ASSOCIATION QUÉBÉCOISE DE LA DOULEUR CHRONIQUE

We are there for you!

March 2015 | Advertorial

www.chronicpainquebec.org

UNMASKING CHRONIC PAIN

Jacques Laliberté knew little about chronic pain until he had a snowboarding accident, at the age of 58. His life, as a young retiree and former GM of a subsidiary of a major oil company, was turned upside down. He was forced to slow down, and many things he once enjoyed became impossible. But with treatment and careful pain management, he managed to gain back one of his great passions—playing tennis. He's careful and takes it easy on the courts. Any attempt to push too hard causes the pain to spike and requires extended rest and increased medication.

› Continued on page 2

10 years

Photo: Sylvain Gagnon

SUMMARY

Under my mask, what do you see?

FIGHTING THE PREJUDICE ABOUT CHRONIC PAIN IS PART OF AQDC'S MANDATE.

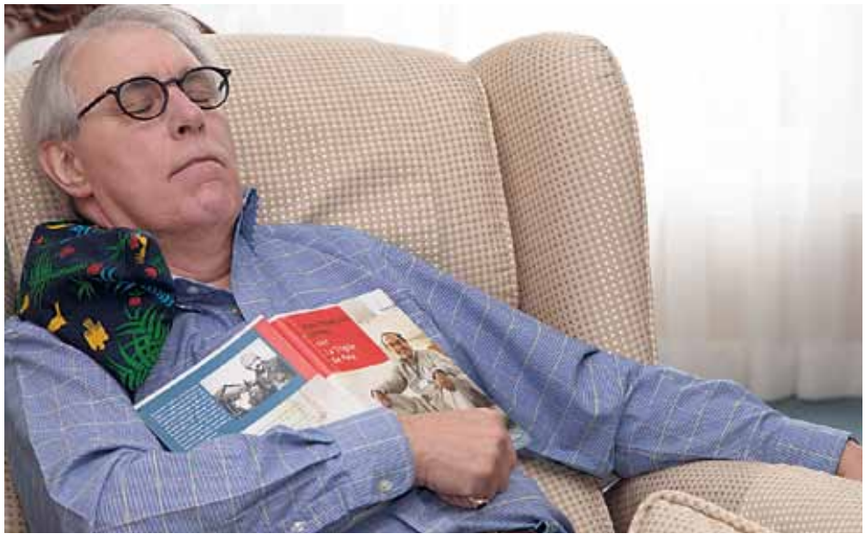
In this special edition, we unmask an often invisible condition—chronic pain. People with chronic pain often look fine, but they're suffering. And they're everywhere. In Canada, one person in five suffers from chronic pain severe enough to affect their quality of life.

The stories of Gaétan Bond, a former member of our board of directors, and Linda Thellen, a busy young grandmother, are filled with hope. You'll meet Christiane Manzini, a researcher at the Centre for Advanced Studies in Sleep Medicine, who taught me the fundamentals of good sleep hygiene. We'll also introduce you to Dr. Frédérick Dionne, a clinical psychologist who recently joined our board of directors. In addition, I'd like to thank the support group facilitators and health professionals who contributed to this publication: Dr. Mark Ware, Dr. David Lussier, Carole Haworth, AQDC founding member and director Dr. Aline Boulanger, and Dr. Manon Choinière, another director and founding member whose unfailing support from the very beginning has been a great blessing.

The AQDC is there for you. For ten years we've been helping people live better with their pain and collaborating with doctors and researchers so they can better understand what their patients are going through. We've been part of the Ministère de la Santé et des Service sociaux (MSSS) sectoral working group on chronic pain since 2004, where we've worked to put in place a continuum of integrated first-, second- and third-line services so that those affected can get the right care at the right time.

There's strength in numbers, so join the AQDC! Membership is free, and our website, www.chronicpainquebec.org, is a great place to learn about chronic pain and how to manage it. Attend one of our many conferences or watch them online—the latest, on opiates, has just been posted—or join a support group. That's what it's all there for. In today's climate of financial austerity, AQDC is particularly grateful to those who support us financially so we can continue our work. Every donation counts!

Jacques Laliberté, AQDC president



After tennis, a hot shower and a well-earned rest break

Testimony ›

Linda Thellen: The joys of grandmotherhood

Linda is a young grandmother who suffers from episodic migraines. Three years ago the migraines started getting worse and now they are part of her day-to-day life. The pain goes up to level 7 on a scale of 0 to 10, despite pain medication.

Reluctantly, she agreed to take sick leave from her work, fearing she might make a mistake and compromise her professional credibility. A flicker of hope appeared this fall when she was treated with botulinum toxin (Botox®) for the first time and experienced a month and a half of respite. She is eagerly awaiting her next treatment. "Progress apparently comes in small steps," says Linda, "so I have to be patient."

Linda also signed up for My Tool Box, the Chronic Pain Self-Management Workshop offered by the McGill University Health Centre, to help her live better with her condition. "I learned to look at pain in a new way," she explains. "They taught ways to achieve better physical, mental, and spiritual health, and that pacing your activities is half the battle." She also joined an AQDC support group, which helped her break out of her isolation. "You get to know people who are coping well, and it gives you a lot of hope," she says. Linda wants to be part of her granddaughter Mélodie's life, and never misses an opportunity to share a special moment with her. Perhaps things are a bit more subdued than she'd like, but Linda aims to keep building that store of happy memories.

Photo: Laurent Dupuis

Linda and granddaughter Mélodie

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Using mindfulness to decrease your pain

A conversation with Dr. Frédérick Dionne, psychologist and author of the book *Libérez-vous de la douleur par la méditation et l'ACT (Set Yourself Free from Pain with Meditation and ACT)*

You say in your book that pain is inevitable, but suffering is optional. Why?

Suffering from chronic pain is like being shot with an arrow twice. The first arrow gives you a physical wound, for example the feeling of numbness or of being stabbed in the back. The second arrow causes an emotional wound, which is your psychological reaction to the pain, that sense of "I've had it. I can't take it anymore. It's not fair. I just can't get over this." Pain rarely comes unaccompanied. Usually there's anxiety, depression, sadness, or anger too. That's normal, because day-to-day life with pain takes such a toll. But it's that emotional response to pain that's behind what we call suffering. And even when there's nothing we can do about physical pain, we can still perhaps do something about suffering. It may be that we have more control over those negative feelings than we have over the pain itself. For example, we might decide to take a proactive approach, continue treatment, take our meds, remain physically active at our own pace, or change our attitude toward the pain… If we set ourselves up to feel better, we can avoid experiencing more than our share of anxiety, or becoming depressed because of the pain. That's what I mean when I say suffering is optional.

Why see a psychologist?

Patients often have the idea, when their doctor or family suggests they see a psychologist, that they're being told the pain is "all in their head." But purely psychological pain in that sense is rare. Physical pain is, in the overwhelming majority of cases, perfectly real. The psychologist's job is to help people deal with the suffering caused by pain—the anxiety, depression, the anger. Pain can also lead to relationship issues and financial, social, and work-related problems. Psychologists can help people manage those kinds of problems by teaching them relaxation and breathing techniques as well as ways to stay active, plan tasks better, accept the pain, manage their thoughts, and apply other strategies to help them live with those emotions better.

Would you say a psychologist is like a coach who helps us achieve our goal of living better with chronic pain?

Right, and there's not so much of a stigma about seeing a psychologist. People seek help to function at a more optimal level, even if they're not experiencing psychological suffering per se. A psychologist can take the role of a coach, providing advice, backup, and support. We do an intake assessment to figure out what a person's strengths are and what to work on, then use it all to suggest a specific, concrete plan of action for that person.

What can a person expect to get out of psychological treatment?

Studies have shown you can actually reduce physical pain through relaxation, hypnosis and meditation, and better management of pain-related emotions and thoughts. But the main benefits of working with a psychologist have to do with quality of life. In my book I talk about the importance of being true to your passions and values and of focusing on what's really important to you—whether it's your children, your relationship, your health, or your work. It's about how to live in harmony with your values and continue to do the things that matter to you despite persistent pain.

Photo: Frédérick Dionne

Dr. Frédérick Dionne, PhD, Clinical Psychologist and Pain Researcher, is a professor of psychology at Université du Québec à Trois-Rivières.

Testimony ›

Gaétan Bond: It's up to us

Gaétan Bond doesn't blame hockey or his teammates, though he still lives with the effects of an accident that left him with degenerative scoliosis. This required the implantation of Harrington rods in his back to straighten his spine and spinal fusion surgery in two places. "It was bad luck, nothing more," says Gaétan.

He has lived with pain 24/7 since age 20, but has never allowed it take over his life. "When you've got a problem like that," he says, "you face it head on and either move forward or retreat. I've always chosen to go forward. I've been lucky to have a supportive family. My wife and my kids and grandchildren are very understanding."

His latest challenge is oil painting. "I'd always dreamed of painting but I'd never really held a brush in my hand," he says. He met the instructor at a Boucherville Visual Arts Workshop opening three years ago. By the following session he had joined the class. "They took me under their wing," he said. "Those people give me so much courage. I have to paint sitting down because of my back, and the instructor showed me a trick to help with the pain—you hold your brush in your right hand and use a stick to support yourself against the canvas with your left. I take two classes a year and in the Summer I paint outdoors. It's become a real passion."

Photo: Laurent Dupuis

Gaétan Bond

Frequently Asked Questions

Become an expert on your pain

Q: How and why did my pain become chronic pain?

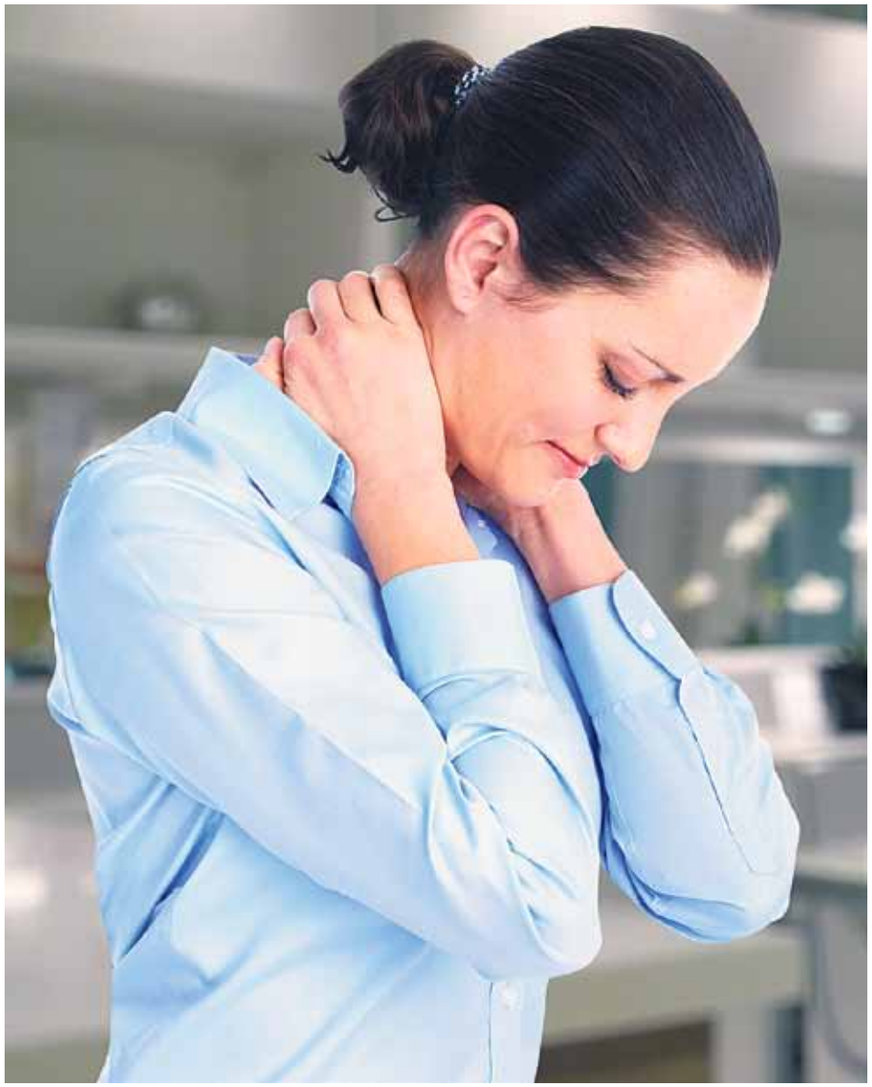
A: Many studies seem to indicate that chronic pain (CP) may have a genetic component. We know that women are more likely than men to suffer from CP. Age also plays a role: the older people get, the higher their risk. Decades of research have also shown that there are two major causes of CP: (1) too many pain signals going to the brain (neuronal hyperexcitability); and (2) the brain's inability to keep pain signals from entering (deficiency of the inhibitory descending pathways). Both phenomena can also occur at the same time.

Moreover, we have an internal pain relief system that involves, among other strategies, the release of endorphins and other substances. A deficiency in or disturbance of this system can lead to the appearance or persistence of CP.

Intense pain, as in the initial days of recovery from surgery, or prolonged pain, as suffered by burn victims, can also affect the central nervous systems on the cellular level so that it no longer responds the same way to pain as it once did (hypersensitivity).

Lastly, CP often has harmful effects on various aspects of daily life, leading to diminished functioning, poor sleep, or depression, which in themselves can perpetuate pain and make it more severe.

(Manon Choinière, PhD, Researcher, CHUM Research Centre, Professor, Department of Anesthesiology, Faculty of Medicine of the Université de Montréal)



Q: What should I do to prepare for my doctor's appointment?

A: It's important to take the time to prepare for each doctor's appointment. If it's an initial consultation for chronic pain, be sure to cover the following:

1. When the pain started and what triggered it
2. Whether it's constant or intermittent
3. Where the pain is and whether it radiates elsewhere in your body
4. How intense it is on a scale of 0 to 10
5. What it feels like (burning, twisting, pinching, electric shock, etc.)
6. Things that seem to aggravate or relieve it
7. How it's affecting your day-to-day home life, work, social life, and sleep

Tell your doctor what you've done to improve your pain and what treatments seem to help. Remember to talk about any side effects from treatment, if you experience any.

(Dr. Aline Boulanger, Director of the pain clinic at CHUM and at Sacré-Cœur Hospital in Montreal)

Q: I have a lot of questions about medications but my doctor is hard to get hold of. Who can help me?

A: Your pharmacist is a great resource and is available anytime, although it's still preferable to make an appointment so you can ask your questions in a more private setting.

(Murielle Marois, Quebec City support group co-facilitator)

Q: I've been prescribed narcotics but I'm afraid to take them. My daughter doesn't want me to either. I don't know what to do.

A: Narcotics are powerful pain-fighting medications. Your daughter has a point—you should only take them if they're actually needed to treat your pain. But if your doctor

prescribed them, it means that she or he believes they're the appropriate treatment for you. People are often afraid of narcotics because they're worried about becoming addicted or experiencing confusion. In fact, it's very rare for someone taking them for pain to become psychologically addicted, that is, to become unable to do without them. Confusion is also rare if you start with small doses. If you experience confusion, remember that everything goes back to normal once you stop taking the medication, which is also true for fatigue and sleepiness. The most common side effect is constipation, which can generally be controlled with laxatives.

The best way to find out whether a narcotic is the right medication for you is to try it as your doctor prescribed. If the side effects outweigh the pain relief you experience, you can stop taking the medication and the side effects will disappear.

(Dr. David Lussier, Geriatrician)

Q: My doctor recommended I go to a pain clinic. Can I expect to be cured? Will my pain go away?

Patients often have high hopes for pain clinics. Generally speaking, you can expect your relief to be partial. For most patients, it's

Q: Why do you recommend exercise for people with chronic pain? When it hurts, you don't always feel like being active!

A: Studies show that sedentary people lose 10% to 15% of their muscle mass per decade after age 50, whether they suffer from chronic pain or not. Exercise is more effective for pain management than ice, heat, TENS, or massage. It needs to be part of everyone's daily life, but it's even more important for people with chronic pain, to keep them from falling into a cycle of deconditioning. Most people become less and less active because it hurts to move. In time, their muscles become so weak that they struggle to do anything and develop a fear of movement (kinesiophobia). Eventually the fatigue becomes overwhelming.

Progressive return to exercise helps the body stand up better and reactivates the muscles. Exercise stimulates the production of endorphins, our natural form of morphine, and may reduce pain intensity and improve pain tolerance. It also reduces the effects of stress and anxiety and improves self-esteem.

Motivate yourself by setting a goal that's meaningful for you—taking care of your grandchildren, continuing to work, staying independent in the long term. If there are things you can't do now, you won't get them back by magic. Everything you give up doing is gone for good unless you find the will and motivation to start doing it again. Push your limits back gradually while respecting your pain, and both your ability to function and your quality of life will improve.

(Carole Haworth, Physiotherapist)

Q: Is fibromyalgia related to another disease, or can you have fibromyalgia all by itself?

A: Fibromyalgia is a disease in itself and can exist in the absence of any other disease. It's possible to develop other diseases along with it, but you can also develop fibromyalgia alone.

(Line Brochu, Vice President of AQDC and Quebec City support group facilitator)

about a 30 to 50% reduction in pain intensity. It may not sound like much, but for most patients it's quite meaningful.

(Dr. Aline Boulanger)

Q: What resources are available to help people who suffer from chronic pain, loneliness, isolation, and loss, but who don't have much money?

A: The AQDC's support groups can help you break out of your isolation and show you valuable skills to manage chronic pain better. Some forms of loss are harder to get through than others. Deep and prolonged sadness can be a sign of depression. Don't be afraid to seek help. Along with medical advice you can get started on therapy with a psychologist or social worker, either privately or through your CLSC. Your CLSC can also explain what programs or tax credits are available and steer you towards the appropriate community resources. Taking back control of your life begins with deciding what's important and possible for you, what you want to have in your life, and what you need to achieve your goals. Dealing with these issues will require you to do some work on yourself.

(Murielle Marois and Suzanne Deutsch, support group co-facilitators)

Twelve tips for a better sleep

Chronic pain makes it hard to sleep properly, and a rough night can worsen the pain the following day. How do you break the cycle?

By Christiane Manzini, Centre for Advanced Research in Sleep Medicine

1› Keep a sleep diary for a month.

Figure out your sleep rhythm by recording your wake times and sleep times, as well as when you wake during the night, get up to go to the bathroom, and go back to bed afterwards. Add in naps and activities during the day (walking, swimming, yoga, etc.) as well as the periods of drowsiness. Fatigue is normal after exercising and may require a moment of relaxation, although not necessarily sleep but maybe a nap. "When you add up the hours of sleep from your sleep diary," says Manzini, "you may be surprised at how much you actually do sleep."

2› Harmonize your sleep patterns with your activities.

Are your activities in harmony with who you are? If you're retired or off work, are nighttime activities getting in the way of the physical or social activities you'd like to enjoy during the day? Careful—too much opting out can lead to isolation!

3› Stop blaming yourself.

Sleep isn't something you learned to do! If you used to sleep like a log but now find that work, kids, stress, grief, or illness are getting in the way, you need to adjust the way you look at sleeping. Our sleep patterns change at different times in our lives.

4› Understand sleep.

Falling asleep can take up to 30 minutes. Actual sleep is divided into between four and six 90-minute periods, each separated by a mini-awakening that might not even be noticed. Periods of wakefulness can range from a few seconds to several minutes and get longer as we age.

5› Don't be discouraged.

When you wake up in the night and can't get back to sleep, it's easy to worry about feeling even worse the next day from lack of sleep. Accepting periods of wakefulness can reduce your anxiety level. If sleep doesn't come within 30 minutes, get up and try a quiet activity. Go back to bed when you feel sleepy again.

6› Don't fall asleep in front of the TV.

When you fall asleep and wake up several times as you watch television, you are teaching your body not to fall into a deep sleep. It is better to sit up to watch television and go to bed at the first sign of drowsiness.

7› Ban computers, tablets, and TV in bed.

Melatonin, the hormone that makes you fall and stay asleep, is secreted in the absence of light. Seek darkness at night. Melatonin is suppressed during the day when you're exposed to natural light.

8› Get your body temperature right.

Your body gets rid of heat while you're falling asleep. Although it's recommended that you keep your hands, feet, and nose (!) warm to help you fall asleep, it's preferable to sleep in a cool room. A hot-water bottle can be used to warm the bed, but don't take a hot bath before you hit the sack because it will slow down the cooling your body needs for a good sleep.

9› (Re)learn how to sleep.

If you really want to fix your sleep problems, set a schedule and follow it faithfully. Establish a bedtime ritual, such as reading, soft music, airing out your bedroom, etc. Choose a bedtime and wake time that allow between seven and eight hours' sleep, and then get up as soon as the alarm goes off, even if you had a bad night. If you want to adjust your schedule, do it gradually. Aim for the number of hours your body needs, which can be divided into one, two, or three blocks at night and another during the day, with no naps after 3 p.m.

10› Don't lounge around in bed.

Ideally, you should always get up at the same time. Take a hot shower to raise your body temperature, have breakfast (very important), and spend time near a window to let the natural light regulate your body clock.

11› Eat properly.

The rhythm of mealtimes is very important. If pain is interfering with your sleep, it's best to have your biggest meal at noon.

12› Get exercise.

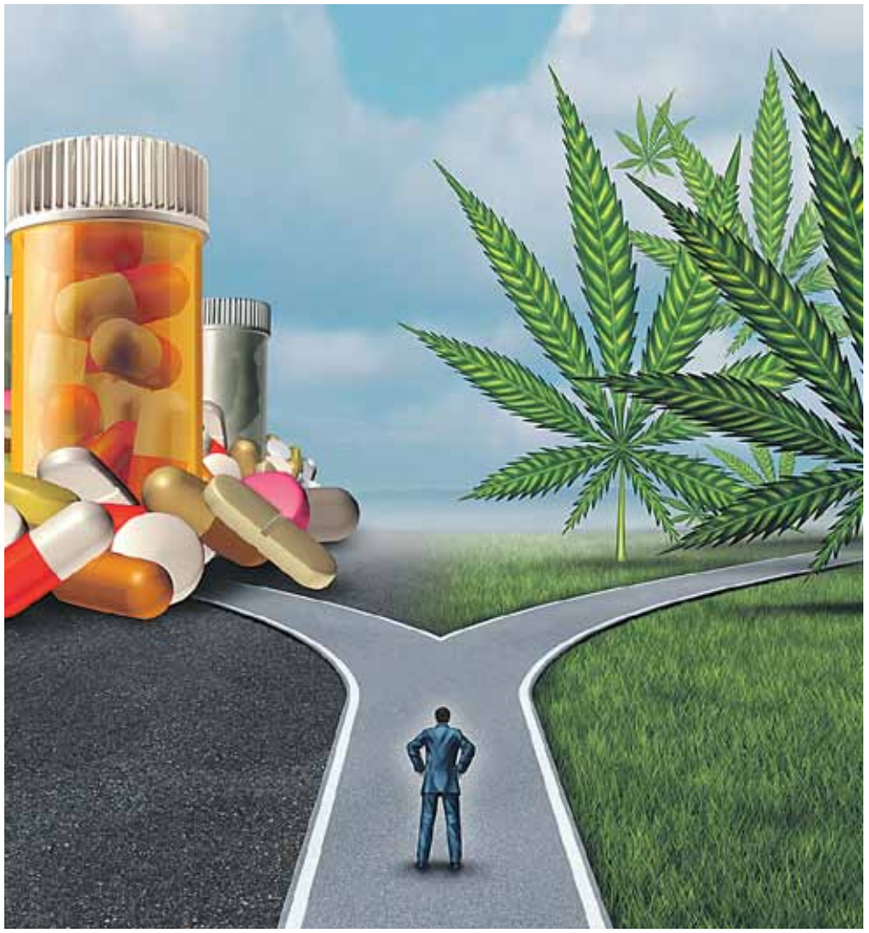
Even if it's difficult, daytime exercise will help you sleep better. Do what you can, starting with 20 to 30 minutes of walking every day.

Medical Marijuana and Chronic Pain

The legalization of medical marijuana has sparked patient interest in exploring its therapeutic potential. However, compared to conventional treatments we still know little about its benefits—only that it seems to provide some relief of neuropathic pain. The AQDC looks at the situation.

Dr. Mark Ware, the lead author of a cannabis study, is the director of clinical research at the Alan Edwards Pain Management Unit of McGill University Health Centre and executive director of the Canadian Consortium for the Investigation of Cannabinoids (CCIC). He is among those in the medical profession who support the therapeutic use of marijuana. But if you come to his office in hopes of walking out with a prescription for marijuana, you might be disappointed.

"It really worries me when patients say 'if you don't give me some I'll go somewhere else,'" says Ware. "Whoa—I'm not here to prescribe marijuana. I'm here to help people manage their pain, which is not the same thing." For Ware, chronic pain management has a physical, pharmaceutical, psychological, and spiritual component. "To manage it, you need all the parts," he says. "Marijuana has its place in the therapeutic arsenal, but it's not recommended in every case."



Medical marijuana is safer and of better quality than what's sold on the street. Production standards are very strict and doctors can prescribe it legally. However, as Ware explains, there is no clinical data on its long-term effects or on whether its therapeutic benefits outweigh the risks.

Because even though it is less toxic than some medications, marijuana is not harmless. It is not recommended for individuals with a history of psychosis or schizophrenia, for example who have a severe or unstable heart condition, for pregnant or nursing mothers and it is strongly discouraged for young people under 25, whose brains are still developing.

Even today, too little is known about its therapeutic possibilities. "We know more about the lung cancer risk and memory effects of recreational marijuana use than we do about its benefits," adds Ware, "partly because it's been an illegal drug." Scientific studies to date have involved people in good health who were pain free, not taking multiple medications such as opiates, and not under treatment for anxiety, depression, or other medical problems.

Rising demand

Dr. David Lussier, director of the Montreal Geriatric Institute's Chronic Pain Management Outpatient Clinic, works with the elderly. He is often asked about marijuana, even by patients in their eighties, who are often prompted by their children or grandchildren. So far, none of them has been prescribed medical marijuana to smoke or cook with.

"It's fairly common for patients to ask for it because they think it's less harmful than opiates," says Lussier. "The problem, I think, is that medical marijuana has been presented in the media as some kind of panacea, something that relieves any kind of pain, with no side effects. That's just not the case." Like all pain medications, marijuana is not a cure. At best, it can alleviate certain kinds of pain.

A third-line medication

According to Dr. Mark Ware, the primary indication for medical marijuana is peripheral neuropathic pain caused by nerve damage from diseases like multiple sclerosis, and only for people who've tried everything and still can't get their pain under control. Its effectiveness in relieving severe back pain or fibromyalgia is unproven.

However, the side effects associated with recreational use, such as dizzy spells, drowsiness, confusion, and loss of balance, suggest we should proceed cautiously. Users of medical derivatives of cannabis (cannabinoids) may sometimes feel the same effects. But the advantage cannabinoids have is that they are safer and dosages are easier to control. According to Ware, a tiny dose can help control pain with minimal psychoactive effects.

Richard Bernard suffers from intense pain caused by polyneuropathy and other conditions, which can vary daily between 4 and 9 on a scale of 0 to 10. He had heard that marijuana might help relieve neurological pain. But he was still reluctant to try it.

"I tried smoking pot when I was young and it wasn't my thing," he recalls. "But I heard there was this other option—cannabinoids—and for pain control you just took a small dose." With his doctor's approval, he tried it for a month. Now his pain ranges between 2 and 3 on the 10-point scale. "It's a gift," he says.

Doctors in Quebec must comply with the laws governing the use of medical marijuana. Those laws do not apply to prescription cannabinoids. A provincial register will be set up to collect important data on people's experiences with medical marijuana.

Marijuana is not really a form of tobacco, but smoking it or being exposed to its secondhand smoke can increase the risk of cancer (Source: Canadian Cancer Society).

Support groups can help you bounce back

Support groups have become the flagship program of the Association québécoise de la douleur chronique (AQDC). Support groups help chronic pain sufferers break out of their isolation and learn to better deal with pain. Research has shown that peer support groups can help reduce distress, increase knowledge uptake, and provide the spark of hope people need to take control of their lives and make improvements that can enhance their quality of life.

"Our vision is to have a support group in every part of the province," says Céline Charbonneau, AQDC treasurer and member of the services committee responsible for support groups. "We want to make the AQDC a go-to resource known throughout the healthcare system—a bit like AA for alcoholism or Leucan for children with cancer. The more support groups we have, the better known we'll be, and that will make it easier for people to get the information and support they need."

The AQDC currently has 12 support groups. There are five in Montreal (Hôpital Sacré-Cœur, CHUM–Hôtel Dieu and Rivière-des-Prairies for francophones; West Montreal and West Island for anglophones), one in Laval, two in Montérégie, one in Mauricie, one in Centre-du-Québec (in partnership with groupe Action Libellule), and two in Quebec City.

Meetings are free and confidential. To join, call AQDC at 514-355-4198 or 1-855-230-4198 toll free or send us an email at aqdc@douleurchronique.org.

Our stories ›

"It's hard to accept the fact that chronic pain is something I'll suffer from for the rest of my life. I need to be with people I share that reality with. I need that kind of community—that helps me see and manage my pain differently."

(Bernard, age 56)

"When you suffer from chronic pain, there aren't always many opportunities to socialize. It's hard to fit in in the world of healthy people. A support group gives us all a place where we can just be ourselves, and it forces us to overcome that sense of being alone. It's also a chance to make new friends. It's amazing what you can learn at the meetings—things about medications, treatments, and tricks to make life easier. You learn as much talking to other members as you do from the actual presentations."

(Denise, age 63)

"Support groups provide answers to my questions, along with 'tools', information, tips, and references I can use to get back some of my quality of life. Being part of a group encourages me to keep plugging away and not give up. It makes me realize I'm not fighting this disease alone."

(Richard, age 60)

"Support groups changed my life! I always look forward to the next meeting. Even on the toughest days I know it will at least help me psychologically. I've found good friends there who understand what it's like to live with chronic pain. You get the chance to share what you're going through, your worries—and your victories! You get support and ideas and tips that help you keep going. I've discovered that support groups are a fantastic resource, and they've really given me a chance to blossom!"

(Mélanie, age 34)

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Or send this form to: Association québécoise de la douleur chronique
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