain patterns were recorded and interpreted by computer algorithms to create a model of what pain - in this case, mild pain in a carefully controlled lab setting - looks like.

The next step is to see whether the same method can be used to measure chronic pain.

"The issue of validation of pain is a critical one," said senior author Dr. Sean Mackey, chief of the division of pain management at Stanford.

"They don't feel like they've been believed, they feel as if their physicians and friends and families think the pain is not real. They're desperately looking for a way to prove to people that they do have pain."

Mackey said he would like to think this technology isn't needed, that doctors could and should be educated that pain is real, that it's a "neurophysiologic phenomenon" - that it is whatever the patient says it is.

In fact, chronic pain conditions are among the most devastating diseases known to man. For example, complex regional pain syndrome - nerve pain that can develop from trauma or surgery, and sometimes without any known trigger - can feel as though the finger ends are being ripped away from the bones.

Drugs used to treat chronic pain, when they work, provide some relief, but they're crude - they target not only pain receptors, but receptors throughout the body, meaning they affect virtually every bodily system, bringing sideeffects such as nausea, fatigue and memory loss. What's more, doctors aren't entirely sure what it is they should be targeting.

This much is known: Having pain that doesn't go away - pain so severe that it makes it impossible to work, to think, even to sleep - is to live in another world. Some people have quality-of-life scores that are equivalent to terminal cancer. "It's probably beyond your comprehension if you haven't experienced it," says Dr. Lori Montgomery, medical director of the Calgary Chronic Pain Centre.

In many cases, chronic pain is caused by a neural response to tissue damage. The nervous system is alive, and it can generate pain.

"Every level of the neuraxis, from the tips of the toes to the top of the brain, can be involved," says Dr. Mary Lynch, director of the Pain Management Unit at the Queen Elizabeth II Health Sciences Centre in Halifax.

In addition, our genes as well as our past experiences, mood and emotions can influence how we feel pain and respond to treatment.

For generations, the prevailing theory on how pain works was straightforward: In response to injury or disease, special pain receptors or nerve fibres in the skin, muscle, joints and other tissues act like a shrill alarm. The alarm sends pain signals through the spinal cord up into a pain centre in the cerebral cortex, where we were thought to "feel" pain.



"The metaphor we use is ringing the bell," Montgomery says. Pull the cord and the bell rings. That was the old model. More recent research tells us that pain is much more complex than we ever imagined, she says.

"There are many nerve pathways, and many different mechanisms that decide whether that alarm signal will make it to the brain or not."

Pain is a survival mechanism. Humans need to feel acute pain - sudden bursts of pain from an injury - in order for the species to thrive. Acute pain tells the brain something is wrong.

Chronic pain doesn't serve the same survival function. It can occur when the alarm gets stuck, even after the fire is out. The nerves keep shooting pain signals up to the brain, as if the tissues were still being damaged. The bell is ringing for no apparent reason, Montgomery says, "or there may be a reason, but we don't understand what it is."

Not only do the pain signals spontaneously fire, they'll now respond to stimuli, says Lynch. Things that shouldn't be harmful - even a light touch - can cause excruciating pain.

"Many patients will say, 'I can't stand to be touched anymore. I can't take a shower - the water on my neck and shoulders is just too painful.' They can't tolerate the feeling of the sheets on their feet at night," says Lynch.

"These are classic descriptions that we hear every day in pain clinics across the country."

But what happens when there is no physical explanation, no "organic basis" to account for the pain?

"You can take a picture of somebody's spine and it looks absolutely normal and perfect, and yet they have horrible pain. So where is the pain?" asks renowned pain researcher Dr. Ronald Melzack, professor emeritus of psychology at McGill University.

"That's the pain we need to start concentrating on."

Pain, he says, used to get three pages in the medical textbooks. Pain was a sensation, he says, "it didn't mean suffering." Nearly 40 years ago, Melzack helped put a language to pain with the McGill Pain Questionnaire, a tool now used the world over to assess pain. It consists of 78 pain descriptors - words such as pounding, drilling, quivering, stabbing, shooting, exhausting, sickening, suffocating - to try to describe suffering. Each is rated on a five-point scale - the higher the pain score, the greater the pain.

But it was his "gate control" theory of pain that revolutionized pain science.

In 1965, Melzack and his colleague, MIT neuroscientist Patrick Wall, published a theory that challenged the idea that there was a one-way, skin-to-brain "pain pathway."



Instead, their gate-control theory argued that nerve cells in the spinal cord act like miniature gates that can block pain signals from getting through and up into the brain, or allow them in.

Melzack once explained it this way: "If you are playing hockey and get kicked in the shin, your gates are often closed because your brain isn't interested in pain at that time." (Kurt Gengenbach once skated an entire game on a broken ankle. He didn't realize the bone was broken until he took his skate off.)

"On the other hand, " Melzack said, "if you have a slight stomach ache and you learn that a friend has just died of stomach cancer, suddenly the gates are opened, and you may have terrible abdominal pain."

Melzack has expanded his hypothesis since. He says humans are born with genetically determined neural networks, which are pain-processing programs in our brains that can be influenced by mood, emotions, memories and other sensory experiences.

This "neuromatrix" can be activated by an injury or illness, he says. But it can also go off spontaneously.

Amputees frequently report stabbing, burning searing pain in their phantom limbs. "How do you account for that?" Melzack says. "The only way you can is that the leg we feel is in our brain."

Experts say that how we think about pain can affect how we feel pain and, for some, the urge is to "catastrophize" the pain - "this pain will never go away, I will never be able to handle this."

Catastrophizing can stop people from taking action, says Michael Negraeff, a clinical associate professor in the department anesthesia at the University of British Columbia and chair of Pain BC. It also increases the amount of pain people report.

"You have to absolutely validate that they are having pain and that all pain is real," he says. "Only then can you begin to work on helping them see what is not helping them."

Attention can also have a significant impact on pain and pain processing, says Dr. Catherine Bushnell, professor of anesthesia at McGill University in Montreal and president of the Canadian Pain Society.

In studies of healthy volunteers who were subjected to experimental pain - heat not hot enough to cause a blister but hot enough to activate the person's pain system - Bushnell's team has found that people rate their pain higher when they're focusing on it. "When you're distracted, you feel less pain."

Emotions modulate pain differently, she says. When people experience positive emotions, "they still feel pain, they still rate it with the same intensity, but it bothers them less, it's less unpleasant," says Bushnell. "These are ways that you can engage in and work on your own therapy."

Some worry the new focus on the mind could make science slip back into seeing pain as purely psychological. Distraction works in a lab where a bit of pain is inflicted for a short time, and in real life



when the pain is light, says Lous Heshusius, author of *Inside Chronic Pain: An Intimate and Critical Account*. But when pain is intense, distraction can make it worse, she says.

"That's why we often withdraw when severe pain strikes," she says. What people living with severe pain need is real purpose, she says. "Something that is still worthwhile living for."

For 12 years, Kurt Gengenbach watched helplessly as pain took over his body, as more and more parts started hurting.

Gengenbach, now 40, was paralysed during a senior high school hockey game, when he went in for a hit, lost the edge of his skate and slammed headfirst into the boards.

Today he suffers from neuropathic pain. With a spinal cord injury, sensory nerves at the level of the injury are also damaged, causing changes in their electrical signalling. Some of those damaged nerves get stuck in the "on" setting, so the pain signals keep firing.

Gengenbach has been living with pain for 22 years. "You don't get used to it, you just learn to deal with it," he says. The most difficult thing, he says, is frustration with people not understanding the pain.

He has a medicinal marijuana licence because marijuana helps control his pain by controlling muscle spasms. Yet some of his attendants refuse to hold his pipe for him, saying they have a right to work in a smoke-free environment. Gengenbach has disposable surgical masks that would cover their face entirely. He takes only one puff at a time from a small bowl pipe. The amount of smoke, he says, is minuscule.

At night, he sometimes lies awake in agony. He can see his pipe next to his bed when he turns his head, but he can't reach out and grab it. It's right there, right beside him. "I can see it. But I can't get it."

"I sometimes beg for the ability to make someone feel my pain for five or 10 seconds," he says. "I feel bad for saying that. . It's very hard for people to understand.

"My pain dictates my life much more than my disability ever has."

EDMONTON JOURNAL

'Just breathing makes it hurt more,' chronic pain sufferer says



Margaret Bristow spends most of her time in her Ottawa apartment dealing with fibromyalgia and neuropathic pain. Most days, such as on this Sept. 14, 2011 morning, her pain is a seven on a scale of 10, and there are days she can't walk more than a few steps. She has to survive on less than \$10,000 a year in disability pension. She is tired all of the time.

As long as the pain holds steady, Maggie Bristow can function.

She can dress herself; she can tie her shoes and brush her hair. She can make a meal. She can walk more than 30 steps without the pain in her hips crippling her.

But even then, the 51-year-old Ottawa woman can't bear to have her arms or legs touched, and when the pain spikes, it feels as if someone has peeled away her skin, and every nerve ending is exposed. She can't even stand to have clothes on.

"When it gets really bad, you question your continuing existence," Bristow says. "You feel useless."

She shifts in her wheelchair, lifting one hip slightly. She grimaces, briefly closing her eyes.

Bristow has fibromyalgia and spinal stenosis, a narrowing in the spaces in the spine. The former administrative assistant can no longer work because of the pain. She receives a disability pension of less than \$10,000 a year.

EDMONTON JOURNAL

The pension doesn't cover all of her medications. It doesn't cover the acupuncture or therapeutic massage that can sometimes make the pain more bearable.

It started with a dull ache in her lower back, a pressure that made it feel as if someone were sitting on it. Then the pain moved into her neck, her legs, her arms, hips and jaw. New places just started hurting. "The latest is the shoulders and chest," she says. "My chest feels like a knife is being jabbed into it repeatedly."

She sleeps propped up, on a hospital bed. She hasn't slept on her back for more than 10 years. It sometimes feels as if her back is broken into a million pieces. "Just breathing makes it hurt more."

There are days she feels sore everywhere except her head. "You know how everything hurts when you have the flu? Take that and multiply it a few times," she says. "It doesn't ever stop."

She has tried Tylenol 3s, oxycodone, morphine and Dilaudid. Nothing worked.

"It was like popping Lifesavers."

The medicines she takes now are helping control the pain, but they make her thirsty all the time and play havoc with her digestive system.

"The worst part is you can't see pain, everyone wonders, 'What's wrong with you? Why aren't you working? Why are you in a wheelchair? is she faking?'"

"If you don't have pain then you have no idea what it feels like."

CALGARY HERALD

Salvation or slippery slope?



Psychologist Dr. Steve Munsie displays some of the pain-killer medications that he has to take daily to manage the pain from chronic kidney stones at his home in Laval in Montreal, Quebec on Friday, September 23, 2011.

Steve Munsie thought the pain was going to kill him.

Later, he became afraid it wasn't going to kill him.

Munsie was born with three kidneys — two on his left side and one on his right. He suffers from chronic kidney stones. When he was younger, he produced one or two stones a year.

Today, he produces as many as 30.

There are days he has virtually no pain and there are days the pain is so intense it makes him freeze up in agony.

Munsie of Laval, Que., is a PhD psychologist. He once managed a team of human resources specialists for Air Canada. Five years ago, he sank into such a profound depression from the pain that he spent six weeks in hospital. Even today, he has a hard time believing it.

"I wasn't expecting a depression — I'm a psychologist," he said.

CALGARY HERALD

"I figured I could avoid that, right?"

He stopped working; his marriage began to suffer. He stopped seeing people and playing his music, because all he could do was focus on the pain.

He was given only enough opioids for the breakthrough pain — those sudden, brutal flares of pain when the stones passed, which for Munsie meant he was either in a good deal of pain, or in withdrawal from the drugs when the kidney stone went away. It felt as if every nerve ending in his body — "billions of them" — were in spasm.

He was finally referred to a pain clinic in Montreal, and it was there that the doctors helped turn his life around.

They gave him methadone.

Methadone is a synthetic opioid. It's considered a fourth-line analgesic to be used when all other treatments have failed. The drug floats through Munsie's body at a low but steady level. He takes it every day, as well as oxycodone on the days the pain is heavy. The drugs help control the nauseating waves of pain that sometimes knock him to the floor.

Opioids are major pain drugs, the most potent analgesics available. But a rise in opioid-related overdoses and deaths, and tighter regulatory controls over prescribing, is frightening some physicians away from prescribing the drugs for chronic, non-cancer pain. Stories of accidental overdoses, of pills being diverted to the street and ground up and snorted or injected like heroin, are spurring calls for a new war against prescription drugs — one experts fear could make the tragedy of under-treated pain in Canada even worse.

"We are at risk of going in reverse," says Dr. Ellen Thompson, an Ottawa anesthesiologist who specializes in pain. After 30 years of practice, Thompson says she can't fully retire because no one will take her patients. She says some newly graduated family doctors are refusing to take on chronic pain patients, "and I can't blame them. They're thinking, 'I don't need this.'"

Opioids have been shown to be effective for serious, intractable pain. For some, this is a pain that can be like a living death. It is a pain people go to bed with and a pain they wake up with and it affects every fibre of their being. They can't think clearly; they can't work. They are anxious and fearful and frustrated and depressed, and sometimes the pain so takes over body and mind that people take their own lives. Studies suggest the suicide rate among people living with chronic pain is two to four times that of the general population.

Opioids slow the transmission of pain signals to the brain. They also alter the sensation of pain. Yet they are far from miracle drugs. They produce, on average, about a 30 per cent reduction in chronic-pain intensity.

Their side effects — nausea, dizziness, sedation, constipation and fatigue — can make them intolerable.

CALGARY HERALD

Some people who use them describe it as if they're moving in slow motion. The drugs can also lead to a perverse increase in pain, causing changes in pain pathways in the spinal cord that make people more sensitive to pain — a phenomenon known as opioid-induced hyperalgesia. And new research has started linking their long-term use with osteoporosis and sleep apnea.

Some critics say that opioids are horribly abused and inappropriately prescribed. Even in cases of serious pain, some doctors refuse to touch the drugs outright. Many were trained under outdated concepts of addiction and a deep distrust of narcotics that essentially boiled down to this: As soon as you gave someone an opioid, they would become addicted — that “you would take your normal, average, church-going housewife with three children and turn her into a drooling lunatic looking for drugs on the street corner,” says Dr. Norm Buckley, professor and chair of the department of anesthesia at Hamilton's McMaster University.

“That almost certainly does not happen, but there certainly was that perception, and so there was a huge resistance to using opioids.”

In the '80s things began to change. Pain societies the world over began pushing for more effective use of opioids, citing studies showing little risk of addiction in patients with no history of substance abuse. Then came slow-release versions of oxycodone and similar drugs. Drug companies that glossed over the potential risks while pushing the potential benefits aggressively marketed the pills to doctors. Prescriptions soared.

Today, Canadians are among the highest users of prescription opioids in the world: in the past decade alone, our opioid consumption has more than doubled, and the biggest increases have been for the heavy-hitters: hydrocodone, hydromorphone, oxycodone, fentanyl, meperidine, methadone and morphine, according to a just-published study by British Columbia and Ontario researchers in the journal *Pharmacoepidemiology and Drug Safety*.

Among the provinces last year, Alberta had the overall highest opioid use rate in the country, Quebec the lowest, but nowhere are the rates falling. Prescriptions for oxycodone are increasing in all provinces.

Overall, in 2010, Canadian pharmacies filled just over 17 million prescriptions for opioids worth about \$725 million, according to IMS Brogan, a prescription drug-research firm.

Suddenly doctors went from using none at all, to, in some cases, prescribing hundreds of pills at a time. While some doctors still clung to old fears about narcotics, critics say that others started prescribing the pills liberally, and for inappropriate indications, without taking the right precautions or asking the right questions.

In Ontario alone, prescriptions for oxycodone increased 850 per cent between 1991 and 2007.

“We're flooded with these drugs. They're everywhere,” says Benedikt Fischer, an applied public-health professor at Simon Fraser University in B.C. In many Canadian urban centres, prescription opioids are more likely to be found on the street than heroin.

CALGARY HERALD

According to a policy paper Fischer and a colleague produced for the federal Department of Justice in April, non-medical use of opioids is now considered the fourth-leading form of substance use in Canada, behind alcohol, tobacco and cannabis. Fischer estimates that between 40 and 50 per cent of all drug-related deaths in Ontario now involve prescription opioids. Surveys suggest most “non-medical” users are getting the drug from a prescription written for someone else.

In Ontario, the number of people seeking treatment at publicly funded addiction clinics for addiction to opioids has almost doubled in five years. Fischer’s paper recommends adding illegal opioid use to the next iteration of a national drug strategy — or that it become the focus of its own strategy entirely, with the proviso that it must not harm the “quality, availability and accessibility of pain care in Canada.”

But pain doctors say it’s not clear how many “non-medical” users are, in fact, using the drugs for pain. Lynch, of Dalhousie University, says people often share their pain meds with family or friends who are in pain. In other words, “non-medical use” doesn’t necessarily mean “recreational use” to get high. What’s more, Lynch says that Canada’s consumption rates are half those of the U.S., but in line with Australia and Denmark.

Opioids do carry a potential for abuse, but they’re not unique in that regard, says Buckley, who questions, is it the drug that creates the abuse, or does the abuser find the drug?

“When you consider the fact people will abuse cooking spray, or they will sniff gasoline . . . you have to consider that some people are going to abuse stuff, somewhere, somehow, no matter what it is.”

Despite the high level anxiety around opioids, Buckley says that no one has really sat down and said, “OK, opioid-related deaths are up, but are deaths due to suicide in patients who have pain problems, are they up, down or the same?”

Nonetheless, this fall, Ontario will begin tracking every prescription written for an opioid in the province — who is getting it, who is giving it, and how much. The province has passed legislation allowing it to track all narcotics and other controlled-substances prescriptions and maintain personal health information in a narcotics database.

The information, the province says, is intended to help “improve prescribing and dispensing practices” and reduce misuse, abuse and drug-related deaths. In Canada, prescription-monitoring programs already exist in several provinces, even though Fischer says there is little scientifically documented evidence that they, in fact, reduce opioid abuse.

What they can do is lead to serious collateral damage. Doctors who fear being targeted for “irregular” prescribing either order opioids later, in smaller doses or not at all. Then there’s what Fischer calls the “hazardous substitution effect.” Doctors switch to therapeutically inferior but more risky drugs that aren’t so tightly controlled.

Doctors “are going to be worried,” says Dr. Roman Jovey, a family physician in Mississauga, Ont. who has focused his practice on chronic-pain management and addiction medicine for 20 years.

CALGARY HERALD

“They’re going to be thinking, ‘who’s looking at my numbers? Are inspectors going to come knocking on my door saying, ‘You’re a bad doctor; you’re prescribing too many opiates’? The only people who will be penalized will be the legitimate people in pain who will find it harder to get appropriate treatment, because doctors are going to be spooked.”

When people in pain can’t get the treatments they need, they start "upping" their over-the-counter drugs. They take huge, organ-damaging doses of acetaminophen or ibuprofen.

They take Gravol or Aspirin or anything they can get their hands on. Some self medicate with alcohol. Some try to buy opioids on the street "and they have no idea what they’re doing or getting," says Barry Ulmer, executive director of the Chronic Pain Association of Canada.

The wariness around prescribing opioids includes even situations of acute pain, such as pain after surgery. Lynch says many patients are being sent home after surgery without enough medication — putting them at higher risk their pain will dig in and develop into chronic pain.

Thompson, the Ottawa anesthesiologist, worries that the threat of sanctions will not only make it harder for patients to get the drugs they need, but that it may drive more requests for surgery for back, neck, knee and pelvic pain.

Surgeries done to treat pain that has no obvious physical source can often cause worse pain. The phenomenon of continuing pain after back surgery is so common it has been given a name: failed back surgery syndrome.

Others say the worries over reluctance to prescribe may be unfounded. A random survey of 658 Ontario primary-care doctors recently published in the journal *Canadian Family Physician* found that the vast majority — 95 per cent — reported prescribing opioids for pain in the past three months.

“Physicians are really concerned with their patients; they’re concerned about getting the best care for their patients that they can get,” said lead author Dr. Elizabeth Wenghofer, an associate professor in the school of rural and northern health at Laurentian University.

However, the researchers didn’t ask the doctors to differentiate between whether they prescribed opioids for chronic, non-cancer pain, or pain related to cancer or palliative care. The survey was also done in 2008 — prior to the Ontario regulations coming out.

Lynch suspects most doctors wouldn’t be concerned about prescribing opioids for cancer pain. “Where you will find reluctance,” she says, “is with chronic non-cancer pain.”

Some doctors won’t accept patients on opioids, she says, or, in some cases, even with chronic-pain problems.

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Doctors who specialize in pain agree that the misuse of opioids is a problem, and that not enough is known about the benefits, risks and side effects of long-term use. But the irony is that while illegal users appear to be having no trouble getting their hands on them, legitimate pain patients struggle to get access.

One reason is that prejudices against people in pain run deep, because in our society to complain about pain is to be labelled a whiner.

"If you have chronic, disabling pain people think, 'you look OK. You look like a normal person. You must be lazy, or weak-willed,'" says Jovey, of Mississauga, Ont.

"Pain is subjective — it's what the patient says it is," Jovey says.

"We don't have a pain-o-meter we can plug into people." Too often the pain is dismissed, he says.

Patients trying to fill prescriptions for opioids have described being told by pharmacists, "This is addictive. What are they giving you this for?"

Thompson says that had she not been born with one of the genes that predisposes people to pain, if she hadn't experienced pain in her own body — chronic back pain, neck pain, shoulder pain, jaw pain — "I probably would have had difficulty understanding what patients are telling me. Now I know."

Yet, "People are still not believed," she says. "The under treatment of pain is the most serious issue in modern medicine in the entire western world."

A new Canadian guideline has been developed for doctors on the safe and effective use of opioids for chronic, non-cancer pain. The 24 recommendations include how to assess patients, adjust doses, switch or stop drugs and how to watch for behavior that might signal a problem. The guideline — backed by medical regulatory bodies across the country — recognizes that patients with chronic, unrelenting pain have a right to be treated.

Opioids help stabilize Steve Munsie's pain — the sharp, nauseating pain that hits hard and fast when he's standing in line at the theatre or the market, a pain that leaving him gasping, "ah, ah, ah," and clutching his side. The spasms and the "knees up" pain that used to leave him curled in bed in the fetal position.

The drugs, he says, "help keep me vertical in the daytime."

Physically, he still struggles with pain. On a recent day he describes his pain as four on a scale of 10. He keeps pressing his hand against his side. "It feels like it needs heat or something."

He's doing volunteer work. He's cycling most days. He finds himself thinking a lot more about the future, which, for Munsie, is remarkable, because for a very long time he lived a minute at a time.

CALGARY HERALD

“To be thinking even about something as minor as, ‘Three days from now I’m going to fill up the car and get the car washed’ . . . I couldn’t even think that way before. I lived every moment as it happened.”

Pain puts people in a prison, Munsie says.

“I’m coming out of a lot of darkness.”

FACT BOX

By the numbers:

Estimated number of prescriptions dispensed by Canadian retail pharmacies for opioids in 2010: 17,086,778;

Estimated dollar value: \$724,556,545;

Estimated number of Canadians, based on survey data, using opioids for “non-medical” purposes: between 500,000 and 1.25 million;

Percentage of Canadians suffering from daily pain: One in five;

Estimated percentage of patients left in moderate to severe pain after surgery: 50;

Leading cause of post-discharge visits to emergency rooms: inadequate pain control;

Estimated risk of suicide in people with chronic pain compared with people without chronic pain: double the risk;

Average wait time for care at a pain clinic: one to three years;

Mean total number of hours designated for pain teaching in veterinary training programs across Canada: 87; and

Mean total number of hours for mandatory teaching about pain in medical schools: 16.

— Sources: IMS Brogan; Benedikt Fischer, Centre for Applied Research in Mental Health and Addictions, Simon Fraser University; Statistics Canada; Canadian Pain Society.

The Gazette

Pain-plagued teens desperately want to be normal



Melissa Schippers, 15, of Gatineau, Que., suffers from complex regional pain syndrome, a chronic pain condition that, in Melissa's case, causes intense burning, aching and stabbing pain in her feet at her home in Gatineau, Que., Aug. 5, 2011.

Melissa Schippers once asked her doctors if they could amputate her feet to stop the pain.

Even now, more than a year after her toes, ankles and knees turned suddenly purple, almost black, during the last few days of Scout camp, her doctors can't tell her when the pain will end.

Her feet and ankles are swollen, the skin pink and splotchy. Some days it seems as if the skin might burst. She walks on the outside edges of her feet, to keep the pressure off. This summer, while painting a mural on the side of her backyard shed, the artistic teenager from Gatineau, Que., was hit by electric-shock-like pain in her feet that was so intense she fell to the ground. Slowly she crawled on her hands and knees to the sliding back door to the kitchen, taking breaks when she had to, and when she finally made it inside, she collapsed on the floor, waiting for the worst of it to be over.

Schippers, 15, has complex regional pain syndrome, a baffling condition that causes severe pain, swelling and changes in the skin. A malfunction in the pain nerves that causes the pain circuits to keep firing is thought to be the cause. It can start with something as trivial as a minor sprain or infection, and can spread, like a cancer, from one part of the body to another.

The Gazette

Melissa was diagnosed with major depression in August. The doctors put her on Wellbutrin, an antidepressant; she's not sure how much it's helping. She's working hard not to let the pain push her down. She goes to physiotherapy as often as she can, to move and strengthen and slowly try to reprogram the nerves and desensitize her feet, but walking on the stair climber can hurt so much, "it's hard to keep a straight face. You kind of just want to cry."

Pain in children is common, under-recognized and under-treated. Studies suggest that intense and frequent pain affects about five to eight per cent of children and adolescents. Yet we're not dealing with pain in children any better, and probably even worse, than we are pain in adults.

Only a handful of multidisciplinary chronic pain clinics for children exist in Canada. Wait times can stretch to a year. And while adults with chronic pain often struggle to have their pain taken seriously, when it's a child with pain — especially when the pain seems completely out of proportion to any physical findings — the impulse is to deny it.

"There's a lot of not believing the kid," says Dr. Christine Lamontagne — "a lot of, 'Are they trying to get something else out of this?'"

Lamontagne is director of acute and chronic pain services at the Children's Hospital of Eastern Ontario in Ottawa. She runs a chronic-pain clinic two days a month; the wait time is eight months. The Ottawa anesthesiologist has appealed for funding for a formal co-ordinate pain program from the local health authority for the past four years. Over and over she has been denied. "We all do this clinic carved out of our own time."

She sees children and teens with juvenile fibromyalgia, diffuse musculoskeletal pain, chronic headaches, chronic abdominal pain and complex regional pain syndrome — Melissa Schippers' personal torment, which can feel as if the body is burning and blistering from the inside. Skin becomes so hypersensitive to touch that even a windy day is painful.

Chronic pain in children can be managed. But misconceptions about pain in children, insufficient education and training in pain for doctors as well as old attitudes that pain drugs are more dangerous for children than adults is causing children needless suffering, experts say.

Pain affects a child's mood, sleep, schoolwork, and relationships with family and friends. Many become anxious and depressed; some have thoughts of suicide. Chronic pain — pain that doesn't go away — has been reported in children as young as three.

Stephanie Clayton was born with a rare condition called a giant omphalocele, a birth defect that caused her stomach, liver and intestines to develop on the outside of her body. It took multiple surgeries to push everything back in. Today, the nine-year-old Toronto girl suffers from intestinal failure. She now has gastroparesis — her stomach is paralyzed — and other problems. She has a tube to drain her stomach, a tube to deliver medications and another for nutrition and hydration.

The Gazette

And on top of all that, she has chronic pain. The pain rules her world, and it rules her family's life — "every single minute of every day," Denise, her mother, says.

It's mostly on the lower side of her stomach — severe gut pain that can go from a squeezing sensation, she says, to punching and kicking. Some days her tummy is so distended, it's almost impossible to bend over to put on her socks and shoes. Stephanie doesn't like to talk about the pain, but if you ask her to draw it, it's always a big, black blob.

"Some days we have a lovely, delightful nine-year-old kid who is climbing trees and skipping and jumping rope and playing like most other kids do," Denise says. "And other days we have a very sick nine-year-old girl who is shouting and screaming at people and in a wheelchair, because her pain is so severe she can't walk."

The pain medications help, but they also have ugly side effects, Denise says. They make Stephanie irritable and tired. "But fighting the pain for her is exhausting."

It was only recently even understood that children could have significant pain problems — that children can feel pain the same way adults do.

The incidence of chronic pain increases dramatically around puberty — especially among girls, though doctors can't really explain why. Sometimes the pain can begin with a virus; sometimes it's sparked by surgery, sometimes it's caused by an underlying "pathology" — for example, arthritis or Crohn's. However it starts, children and teens with pain report fewer friends. They're bullied more at school, because anyone who is a little different is easier to pick on. They miss classes; they may get more time to finish assignments because it's hard to focus your mind when your body is in pain. Melissa Schippers said some kids in her school last year tried to get out of gym by saying they had feet problems, too.

Some teens worry about telling their friends about how much pain they feel; they try to hide the horror of it from their peers, says Paula Forgeron, a clinical nurse specialist in the complex pain service at the IWK Health Centre in Halifax and post-doctoral fellow in pediatric pain research. They worry about having a pain flare-up at the school dance, or when they're out with friends. For some, pain is a social death.

She once surveyed six teens, ages 13 to 17, who had been living with pain for 13 months, to 10 years. They had pain — daily pain — in their shoulders, neck, back, hands, feet, knees, pelvis and stomach. They were unique in where their bodies hurt but two things bound them: the struggle to be normal, and the struggle to deal with the pain.

None of her patients, not one, has ever tried to use their pain as an excuse, she says. "They don't want to be home, they want to be in school," Forgeron says. They want to be healthy.

Lamontagne, of CHEO in Ottawa, says pain in children urgently needs to be recognized as the significant problem that it is.

The Gazette

"Often the first thing we hear when they come to our clinic is, 'Thank you. Thank you for listening. Thank you for believing me.'"

Melissa Schippers' team of specialists can't explain what happened last summer, when the purple colour slowly crept from her toes to her knees. "It felt like a sharp pain, like I wanted to cut off my feet." She was known as "purple girl" for the day.

She can tolerate a lot of pain now. She can keep a straight face, "until it goes extreme." The drugs cause side effects that the doctors didn't warn her about, such as dry mouth and dizziness and "you can't see where you're going, you can't see anything." She's having trouble with her memory; she has trouble remembering what she did even yesterday. "They told me that it's probably because of the depression, the medicines and the pain."

She's had to stop playing badminton and other sports. She's had to stop running around and doing all the things she once did. It's hard to spend time with friends, "because I'm always going to the doctor now."

Her doctors told her she couldn't take gym this year. She can't take long walks anymore. "I have to be very careful about going shopping, and make sure there's a bench around, when it gets really bad."

She didn't believe it at first, when the doctor told her she was depressed, "until it hit me when I got home."

Schippers enjoys painting and drawing. It helps her not to think about how much she hurts. She finds hope with every new appointment that something is going to help. "But it frustrates me, because I don't know when this is going to end.

"I don't know if it's ever going to stop," she says. "It's like a book full of questions that nobody can answer, and I just kind of carry it around every day."

Senator calling for pain recognition



Senator Kelvin Ogilvie outside the Senate chambers on Parliament Hill in Ottawa, Ont., Oct. 4, 2011.

Chronic pain should be recognized as a legitimate illness that affects a wide swath of the population, says the Conservative senator spearheading a review of Canada's federal-provincial health accord.

"Very clearly this is a major issue for society to deal with," Kelvin Ogilvie told Postmedia News.

"It's very difficult for people who have been largely pain free except for the odd toothache or minor accident or whatever to genuinely relate to somebody who has a very severe chronic pain that is not attributable to a specific, treatable event," said Ogilvie, chair of the Senate committee that's reviewing the health accord due to expire in 2014.

Even when there is no obvious physical source for the pain, the effect is real, he said.

His comments come as Canadians from across the country respond to a special four-part Postmedia News series documenting the lives of people living with chronic, incapacitating and daily pain.

The stories "made me burst into tears and sob uncontrollably with each word read," wrote one woman from Victoria. "Even writing this email to you, in tears, I am in pain. I can feel my nerve throbbing from my low back into my toes. I touch the top of my foot and all I feel is pins and needles."

It hurts when she stands, she says; it hurts when she sits and when she lies down. "I don't know how much more I can take."

The woman had been seeing a pain specialist until last May, when she says he told her that because the epidural injections were no longer helping there was nothing more he could do. "My doctor, someone in the profession of treating pain, essentially broke up with me. What do I do when I have no one left to help me?"

One 50-year-old Ottawa-area woman who has suffered from chronic headaches for 40 years said the series gave a voice to those living with unrelenting pain.

"Over the years I have taken so many pills that I truly should be dead," she wrote. "I cannot begin to explain the exhaustion this type of pain gives you . . . We all have horror stories about our journey to find some relief."

Patient groups and health professionals across Canada say that chronic pain needs to be officially recognized as a chronic disease in its own right and that more resources urgently need to flow to early intervention and prevention, support for patients and their families and better multidisciplinary pain care at the community level.

Ogilvie stopped short of endorsing a national pain strategy.

"But there is no question that pain is an extremely important issue," he said. Pain "affects a wide cross-section of society on an ongoing basis."

An estimated one in five Canadians lives with chronic pain of some kind, yet pain is poorly treated in Canada. The Postmedia News series described how some doctors are refusing to take on patients with chronic pain, and how fears about addiction and abuse surrounding opioids means people continue to suffer with uncontrolled pain.

"Those physicians who absolutely will not prescribe opiates regardless of the circumstance . . . As an individual I find that unacceptable," said Ogilvie, an eminent scientist who invented a drug used worldwide to fight infections due to weakened immune systems.

"The evidence clearly shows that for some people with very severe chronic pain, and particularly those who are in a terminal situation with severe chronic pain, that certain opiates are far and away the best under certain circumstances to mitigate their pain," he said.

"There's no reason why someone should suffer unnecessarily in their last days of life," Ogilvie said. "Hopefully we will reach a point where nobody needs to suffer — whatever stage in life they're in— from severe pain."

TIMES COLONIST

Ogilvie, who has experienced kidney stones — "I know some degree of significant pain" — and who has been close to people who suffered pain from terminal cancer, will chair a health research caucus on pain on Parliament Hill later this month.

Co-hosted by Research Canada and the Canadian Pain Society, the gathering for parliamentarians will feature some of the country's leading pain scientists. Their work could lead to lead to better treatment and better understanding of one of the most universal of all human experiences.

Chronic pain patients who wrote to Postmedia News after reading the series described a life of torture, "a constant struggle to continue on, and there doesn't seem to be help or understanding anywhere." They told of re-mortgaging their homes or cashing in retirement savings to pay medical bills or for treatments they cannot get in Canada. They described frustrating and demoralizing battles with workers' compensation boards.

"They seem to have a policy of 'deny, deny, and deny' in hopes you'll go away," one Ottawa man wrote.

"The worst part is the way people look at you when you try to explain what the pain is like," said a reader from Edmonton who suffers from complex regional pain syndrome, a debilitating condition that causes pain that never stops. "The disbelief, the jeering, the snide commentary, and most especially, the fact that people think you are lying to get something out of it. No one but another person who has chronic pain can possibly understand how bad it is."

Others echoed the frustration of trying to explain the reality of living a life defined by pain.

"Many of us are no more than one refill away from losing our will to live, and we must often fight the same ignorance over and over, month after month, year after year," one man wrote after reading the stories in the Montreal Gazette.

"The patient in pain yearns to be believed."

EDMONTON JOURNAL

Chronic pain a disease, too

Re: "Canadians with chronic pain struggle to find help and hope; Few options available for the estimated six million people who never stop hurting,"

I would like to commend Postmedia News writer Sharon Kirkey on this series of articles. She has obviously done a lot of work researching and writing this series and has captured much of what people in pain go through on a daily basis, and I do hope those who can create some change in this area of medicine will take note and actually do something.

I have written over the years about the serious nature of pain: its consequences on those who suffer, their families, our health care system and our communities, yet pain remains undertreated, misunderstood and often ignored.

Over the years this problem has grown and now affects more people than heart disease, cancer and diabetes combined and as we all age it becomes a bigger and bigger problem.

It is sad that in the 21st century we continue to ignore such a huge problem and pass it off as something "in your head."

It is sad that less than 0.25 per cent of medical research dollars in Canada are spent on pain research when pain affects so many of us.

It is sad there is such a huge chasm in knowledge and understanding between medical disciplines and even among many in the same discipline.

It is sad that people in pain are stigmatized and judged by friends, family and health-care providers as "drug seekers," as having a "psychological disorder," as "lazy," as "being flaky and unreliable," as "hypochondriacs," as "malingerers" and the list goes on.

If a person is on opioids any other health problem is attributed to opioids or is not taken seriously.

Chronic pain sets the stage for a complex set of physical and psychosocial changes that are an integral part of the chronic pain problem and that add greatly to the burden of a pain sufferer.

It is time to recognize pain as a disease in its own right and get on with solving the problem. It is time the head in the sand approach was dispensed with.

Let's hope these articles are the catalyst needed to effect change. God knows it is time.

Barry D. Ulmer, executive director, the Chronic Pain Association of Canada, Edmonton

EDMONTON JOURNAL

Help is close by

Thank you for the excellent information series on chronic pain. The articles are correct in saying that depression, not being believed, hopelessness and isolation act together to make the situation worse.

There are helpful things people can do for themselves here in Edmonton while they get the best medical advice and wait for a cure.

At the Hope Foundation where I work, we run groups to help people with chronic pain overcome hopelessness, feel more positive and learn to speak up for their needs. We offer counselling for depression. Alberta Health also has programs aimed at living well.

This message is important because depression causes people to lose hope. They stop looking for help. They stop going out. They stop noticing things that could distract them from the pain. They lose the will to describe their symptoms because they are certain nobody believes them.

You don't have to cure the chronic pain to have hope. You can treat depression without curing the pain. You can find people who are willing to work with chronic pain.

Wendy Edey, R. Psych, Hope Foundation of Alberta, Edmonton

The StarPhoenix

A little relief

Any and all progress made in the research on chronic pain (Pain research making gains, SP, Oct. 3) is good news, because hope resides in that endeavour.

Unfortunately, knowing what level of the neuraxis is mostly involved in the transmission of a certain pain comes as poor consolation to desperate patients whose pleas for help are too often met with incredulity and dismissive remarks.

A specialist in Regina to whom I had been referred by my family doctor went further than the usual rolling of the eyes: He flatly refused even to hear about my symptoms and showed me the door, saying, "I can't help you.

Goodbye, sir." I lost a couple of hours of work for those two memorable minutes.

Unless research can actually force a needed change of culture, it will go nowhere near its avowed objective of "stamping out once and for all the skepticism faced by many who suffer severe, persistent pain," and its corollary, the validation of pain as a "neurophysiologic phenomenon" and that "it is whatever the patient says it is."

I wouldn't hold my breath on the latter, but the former seems to be attainable.

In that regard, the first Canadian pain summit, to be held in Ottawa next year, is quite promising.

Andre R. Gignac Saskatoon



World of pain is real

Re: The burden of no proof, Oct. 2.

Sharon Kirkey's recent series on chronic pain brought to light an important, albeit often invisible, condition.

For the last few years I have watched my daughter and two friends struggle with chronic headaches or migraines - pain so bad, that they despair.

Doctors, prescriptions, more doctors, side effects, experimental therapies, depression. Their world of pain is punctuated by a search for relief, however fleeting.

Chronic headaches are invisible. They rob one of friends, of time, of joy. In a worst-case scenario, of life.

And how does one respond when friends, family, employers and even doctors believe chronic headache pain to simply be "all in their head"?

It's time to take chronic headache pain seriously. The medical profession must do more than medicate - or not. At the same time, politicians must see that treating pain is as worthy of funding as knee and hip replacements.

Edith Kehoe



Over **20 million** Canadians have read the pain series to-date...and counting!

To view pain-related images, videos and access additional resources please visit:

www.canada.com/pain