

The Status of Pain in Canada – moving toward a Canadian Pain Strategy  
Recommended by the Canadian Pain Coalition, *The National Voice of People with Pain*

Brief for the Parliamentary Committee on Palliative and Compassionate Care

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## **Executive Summary**

One in five Canadians suffer needlessly in pain when at the very least their pain could be relieved. In 2010, pain remains a silent epidemic in our country because Canadians do not yet recognize it as a health priority. Pain community leaders speak out on behalf of over six million Canadians silenced by unrelenting, undertreated pain, by demeaning misperceptions and cruel stereotypes of pain, by youth, age and illness, and by the inadequacies of a health care system that is completely unprepared to provide effective pain care.

A National Pain Strategy for Canada that recognizes pain as a chronic disease, promotes improved access to services for people with pain and addresses the awareness, educational, clinical and research needs to support effective pain management is required.

Since the International Pain Summit in Montreal on September 3, 2010, where delegates unanimously affirmed the declaration that “Access to Pain Management is a Fundamental Human Right”, the world is expecting Canada to take a leadership role in establishing a National Pain Strategy. The strategy would meet the needs of Canadians as described in the Canadian Pain Coalition’s *Charter of Pain Patient Rights and Responsibilities* which states, “Pain patients are entitled to have their reports of pain taken seriously and receive compassionate and sympathetic care...” The Charter also states, “To the extent they are able, patients or their parents/caregivers are responsible: ... to actively participate in their own care and in decisions about their care in partnership with health care professionals...”

## **Recommendations:**

1. Official recognition of chronic pain as a chronic disease in Canada
  - a. This will promote an attitudinal shift about pain in Canada which would foster a resolve that access to pain management is a fundamental human right.
  - b. This will promote a willingness to invest in effective pain care
2. Create and implement a Canadian Pain Strategy
  - a. Canadian Federal, Provincial and Territorial governments work with the Canadian Pain Society and the Canadian Pain Coalition and their partners to create a strategy that will reshape the Health Care Systems of Canada to be more sensitive to pain and provide effective pain management
3. Canada’s Health Care System becomes more supportive of pain care
  - a. Create tiered health care relating to pain
  - b. Create community networks or teams for multidisciplinary pain management
4. Education for the general public and health care professionals about pain and pain management
  - a. Ensure dedicated education about pain in medical school and other health professional curricula
  - b. Support immediate educational upgrades regarding pain for currently practicing health professionals
  - c. Provide timely access following a diagnosis of chronic pain to medically vetted chronic pain self-management courses for people with pain

5. Research for underlying causes of chronic pain and more effect delivery systems for pain management
6. People with Pain engaged as a integral part of the solution

# The State of Pain in Canada – The Person with Pain Perspective

## Understanding Pain

The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage”.<sup>1</sup> Pain is divided into two broad categories; acute and chronic.

Acute pain which is associated with ongoing tissue damage serves as the body’s warning system that something is wrong and medical attention may be required. The experience of pain can be minimal or excruciating at the time however when the cause of the pain and the pain itself are treated with best practice medicine and healing occurs, the pain usually subsides and is forgotten. Examples of causes of acute pain are childbirth, a broken limb, appendicitis or surgery.

Chronic pain, which is generally taken to be pain that has persisted for longer than three to six months or beyond the natural time of healing serves no purpose in the body. This pain can range from mild to excruciating however it does not subside and is constantly present or intermittently persistent. Examples of causes of constant chronic pain are: pain accompanying chronic diseases like arthritis, diabetes, and multiple sclerosis; 20% of acute pain that is not adequately managed; pain associated with cancer treatments and pain that continues without explanation after normal healing has occurred. Migraine headache represents intermittently persistent pain which has severe impact on a regular basis but in most cases is not constant.

Regardless of the cause, when pain becomes long term it develops its own set of physiological and psychological mechanisms and therefore should be referred to and managed as a chronic disease. This type of pain must be managed with an inter-disciplinary approach with active involvement by the person with pain, accompanied by an adaptive lifestyle, otherwise it is not managed.

## Pain Hurts Canadians

### *Human Cost of Pain – Impact on the person with pain*

People of all ages are afflicted with pain from the tiniest infant to the person who experiences pain at the end of life. For them poorly managed chronic pain is devastating. It can destroy their lives and families. It assaults their dignity and self esteem. At the very least the pain is disruptive and demoralizing. At its worst, the pain can turn deadly.

People with chronic pain speak about their pain like this: “It burns, it stabs, it throbs, and it stings. It never stops. It hurts so badly I can hardly function. It’s killing me. I can’t hold my baby because of my pain. I can’t support my family because of my pain. It’s ruining my life. It’s destroying my family. I can’t live anymore with this pain. My pain is evil. Why can’t someone make it stop, please...”

While research indicates that in comparison with chronic diseases such as chronic lung or heart disease, chronic pain is associated with the worst quality of life,<sup>2</sup> the impact of chronic pain on a person's well-being and quality of life cannot be truly comprehended by those who do not experience long term pain. The IASP definition as described above may be adequate for a cursory clinical description of pain however the life experience of chronic pain goes well beyond "an unpleasant sensory and emotional experience..."

Moderate to severe chronic pain is life altering. The pain profoundly impacts every aspect of a person's life. The financial burden of pain appears when the pain affects an individual's ability to work at the same level as prior to the onset of the pain. A survey conducted in 2008 of 800 people with moderate to severe chronic pain revealed that 60 per cent had lost their job, suffered loss of income or had a reduction in responsibilities as a result of their pain.<sup>2</sup> The out of pocket costs of managing chronic pain for individuals including medication purchases, therapies and time lost from work by them and household members is significant.<sup>3</sup> The financial burden of pain creates overwhelming stress for everyone involved.

The pain can drastically reduce a person's physical abilities to function and participate in basic personal care, daily living, work, and interactions with their families and social networks. This results in losses of independence and a sense of personal accomplishment which greatly diminish the individual's concept of personal worth, self-esteem and self-confidence. When no longer active at work, socially or in their family, the individual becomes isolated, very lonely and is plagued with self-doubt. The person's world can narrow to where the main focus is on just existing with the pain and what they cannot do. Interpersonal relationships with colleagues, family and friends are challenged because of everyone's lack of understanding about the mechanisms of chronic pain and how it affects the person in pain.

Poorly managed pain creates a pain cycle that spirals downward towards a life experience where people truly suffer both physically and psychologically. The cycle begins when pain prevents or interrupts sleep. Lack of sleep increases the experience of pain which in turn promotes emotional, distressing responses of fear, anger, anxiety and stress. The ability to sleep is further compromised and the cycle begins again. If the pain cycle continues uninterrupted and its mechanisms are further compounded by isolation, global stress related to life and lack of effective pain care, the person's ability to cope deteriorates markedly. Their mood becomes gravely affected, they grieve the significant losses in their lives and they may experience depression for the first time in their lives which is directly attributed to their pain. For some this becomes a scary, desperate, dark place where hopelessness and helplessness reign. For some no longer able to bear the life altering assault of the pain, suicide becomes an option. The majority of Canadians with pain are neither familiar with the concept of the pain cycle nor have they had access to training in coping strategies that they can use to break the pain cycle.

#### *Human Cost of Pain – Impact on family*

The person with pain does not deal with their pain in isolation. Families are deeply affected by the all encompassing impact of chronic pain. Financial stressors occur when an adult's

employment status changes because of their pain or a breadwinner must remain at home to look after a child or elderly person in pain. Roles change in the family. As the adult in pain struggles to modify or relinquish responsibilities others are weighed down when they must support the person in pain and pick up the slack. Family members grieve their own losses and experience anger related to the pain. Children keenly feel the “absence” of their parent who may no longer be able to hold them. Much interpersonal work and communication is required to find a new equilibrium in a family affected by long term pain. Some families adapt others do not.

#### *Human Cost of Pain – Interacting with Canada’s Social and Health care Systems*

General misunderstandings about the nature of chronic pain create extreme challenges for the person with pain. For the most part chronic pain is seen as an unfortunate symptom of another disease or condition but generally as something that just has to be lived with. As described earlier in this document, it is much more involved and has far reaching personal consequences. When pain becomes long term it develops its own set of physical and psychological mechanisms and must be accepted as a disease. The misconceptions however pervade the interactions by the individual with both Canada’s social and health care systems.

People with pain encounter the stigma and shame of pain when others judge them to be malingerers and drug seekers. They encounter work place difficulties with employers and colleagues who lack the understanding and knowledge of how to make accommodations for individuals to help them remain at work. Interactions with Insurance Companies, Workers Compensation Boards and legal actions based on misperceptions of chronic pain can present untold hardship for people worn down by pain.

Effective interactions of Canadians in pain with their health care systems are flawed because of misunderstanding about the nature of chronic pain and the appropriate, triaged multi-modal care required and the need for people with pain to become actively involved in their care. Many do not seek treatment and suffer in silence because they are unaware that there is no need for them to live with pain. Canadians should expect the level of care referred in the Canadian Pain Coalition’s *Charter of Pain Patient Rights of and Responsibilities* (Appendix 1) which states, “Pain patients are entitled to have their reports of pain taken seriously and receive compassionate and sympathetic care...” People with pain should be aware that the Charter also states, “To the extent they are able, patients or their parents/caregivers are responsible: ... to actively participate in their own care and in decisions about their care in partnership with health care professionals...”

For those who engage the system for pain treatment these misconceptions impact their relationship with health care providers who receive inadequate training about pain and best practice pain management.<sup>4</sup> When pain relief is not achieved with a uni-modal approach from one practitioner, they will visit another in search of relief. Often when individuals are not prepared to accept a diagnosis they will continue their search for an answer they find acceptable. These two scenarios do not lead to effective pain management and burden the health care system.

Many people with pain encounter the fear and skepticism of physicians reluctant to prescribe opioids when appropriate as part of a well-rounded pain program. Based on society's biases, Canadians themselves are fearful of becoming addicts when they are prescribed opioids for pain. As such they may not use the medications as directed, take them sparingly or not at all which complicates effective care and the patient, professional relationship. These are fears based on lack of public education about effective pain management involving medication where applicable.

Interdisciplinary pain management is the accepted and well-documented effective benchmark treatment for most people with chronic pain. This type of treatment is available at a limited number of public Multidisciplinary Pain Treatment Facilities in Canada. These facilities have extensive waiting lists. Wait times can be as long as five years. Fifty percent of those on the lists must wait a minimum of six months or more and during this time the effects of pain in their lives become entrenched.<sup>3</sup> This complicates eventual treatment outcomes and increases the onset of disabilities.

### **Canadian Geography Affects Pain Care**

Where you live in Canada determines level of access to pain care. Rural areas experience strains on all health services with pain included in this challenge. Access to medications for pain care is not standard across Canada. Provinces and Territories have different health care systems with varying priorities. For instance, British Columbia residents benefit from a health care system that has more recently become sensitive to pain. Atlantic Canada and Alberta have developed triage pain care systems that are proving effective. Developing a Canadian Pain Strategy that accentuates the best that is being done in Canada will benefit all Canadians.

### **Pain Costs Canada**

Pain is not noticed as a health priority or major problem for Canada therefore the burden of pain is not perceived by Canadians. Understanding the economic impact of pain may act as stimulus for recognition and action. Heart disease, cancer and HIV are highly perceived as impacting Canada's health yet chronic pain costs Canada more than the three diseases combined. Two recent studies reveal that direct health care costs for pain in Canada are more than \$6 billion each year. As Canadians age, they will naturally experience pain issues which will further burden the system. Lost productivity costs relating to sick days and job loss are estimated at \$37 billion each year.<sup>2</sup>

### **Canadian Health Care – Helping Canadians, Reducing Costs, Stopping Needless Suffering**

It is possible, when given the appropriate support and education, for people with pain to learn effective coping strategies that will assist them in reducing their pain and to develop an adaptive lifestyle that affords them a better quality of life in spite of the pain. Most people with pain would rather be productive and involved in life than isolated and suffering. Canadians in pain have inner strength and courage to carry on. They require the support of

Canadian Health Care systems that are sensitized to their treatment needs coupled with fast intervention times.

With advances in techniques and imaging, better diagnosis and treatment options for pain conditions are available. We know that once pain pathways form in chronic pain that the best we can hope for is to reduce the pain by 20%. Canadians require further research into pain mechanisms and pain management delivery systems.

As Canada reviews its Health Care during the next three years, this is an ideal time to support the creation of a National Pain Strategy that would address the issues of health professional and public education about pain management, research needs and access to services for people with pain.

### **The emerging role of People with Pain in Pain Care**

During the last twenty years in Canada, the role of people living with pain has begun a slow but very necessary evolution from the passive patient towards the person with pain who will become involved in their pain care and speak out for what they need.

A grassroots movement has emerged where a small number of people with pain have stepped forward as leaders in the pain community in an effort to help others like themselves. Pain leaders speak out on behalf of over 6 million Canadians silenced by unrelenting, undertreated pain, by demeaning misperceptions and cruel stereotypes of pain, by youth, age and illness, and by the inadequacies of a completely unprepared health care system.

Pain leaders have established organizations that provide education and support for our peers and their families. Most of them promote public awareness of pain issues and advocate for the recognition of pain as a health priority and more recently a disease. We advocate for better access to pain care and a place at the table to influence research, decisions and policy that affect our pain care. In 2010, under the Canadian Pain Coalition we strengthened the National Voice of People with Pain by creating a collective advocacy agenda that includes having pain recognized as a chronic disease, establishing equitable access to services for pain including medications and partnering with the Canadian Pain Society toward a National Pain Strategy.

Canadian pain organizations provide community-based, medically vetted education that augments health professional interventions. People with pain train to become facilitators for chronic pain self-management courses. They are stepping forward to establish and lead self-help groups. Pain leaders strongly encourage Canadians to access reliable pain information and programs, to get involved in their pain care and to help with our pain movement.

Pain leaders are working collaboratively with professionals to address all pain issues in Canada. We know that working together with one voice is the key to success.



In order to reduce pain in our country, people with pain must do their part to assume responsibility for actively contributing to their care (Appendix 1). Most have the capacity to do this however they require the knowledge, tools and support to achieve it.

### **People with Pain an integral part of the solution**

It is important that the Voice of People with Pain be heard and believed. It is imperative that it be respected and valued as an authority on the life experience of pain and on what we know is needed to reduce pain and the needless suffering it causes. It is necessary that the Voice of People with Pain be included where discussions, planning and decision making are held to determine research priorities, solutions to establishing effective pain treatment/management and policies and laws that affect pain care.

### **Call to Action**

Pain community leaders are ready to work side by side with the Parliamentary Committee on Palliative and Compassionate Care, other government agencies, health leaders and professionals to improve the prevention, understanding, treatment, and management of all types of pain. Together, we must take steps to eradicate the silent epidemic of pain and stop the needless suffering. Millions of Canadians of all ages are counting on the steps that are taken next. The Canadian Pain Coalition gives the following recommendations to improve pain care in Canada:

### **Recommendations:**

1. Official recognition of chronic pain as a chronic disease in Canada
  - a. This will promote an attitudinal shift about pain in Canada which would foster a resolve that access to pain management is a fundamental human right.
  - b. This will promote a willingness to invest in effective pain care
2. Create and implement a Canadian Pain Strategy
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## Charter of Pain Patients' Rights and Responsibilities

As we begin the new millennium, pain in Canada is epidemic. Studies show that over half of hospitalized patients experience unnecessary pain. Reports of chronic pain in Canada range from 17 to 31% of the general population.

The burden of pain in Canada is felt in economic terms with loss of work, more demands on health care services, and in significant decreases in quality of life. Yet, in spite of the magnitude of the problem of pain in Canada, the suffering of patients is not heard and too often their pain is not taken seriously. The following Charter has been created in the spirit of changing how patients in pain are treated.

### **PREAMBLE**

- ⊗ Members of health care professions, as well as the general public, need to be made aware of the fact that chronic pain is a condition not a symptom.
- ⊗ Consumers must advocate for greater awareness of all aspects of pain.
- ⊗ Patients would benefit from professional guidance and resources to help them assimilate information from different sources.
- ⊗ All health care professionals could take on a bigger role re treatment plan emphasizing the whole individual.
- ⊗ Patients have responsibilities as well as rights and should work in partnership with health care professionals, actively participating in their care.
- ⊗ Children, the elderly, or those who are cognitively impaired or unable to communicate, have the right to have their parents or caregivers equally involved in their care.

### **RIGHTS**

#### **Pain patients are entitled to:**

1. have their reports of pain taken seriously
2. receive compassionate and sympathetic care
3. have treatment/care, follow-up and periodic reassessment
4. actively participate, or have their parents or caregivers participate, in their treatment plan development
5. timely access to best-practice care
6. have adequate information in order to consent to their treatment
7. information and support, including access to health records

### **RESPONSIBILITIES**

#### **To the extent they are able, patients or their parents/caregivers are responsible:**

1. to be knowledgeable about pain
2. to engage in open communication with their health care providers
3. to actively participate in their own care and in decisions about their care in partnership with health care professionals
4. to do their best to comply with their treatment
5. to advocate for better pain management

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## UNE CHARTE DES DROITS ET RESPONSABILITÉS DES PATIENTS SOUFFRANT DE DOULEUR

En ce début de millénaire, la douleur a pris des proportions épidémiques au Canada. Des études démontrent que plus de la moitié des patients hospitalisés souffrent inutilement de douleur. Les rapports sur la douleur chronique au Canada montrent que ce problème touche entre 13% et 30% de la population en général.

Le fardeau des problèmes de douleur au Canada se traduit en termes économiques par des pertes de productivité, une utilisation accrue des services de santé et une diminution significative de la qualité de vie des personnes atteintes. En dépit de l'importance des problèmes de douleur au Canada, la souffrance des patients n'est pas entendue ou reconnue, et trop souvent leur douleur n'est pas prise au sérieux. La charte suivante a été créée dans le but de modifier et d'améliorer le traitement des patients qui souffrent de douleur.

### PRÉAMBULE

- ❖ Les professionnels de la santé, ainsi que le grand public, doivent être informés que la douleur chronique est une maladie et non un simple symptôme.
- ❖ Les consommateurs doivent faire des pressions pour que l'on reconnaisse toutes les conséquences de la douleur.
- ❖ Les patients ont besoin de soutien et de services professionnels accrus pour les aider à mieux comprendre l'information diffusée à partir de diverses sources.
- ❖ Tous les professionnels de la santé pourraient assumer un plus grand rôle en regard de plans de traitement qui mettent l'accent sur l'individu dans sa totalité.
- ❖ Les patients ont des responsabilités et des droits et doivent travailler en partenariat avec les professionnels de la santé, en participant activement à leurs soins.
- ❖ Les enfants, les personnes âgées, ou ceux qui ont des déficits cognitifs ou qui sont incapables de communiquer ont aussi le droit d'avoir leurs parents ou leurs aidants naturels activement impliqués dans leurs soins.

### DROITS

**Les patients souffrant de douleur ont le droit:**

1. d'être pris au sérieux lorsqu'ils parlent de leur douleur
2. de recevoir des soins empreints de compassion et sympathie
3. d'avoir des traitements et des soins de même qu'un suivi approprié et une réévaluation périodique de leur condition
4. de participer activement (ou que leurs parents ou leurs aidants naturels participent de façon active) au développement de leur plan de traitement
5. d'avoir accès à des soins appropriés qui sont basés sur les «bonnes pratiques cliniques» et ce, en temps opportun
6. d'avoir les informations pertinentes pour leur permettre de consentir de façon éclairée au traitement proposé
7. de recevoir toute l'information et le soutien nécessaire, incluant l'accès à leur dossier médical

### RESPONSABILITÉS

**Dans la mesure de leurs capacités, les patients qui souffrent de douleur ou leurs parents/aidants naturels ont la responsabilité:**

1. de s'informer adéquatement sur la douleur
2. de communiquer ouvertement avec leurs pourvoyeurs de soins de santé
3. de participer activement à leurs propres soins et à la prise des décisions relatives à ces soins et ce, en partenariat avec les professionnels de la santé
4. de faire tout ce qui est possible pour se conformer à leur traitement
5. de militer pour un meilleur traitement de la douleur