



THE PAINFUL TRUTH

The State of Pain Management in Canada



Boston
Scientific



THE
PAINFUL
TRUTH
SURVEY

CONTENTS

- 04 Foreword
- 05 Executive summary
- 06 Introduction
- 07 Living day-to-day with pain
- 09 A heart-breaking impact on loved ones
- 10 Economic woes: a burden to individuals and society
- 11 An underdiagnosed and misunderstood condition
- 12 Discouraging treatment experiences
- 13 Surgery often repeated
- 14 A need for alternative treatments
- 15 The time is now
- 16 Supporters and references

THE PAINFUL TRUTH

Survey report

FOREWORD

More than one in five Canadians suffer from a condition that costs our country more than cancer, AIDS, and heart disease combined,¹ a condition that typically affects them for longer than 5 years. Sometimes, it can last a lifetime. It can have a significant impact on their ability to be active, both professionally and socially. Worse still, this disease affects not only their quality of life, but also that of their friends and relatives. It may sound unbelievable, and it may not be widely known, but this is the reality of chronic pain, a common disorder defined as pain lasting for more than six months.

The causes of chronic pain are so diverse – and sometimes there is more than one cause – that these people go without diagnosis in more than a quarter of cases. With more than half of chronic pain patients unsatisfied by medication alone, our healthcare system has understandably struggled with the challenge of how to meet their needs. The time for change – the time for progress in identifying and publicizing information on the innovative alternatives – is now.

The Painful Truth Report aims not only to provide healthcare professionals with a better understanding of the state of chronic pain in Canada, but also to bring to light the hardship the condition can cause in the lives of sufferers and their families, and the detriment it can cause to their relationships and ability to work. The numbers herein represent chronic pain from the patient's perspective, including the unsuccessful surgeries, the frustration in trying to find appropriate care, and the failure of medication to provide relief.

To me, improving the current state of chronic pain management in Canada is of critical importance. More than 71% of chronic pain sufferers are still in pain for 12 or more

hours per day despite having tried, on average, 2.4 different treatments. They've also waited nearly 18 months for a diagnosis and only 1 in 5 reported coming away from their first conversation with a healthcare professional with a feeling of hope. Non-pharmaceutical therapies, despite having been recognized as effective by specialists, are rare. In the case of neuromodulation, more than 77% of this survey's respondents were unaware of the procedure.

As a neurosurgeon and chronic pain specialist, I recognize the challenge in diagnosing neuropathic pain, but I also understand the importance of remaining open-minded regarding the new developments we've made with other effective treatments, especially non-medicinal options like Spinal Cord Stimulation (SCS). These are a step forward, and a much-needed one at that, towards building a better range of therapeutic options, towards rekindling hope for the patients, and towards providing a better quality of life to those who need it most.

With this report, we hope to raise awareness of the reality that these Canadians face, and that this study will be part of a longer conversation that continues the assessment of the risks, benefits and cost-effectiveness of alternative treatments among patients and their families, and among healthcare providers and administrators.



Dr. Michel Prud'Homme, MSc., Ph.D., M.D.
President
The Canadian Neuromodulation Society

Canada is suffering...

Chronic pain affects **1 in 5²** Canadian adults.

On average, sufferers have been living with pain for almost **6 years**.

Canadians have tried an average of **2.4 prescribed treatments** to alleviate their chronic pain.

The annual cost of chronic pain to Canadian taxpayers is estimated to be as high as **\$62 billion³**.

27% of chronic pain patients have not yet received a diagnosis.

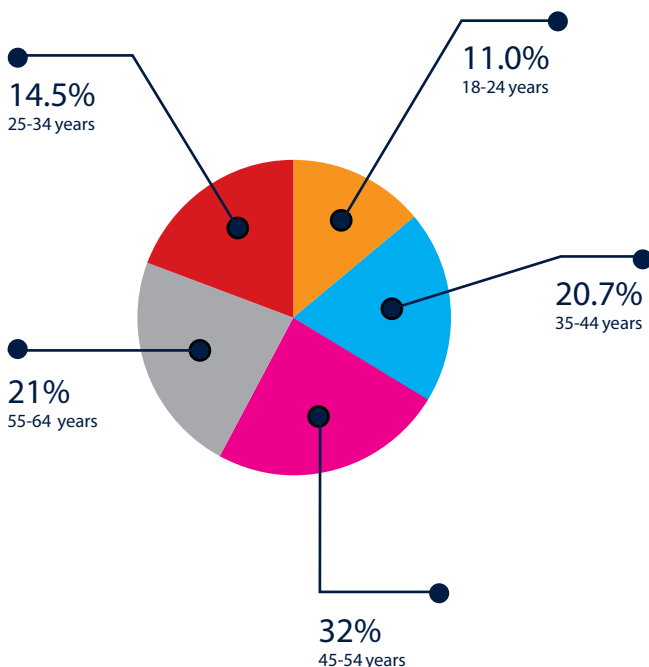
THE PAINFUL TRUTH EXECUTIVE SUMMARY

The Painful Truth Report was launched to heighten awareness of the prevalence and burden of chronic pain in Canada. Through its efforts, we strive for a change in how people with this type of pain are diagnosed, and to improve their access to innovative and cost-effective treatment and management options, like Spinal Cord Stimulation (SCS).

Sponsored in cooperation between the Canadian Pain Coalition and Boston Scientific, this research, conducted through a survey by Leger, The Research Intelligence Group, sheds light onto the impact of chronic pain on both the lives of sufferers and their families. Further, the study explores their experiences with treatment and highlights a significant unmet need in optimal pain management in Canada.

Building on data from a similar study in the European Union, The Painful Truth also provides insight into the way in which treatment opportunities differ in different parts of the world, and how patient experiences can be similar even an ocean away.

Total Survey Respondents by Age



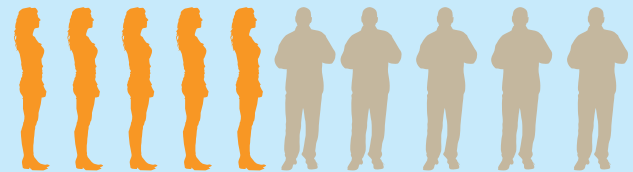
METHODOLOGY

A random sample of **1,003 adults aged 18 to 64**, who define themselves as chronic pain sufferers.



Chronic pain is defined as **pain lasting 6 months or longer** when not related to cancer.

Respondents were **52% men** and **48% women**



Responses were solicited through a national online survey in April 2014.



INTRODUCTION

Chronic pain is a condition that is misunderstood. It can disrupt the lives of sufferers, causing intense physical challenges and emotional anguish. It has been associated with worse quality of life than either chronic lung or heart disease⁴, affects one in five adults in Canada², and it is one of the most common conditions for which people seek medical attention.⁵

Types of chronic pain

Chronic pain involves a variety of physical and psychological factors, but the subjective and personal nature of pain makes it difficult to measure and define.

Though most people are familiar with pain coming from a known source, chronic pain can occur when no obvious cause can be found. This is thought to be due to changes in the nervous system.

There are two main classifications of chronic pain, though people can suffer from a combination of both⁶:

- **Nociceptive pain** is associated with tissue damage, as with a cut, burn or broken bone, and indicates healing or repair functions, often including inflammation.
- **Neuropathic pain** is caused by damage to nerve fibers in the peripheral or central nervous system. It is called 'maladaptive' because unlike nociceptive pain it does not go away once healing and repair

have occurred. Patients suffering from neuropathic pain describe the feeling as a numbness, tingling or burning similar to an electric shock-like sensation.

Most people will experience nociceptive pain at some point, but neuropathic pain is often under-diagnosed and as a result, under-treated.⁷ This type of chronic pain can be associated with severe disability and psychological illness.⁸

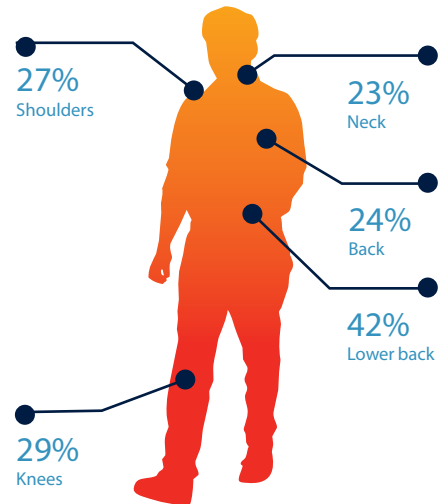
A lifelong condition

The survey revealed that on average, Canadian sufferers have lived with their chronic pain for around six years, and one in eight have lived with the condition for longer than fifteen years.

The Painful Truth Survey found that only 30% of respondents believed their pain could be cured.

Furthermore, 8% – nearly one in ten – told us that they didn't think their pain could be managed or cured at all, highlighting a lack of hope for the future.

Areas of the body most affected by pain, by survey respondents



More than half of respondents (55%) stated that the back and lower back were the most common areas to experience pain.

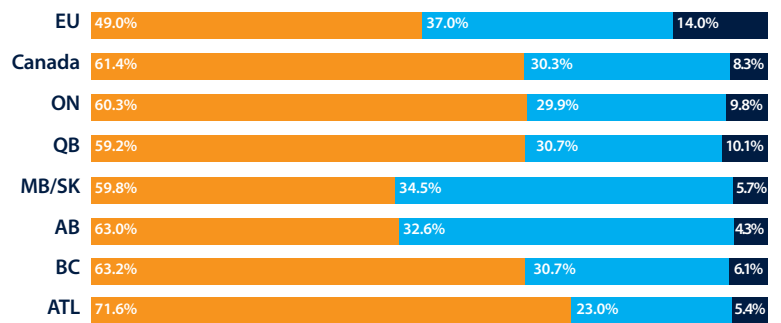
FAST FACTS

In Canada, the back – specifically the lower back – is the most commonly reported location for chronic pain.

Common Causes of Back Pain:

- Injury or trauma
- Arthritis
- Spinal disc abnormalities or herniation (a "slipped disc")
- Failed Back Surgery Syndrome (FBSS) – a persistent lower back and leg pain affecting those who have undergone an unsuccessful spinal surgery
- Indeterminate – in many cases, unfortunately the cause of pain is either undiagnosed or unknown

Figure 1. THE UNDERSTANDING OF CHRONIC PAIN BY SUFFERERS



■ It cannot be cured – it is a long-term condition that can only be managed with medication to improve symptoms.
■ It can be cured with the right type of treatment or surgery.
■ It cannot be cured or effectively treated or managed with any available medication.



LIVING DAY-TO-DAY WITH PAIN

The impact of chronic pain on a person's quality of life can be devastating. Not only can it be significantly physically disabling, but it also increases the risk of psychological disorders, such as depression and anxiety. In discomfort and without the hope of relief, many sufferers find it difficult or impossible to sleep, work and function normally.⁸

The Painful Truth Survey revealed that simple daily activities like bathing, getting dressed, cleaning, shopping and even sleeping were more difficult for people with chronic pain. Unsurprisingly, the ability to exercise was most troubling for respondents, with 70% finding physical activity difficult to manage, and 15% completely unable to do it at all.

Being social, something many of us can take for granted, can also be difficult for chronic pain sufferers, as more than a third have trouble driving, or even travelling outside of their homes.

These are long-term issues, and unfortunately they can lead to isolation, compounding the hardship affecting sufferers. In fact, people afflicted with chronic pain are more likely than others to consider suicide, and over twice as likely to actually commit suicide.⁹

Exhaustion is an added burden of chronic pain, with two thirds of survey respondents reporting that they have difficulty sleeping.

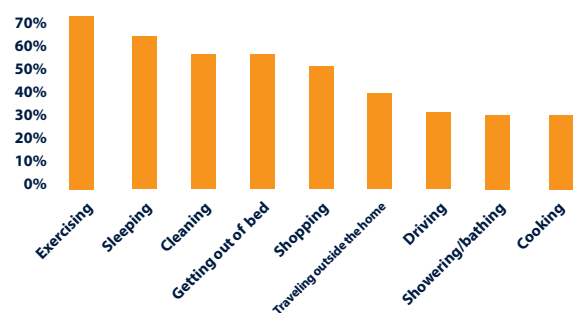


When my pain is at its worst, I'm unable to do anything. I am literally bedridden with pain. Basic daily activities seem impossible and overwhelming and I become housebound. The impact this has on you over time is huge. I've struggled with depression and a feeling of hopelessness and at one point felt suicidal. Over time, you start to figure out some strategies and techniques that work for you, but it varies from person to person. I find that being physically active every day that I'm able, engaging in regular exercise and eating nutritious foods helps me to deal with the pain and manage better.

-Sandra, Vancouver, BC



Figure 2. DAILY ACTIVITIES MADE DIFFICULT BY CHRONIC PAIN





Nearly 4 in 10 people living with chronic pain struggle to take care of their children, and 3.6% cannot manage it at all.



Chronic pain can be debilitating and have a tremendous negative impact on a patient's life including physical effects, emotional and psychological trauma, financial hardships, a deterioration of personal relationships as well as loss of identity and meaning in life. We need to improve quality of life for Canadians living with chronic pain, by increasing awareness and education in pain management for healthcare professionals, patients and caregivers, as well as improving access to interdisciplinary pain management therapies.



-Dr. Anita Chakravarti, Saskatoon, Saskatchewan



A HEART-BREAKING IMPACT ON LOVED ONES

Though many of us can imagine the direct impact of chronic pain on the individual sufferer, some of the more discreet, silent impacts of the condition can often go unnoticed, particularly the strain it places on loved ones.

Due to the debilitating nature of chronic pain and the high percentage of respondents who told us that household duties were much more difficult when dealing with the condition, many sufferers may become physically or emotionally dependent on others. Spouses may be required to take on additional household responsibilities, leading to an emotional impact

While 27% of survey respondents said that their relationships had become harder at times, more than 1 in 20 told us that they had even separated or divorced as a result.

that could affect the entire family. Those with children are faced with an additional strain.

'My pain has ruined my marriage'

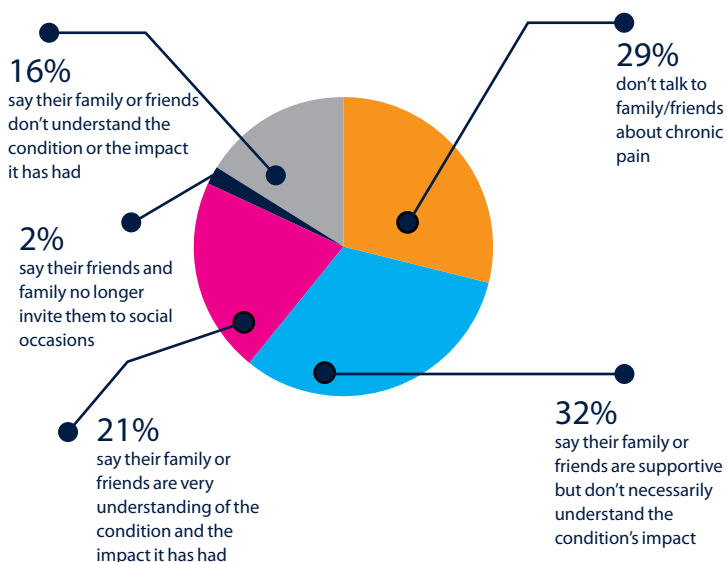
It can be extremely difficult to live with a loved one and watch them suffer. According to research, faced with a partner in chronic pain, many may be worried or uncertain about their future condition and may feel helpless and lose hope as they try to understand the condition.¹⁰

Interaction as a couple can be strained, and many survey respondents indicated that sex and intimacy are one of the most impacted areas of a relationship (19%), and even the ability to enjoy activities together is often compromised (30%).

'I can't talk to my friends and family'

Only 1 in 5 survey respondents said that their friends and family are very understanding of their condition, and 32.2% reported that while supportive, their loved ones didn't really understand chronic pain. Another 28.5% highlighted that they don't even talk to their family and friends about their chronic pain.

Figure 3. SUPPORT FROM FAMILY AND FRIENDS



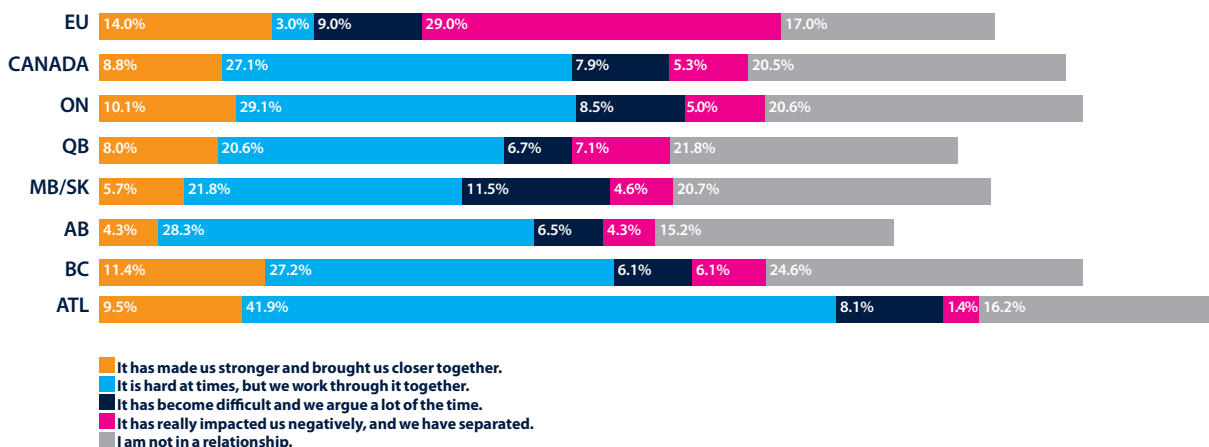
Chronic pain is a condition that doesn't just impact the individual living with pain, it has a profound effect on family and even friends. The family can experience grief, mourning the loss of the person they once knew, and a feeling of helplessness that they don't know how to help their loved one. Roles and responsibilities often have to be redefined within relationships.



-Lynn Cooper, President, Canadian Pain Coalition



Figure 4. CHRONIC PAIN AFFECTING RELATIONSHIPS



ECONOMIC WOES: A BURDEN TO INDIVIDUALS AND SOCIETY

The economic effects of chronic pain on the individual sufferers can be devastating, as living with the condition can make working difficult or even impossible. But the burden doesn't rest entirely on the shoulders of those afflicted directly by the condition. The Canadian healthcare system is under an immense pressure on a daily basis, and research has indicated that up to 78% of the visits to emergency rooms are due to pain.⁵ Chronic pain specifically has been estimated to cost the Canadian taxpayers \$62 billion per year.³

From an individual perspective, the numbers are no less troubling. More than anything else, 30.4% of survey respondents believe that their chronic pain affects their ability to work. Similarly, 34% said that their employer does not offer enough support or resources to help them perform their jobs while suffering from chronic pain. Respondents also reported that in the last 12 months, they had missed an average of 8 days of work due to their condition, with 4% having missed more than 49 days of work due to chronic pain. What's worse, four in 10 believe they have missed out on opportunities at work simply because they suffer from chronic pain.

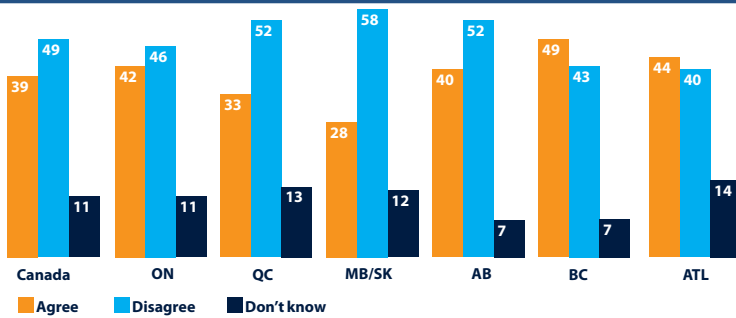


Financially, chronic pain can place enormous strain on the individual living with pain, but also on their partner or family. In addition to out of pocket medical costs and paying for alternative therapies, many people with chronic pain face a reduction in earnings, particularly those who are no longer able to work.

-Lynn Cooper, President,
Canadian Pain Coalition



Figure 5. I HAVE MISSED OPPORTUNITIES IN CURRENT OR PREVIOUS EMPLOYMENT DUE TO CHRONIC PAIN



When asked to quantify the negative effect that their condition has had on their employment, 38% of respondents said that they believe their chronic pain has negatively impacted their household income, with an average decrease of 33% across Canada. This understandably leads to further strain on sufferers, which is particularly worrying as some people with severe chronic pain may find they need to pay for support for the things they can no longer manage, such as housekeeping.

Of the people who say their earning has been impacted, the largest decrease is in British Columbia, where the average is 38% of their household income.

Figure 6. HAS CHRONIC PAIN NEGATIVELY IMPACTED YOUR ANNUAL HOUSEHOLD INCOME?

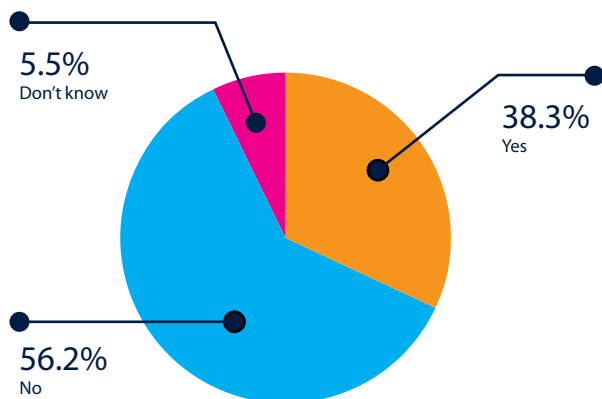
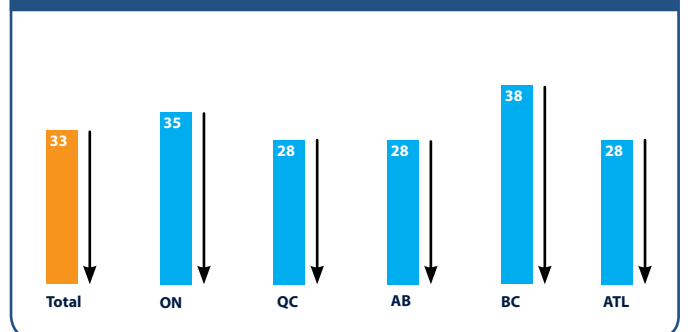


Figure 7. AVERAGE % DECREASE IN ANNUAL HOUSEHOLD INCOME



AN UNDERDIAGNOSED AND MISUNDERSTOOD CONDITION

Despite the advances in treatment and the ongoing movement to improve the standard of care for chronic pain sufferers, there is still a significant unmet need across Canada. Chronic pain can be misunderstood even by healthcare professionals, and diagnosis is often slow.

When asked how they felt after their first conversation with a healthcare professional about chronic pain, 41% of sufferers felt negatively, with almost a quarter saying they were frustrated by the experience. When asked how their healthcare professional first reacted when they mentioned chronic pain, 2% said they expressed negativity about the condition or treatments, 9.5% said they were dismissive of their symptoms or, though considerate of the condition, 14.8% said they were simply not being proactive in their approach to treatment.

Sufferers also frequently experience lengthy delays with diagnosis and referrals, meaning their pain may not be effectively managed for some time.



Only **1 in 5 (22%)** came away from their first conversation with their healthcare professional feeling hopeful about their chronic pain.

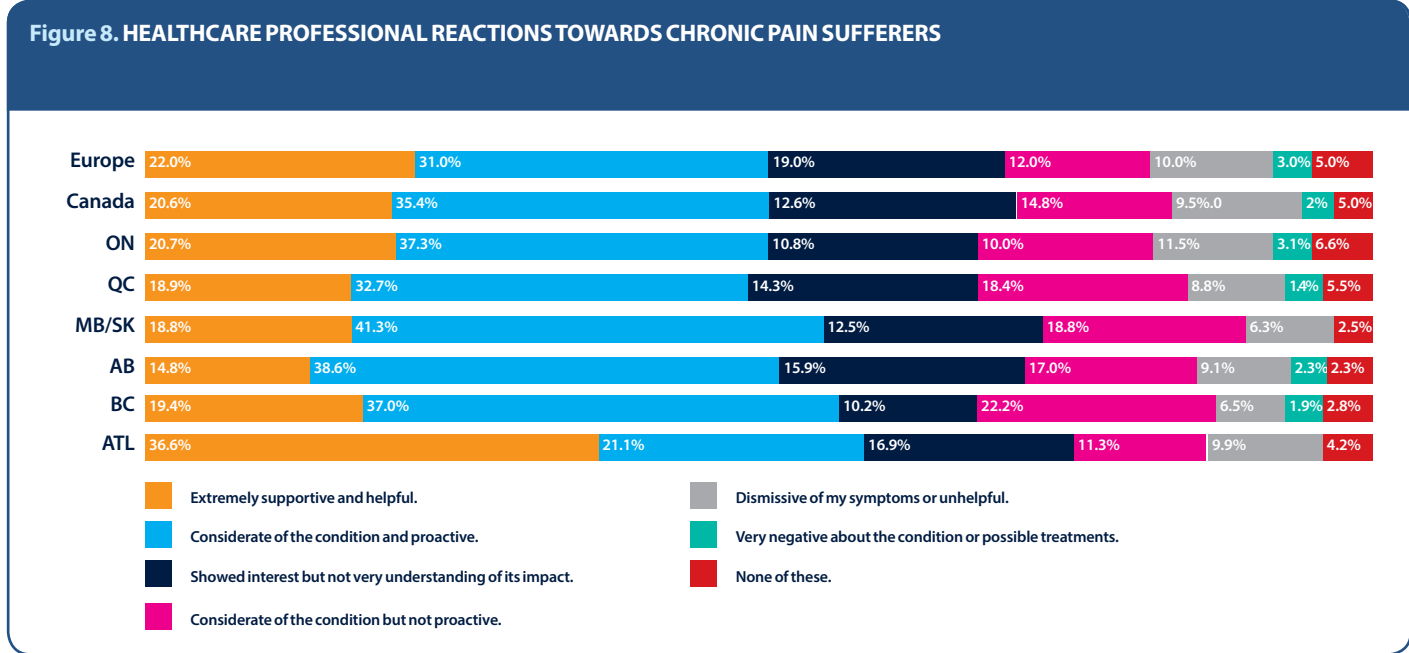


My pain first started when I was in my early 20s. One day I woke up with pain in my left hand and it wouldn't go away. I saw doctor after doctor as they tried to figure out what was going on and went through a lot of trial and error. I've been through multiple rounds of different treatments, all in the hopes of finding some relief, especially as the pain spread throughout my body. But it's hard to explain pain and many start to think it's all in your head. After 20 years of misdiagnoses I managed to find a great neurologist who suspected RSD and referred me to a pain clinic. They helped me manage my pain in a more holistic way. Now, in my mid-50s, although the condition has worsened, I am able to control my pain through a spinal cord stimulator, which has really turned my life around.

-Bill, Guelph, Ontario

Despite the fact that 62% of respondents saw their healthcare professional first when looking to learn more about their pain, research has shown that doctors are undertrained in pain management. In fact, veterinarians receive 5 times more training in pain management than Canadian doctors who treat people.¹²

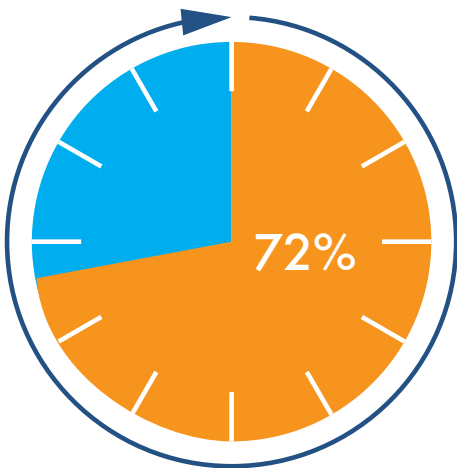
Of respondents to The Painful Truth Survey, 26.5% have not yet received a formal diagnosis for their chronic pain. Of those who have, the average time between the first meeting with their healthcare professional and their diagnosis was nearly 18 months.



DISCOURAGING TREATMENT EXPERIENCES

Due to the nature of chronic pain, conventional medication may not be sufficient. According to the Canadian Pain Coalition, up to 30% of pain may be reduced with medication and this still leaves room for a well-rounded pain management plan that includes multidisciplinary pain management techniques and self-help strategies. Of respondents to The Painful Truth Survey, only one quarter feel they have had a good or excellent experience with conventional medication alone.

These conventional medications, including non-steroidal anti-inflammatory drugs (NSAIDs), anti-neuropathic agents and opioids, continue to be a mainstay of treatment for pain, despite the knowledge that multidisciplinary



72% of pain sufferers are still in pain 12 hours or more per day despite treatment.

pain management is effective and despite the introduction of new treatment options in recent years, like Spinal Cord Stimulation (SCS) or electrotherapy. According to Canadian research, almost 70% of long-term opioid users were worried about their addiction potential,² and death related to pain medication doubled in Ontario between 1991 and 2004.¹³

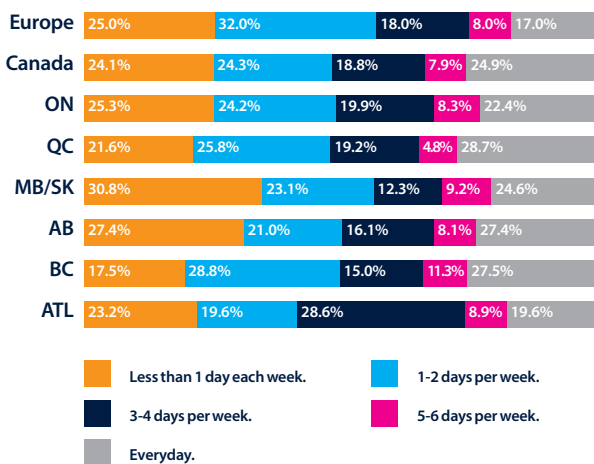
The Painful Truth Survey also revealed that a third of respondents have been prescribed three or more treatments for their condition, but almost half of those (48%) only experience pain relief for up to 2 days per week. In fact, 72% reported that they are still in pain for 12 hours or more per day, despite treatment.

Figure 9. EXPERIENCE WITH PRESCRIBED TREATMENTS



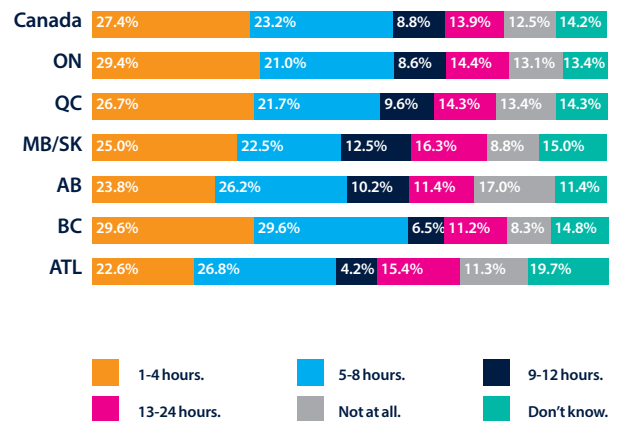
Only a quarter (25.3%) are satisfied with pharmacological treatment.

Figure 10. PAIN RELIEF ON A WEEKLY BASIS



Almost half (48%) of sufferers who have seen a healthcare professional only experience pain relief for a maximum 2 days per week.

Figure 11. PAIN RELIEF ON A DAILY BASIS



1 in 8 (12.5%) do not experience any pain relief at all.



SURGERY OFTEN REPEATED

The Painful Truth Survey discovered that of people suffering from back or lower-back pain, 1 in 10 (11%) have had one or more back surgeries to treat it.

Even when people have undergone a spinal surgery, it's common for them to undergo another surgery to either correct problems related to surgery or to replicate results that had only provided temporary relief. Of the people who had been treated with back surgery, almost half (49%) had endured repeat surgeries.



Spinal surgery is becoming much more common for those with back pain, but is still an invasive and complex procedure. It can have excellent outcomes for some patients, but it's not for everyone and unfortunately some are subjected to multiple surgeries and ultimately are unsuccessful. For those facing repeat surgeries, other options need to be considered.



**-Dr. Andrew Parrent,
London, Ontario**





A NEED FOR ALTERNATIVE TREATMENTS

With a third of sufferers having tried three or more prescription treatments to alleviate their chronic pain, and almost half still living in pain most days of the week despite their current treatments, the need for alternatives, including a multidisciplinary pain management plan is obviously high. With so many desperate for relief, it is unsurprising that there are many different treatments being sought today. The Painful Truth Survey found that at least 20 different methods of treatment had been pursued by respondents.

These treatments range from anti-convulsants (2.8%) to electrotherapy (6.1%) and newer procedures like Spinal Cord Stimulation (1.2%). Many of these show promise, but have not yet been widely prescribed due to low uptake of and awareness by sufferers and even healthcare professionals. In fact, despite a wealth of new research to show their benefits, treatments like SCS are more likely to be discovered on television (21.8%) than in a doctor's office (17.9%).

WHAT IS SPINAL CORD STIMULATION?

One of the more innovative procedures available to patients with chronic pain, Spinal Cord Stimulation (SCS) is not widely known even among the people it would most benefit. Of the respondents to The Painful Truth survey, only 22.9% had even heard of the technique.

- The technique involves a small device being implanted beneath the skin's surface, which electrically stimulates specific nerves of the spinal cord where pain signals to the brain can be intercepted, resulting in an inhibition of pain sensation.
- The frequency and duration of the stimulation is controlled by the individual with a remote device. SCS can be used to treat sufferers with pain in more than one area.

THE TIME IS NOW

As the population continues to live longer, there is now more than ever a need for improvement in the diagnosis and management for people with chronic pain. Though innovative and cost-effective options do exist, not everyone responds to pain the same way and sufferers and healthcare professionals alike do not always have the necessary information.

Training in pain management among healthcare practitioners is also a concern, which makes treating the condition a serious issue that needs to be addressed in all provinces and territories Canada-wide.

Though the Canadian Pain Coalition and the Canadian Pain Society launched the National Pain Strategy in 2012, more can still be done to enact change.

A national plan for pain management should include:

- Provision of comprehensive information about all chronic pain management options for healthcare professionals and sufferers.
- Access to evidence based chronic pain management within Canada's health systems.
- Tools for healthcare professionals to aid prompt diagnosis of chronic pain and clear referral pathways to specialist services.
- Evaluation of the long-term cost benefits of new technologies, like Spinal Cord Stimulation, and a framework to improve access to treatment. These treatments can have a positive effect not only on the patients' quality of life, but on the economic impact of chronic pain in Canada.
- Enhanced training for healthcare professionals at all levels on diagnosing, treating and managing chronic pain, including new and innovative options as they emerge.
- Support for chronic pain organizations and the services that they provide.



About Canadian Pain Coalition

The Canadian Pain Coalition (CPC), incorporated as a not-for-profit in 2004, is a partnership of pain consumer organizations, individuals living with pain, health professionals treating pain and scientists studying more effective ways of managing pain. The goals of the CPC are to: (i) promote sustained improvement in the understanding, treatment, management and prevention of all types of pain in Canada; (ii) promote awareness of pain issues among the general public; (iii) provide educational information about pain conditions and management to people living with pain; and, (iv) to be the "National Voice of People with Pain" in discussions with government and policy makers. CPC accomplishes these goals through its education and awareness programs in conjunction with advocating for improved access to multi-disciplinary pain management within Canada's health systems and participating in research that improves the lives of all Canadians living with pain. For more information about the Canadian Pain Coalition visit www.canadianpaincoalition.ca

CPC disclaimer: The Canadian Pain Coalition (CPC) does not endorse or recommend any product, course of action or person related to chronic pain management. CPC recognizes that informed choice of pain management options is important.

About Boston Scientific

Boston Scientific transforms lives through innovative medical solutions that improve the health of patients around the world. As a global medical technology leader for more than 30 years, we advance science for life by providing a broad range of high performance solutions that address unmet patient needs and reduce the cost of healthcare. For more information, visit us at <http://www.bostonscientific-international.com>.

REFERENCES

- 1 Phillips, C. J. and D. Schopflocher (2008). *The Economics of Chronic Pain*. Health Policy Perspectives on Chronic Pain. S. Rashed, P. Taenzer and D. Schopflocher. UK, Wiley Press.
- 2 Moulin, D. E., Clark, Alexander J., Speechley, M., Morley-Forster, P. K. "Chronic pain in Canada—Prevalence, treatment, impact and the role of opioid analgesia." *Pain Research & Management*. Vol 7(4), 2002, 179-184. (pulled from http://www.canadianpainsociety.ca/pdf/pain_fact_sheet_en.pdf)
- 3 von Baeyer, C. (2011). "Interpreting the high prevalence of pediatric chronic pain revealed in the community surveys." *Pain*. 152:2683-2684.
- 4 Schopflocher, D., R. Jovey, et al. (2010). "The Burden of Pain in Canada, results of a Nanos Survey." *Pain Res Manage*: In Press. (pulled from http://prc.canadianpaincoalition.ca/en/canadian_pain_fact_sheet.html)
- 5 Todd, K. H., J. Ducharme, et al. (2007). "Pain in the emergency department: results of the Pain and Emergency Medicine Initiative (PEMI) Multicentre Study." *J Pain* 8: 460-466 (pulled from http://www.canadianpaincoalition.ca/media/canadian_pain_fact_sheet_22_10_10_en.pdf)
- 6 Costigan, M., Scholz, J. and C. J. Woolf. "Neuropathic Pain: A Maladaptive Response of the Nervous System to Damage." *Annu Rev Neurosci*. 2009; 32: 1–32.
- 7 International Association for the Study of Pain. *Pain Clinical Updates*. 2010; Vol. XVIII, Issue 7: 1-6.
- 8 Choiniere, M., D. Dion, et al. "The Canadian STOP-PAIN Project-Part 1: Who are the patients on the waitlists of multidisciplinary pain treatment facilities?" *Can J Anaesth*. 2010 Jun;57(6):539-48. (pulled from http://www.canadianpainsociety.ca/pdf/pain_fact_sheet_en.pdf)
- 9 Tang, N.K. and C. Crane. "Suicidality in chronic pain: a review of the prevalence, risk factors and psychological links." *Psychol Med*. 2006 May;36(5):575-86.
- 10 Lewandowski, W. et al. *Chronic Pain and the Family: Theory-Driven Treatment Approaches*. *Issues in Mental Health Nursing* 2007; 28:1019-1044.
- 11 Lynch, M. E. et al. "Research funding for pain in Canada." *Pain Res Manag*. 2009 Mar-Apr; 14(2): 113–115.
- 12 Watt-Watson, J. et al. "A survey of prelicensure pain curricula in health science faculties in Canadian universities." *Pain Res Manag*. 2009 Nov-Dec; 14(6): 439–444.
- 13 Dhalla, I. A., M. M. Mamdani, et al. "Prescribing of opioid analgesics and related mortality before and after the introduction of long-acting oxycodone." *CMAJ*. 2009. 181: 891-896.

