ACTION Ontario Patient Advocacy Newsletter

OUCH

Optimism and Understanding Creates Hope

Volume 1 Issue 3 June 2010

Aging With Chronic Pain Takes Center Stage

By: *Dr. Angela Mailis-Gagnon*

The year 2007 was declared the "global year against pain in older persons" by the International Association for the Study of Pain (IASP). IASP is the largest professional organization focusing specifically on pain research, education and treatment. It has national chapters in over 100 countries around the world.

So, why did an organization like the IASP have to proclaim 2007 as the "global year for pain in older persons?"

The reason for this type of initiative is to raise professional, government and public awareness in an area that is considered to have major importance; dealing with pain and an aging population. The truth is, governments are now faced with an unquestionable reality: the proportion of the world's population over the age of 65 is increasing.

Persistent pain, often defined as pain lasting more than three months, also increases with age up to the age of 85.

Different studies show at least 18% of young adults in the general population suffer from persistent, bothersome pain; the figure increases to 30-65% in those aged 55-65 years of age and then goes down to 25-55% in those older than 85 years.

Why does pain appear to increase as we get older? This seems to be partially due to increases in the number of injuries, diseases or surgeries in people as they age. Also, as people age, the body itself seems to be less able to control pain or recover from painful conditions.

On the other hand, why does pain seem to decrease after the age of 85? The reasons are not well understood.

Experimental studies show that our ability to feel pain decreases with age. It is also possible older people are more stoic or accept mild pains and aches as part of the normal aging process.

Even if there is a slight reduction in the occurrence of pain in the very old, we should not forget that, at best, two out of five older people still suffer from persistent and bothersome pain and often under-report it.

There is still more about this issue we need to identify. In developed countries it is estimated about 5% of the population 65 or older live in long term care facilities AND

Dr. Angela Mailis-Gagnon discusses treatment options with a neuropathic pain patient in her office at the Krembil Neuroscience Center, Toronto Western Hospital

(Continued on page 2)

Did You Know?

Approximately 80% of all visits to primary care physicians in the province of Ontario are pain related.

For doctors to bill the province for a visit there has to be a diagnosis with a corresponding billing code.

Yet, under current provincial guidelines for family doctors there is no billing code designated for pain.

Now, we can understand one of the problems for diagnosis and possible misdiagnosis at the grassroots level.

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Chronic Pain and Aging

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more than half of those living in such facilities suffer from some type of diminished thought process or dementia. A number of studies also show an extremely high rate of pain in these care facilities.

The story about the elderly and chronic pain in our country is not a pleasant one to relay (as told by Statistics Canada in the document "Chronic Pain in Canadian Seniors"). A couple of years ago Stats Canada released data from two separate health surveys taken in 1996-97 and 2005. The surveys tried to determine the incidences of chronic pain sufferers between people 65 and older living at home or in long term health care facilities.

The results made headlines: chronic pain affected 27% of people 65 or older living at home, compared to 16% of those aged 18-64. However, the occurrence of chronic pain in people 65 or older living in long term care facilities was 11% higher than those living at home at 38%.

Older women at all ages consistently reported more chronic pain than men. The numbers were the largest among older people living in households: 31% of women reported chronic pain as compared with 21% of men.

Stats Canada pointed out that lower education or income affected the occurrence of chronic pain among seniors living in households, as well as the number of other health conditions a person may have. The more conditions a person had, the higher the occurrence of chronic pain. Over half of seniors in households (56%) reported two or more chronic conditions, as did 83% of seniors living in long term health care institutions.

How did chronic pain compare with other diseases often seen in older people? Believe it or not, Stats Canada told us chronic pain was more common for seniors in private households, than diabetes, heart disease and Alzheimer's disease, among others. In institutionalized seniors, only incontinence, arthritis and Alzheimer's disease were more common than chronic pain.

According to Professor Harald Breivik from the World Health Organization, (-as cited in the 2008 Stats Canada report Chronic Pain in Canadian Seniors), "Chronic pain is one of the most underestimated health care problems in the world today, causing major consequences for the quality of life of the sufferer and a major burden on the health care system in the Western world. We believe chronic pain is a disease in its own right."

In summary, chronic pain was found to affect more than one-quarter of people 65 or older living in households and close to four out of every 10 in health care facilities, and has a profound impact on enjoyment and quality of life. More seniors are afraid of living a life in chronic pain than facing death.

The Stats Canada studies stressed that chronic pain will become a bigger problem as we get older than it is now. In 2005 (when Stats Canada did their studies) persons over 65 constituted 13% of the general population. By 2031, it is estimated this number will nearly double to 23-25% of the total population.

Chronic pain frequently goes untreated or undertreated. It is at present a big problem for older individuals and will increase in magnitude as our population ages. A comprehensive management of pain for all should start at the primary care level (the offices of the family doctors) and continue through all levels of care up to specialty clinics and hospitals.

> "Chronic pain is one of the most underestimated health care problems in the world today. We believe chronic pain is a disease in its own right."
> Professor Harald Breivik,
> World Health Organization

Dr. Angela Mailis-Gagnon
Director,
Comprehensive Pain Program
Toronto Western Hospital

> "More seniors are afraid of living a life in chronic pain than facing death."
> Dr. Mailis-Gagnon

Submitted by:

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For more information please visit:

www.globalaging.org/health/world/2008/pain.pdf

www.statscan.gc.ca

Editor's Message

Dear Readers,

The year 2010 is quickly shaping up as the first, of hopefully many, unofficial "year of patient input." New initiatives with respect to patient involvement in the decision making process regarding health care are being discussed and ACTION Ontario/ PNP has been invited to participate.

In March ACTION PNP was invited to make a presentation to the Canadian Pain Summit on behalf of neuropathic pain patients with follow-up representation at Queen's Park. Then, in May, members of ACTION travelled to the Canadian Pain Society Conference in Calgary in order to further advocate for neuropathic pain.

Members of the ACTION PNP committee volunteer within the scope of their own neuropathic pain to assist all of us in moving towards greater recognition within the pain community.

This edition of OUCH discusses some of the issues surrounding neuropathic and chronic pain commonly associated with our aging population. I would like to thank Dr. Angela Mailis-Gagnon, Dr. Barry Sessle and Rachel Weisz for their contributions and continued dedication in the advocacy for people suffering from neuropathic pain.

In this issue I have also included a poem by a very brave and articulate young woman from Australia named Deb Wilcox. Deb suffers from a painful and debilitating form of genetic arthritis called Ankylosing Spondylitis. As with all poetry, the vocabulary and expressions are unique to the author. The experience of pain the poem conveys however are universal; pain does not discriminate, it is unrelenting, not easily defined, understood or accepted, even by family and friends.

Finally, our thanks go out to all our readers who took up our "membership challenge" and passed along the February edition of OUCH to friends and family. Because of the response, we are extending the membership initiative until September. So, once again a membership form will be included with this edition of OUCH.

Just a reminder there is no cost to joining ACTION PNP and a membership form is also available on the ACTION Ontario website www.actionontario.ca.

Please feel free to contact me at email@actionontario.ca with any topics you would like to see addressed in future editions.

Wishing you all a safe, happy, carefree and pain free summer!

As Always
Janice Frampton
Editor

Quietly whispering into my head, i thought you were gone..but your back instead.
I try to ignore your constant chatter, keeping myself busy with other matter.
You try a bit harder to get some attention.. i have tried so many strategies its so hard to mention.
You get a bit louder ,you want me to know...your a pain in the ass, why wont you go?
I keep myself busy with daily life, i figure that way you`ll stay out of my life.
Your quite angry now and you just dont stop screaming, i even am hearing you whilst i`m dreaming.
Days go bye and soon they became years, oh my God at times you`ve had me in tears.
You're very angry now and you scream day and night...ok ok ok you win this fight.
I lay in pain with no relent, is this really how life was to be spent?
Friends and family lend a hand, but they cant feel this pain so they`ll never understand.
Its nobodies fault that i have this disease, i dont want it gone..I just wish to live with ease.
When people remark" How are you today"? I just smile and say yeah im ok!
Because if i told them such pain that i live with day and night, they may not leave with such delight.
I wish my pain could be seen with the eye, because then no longer would i have to lie.
I know im not alone as thousands of AS suffers will know, its a difficult road we all must tow.
I watch passers by moving around with ease, i thank god they dont have this disease.
I inject myself and take medication, hey i have even tried meditation.
Your voice grows quieter and i feel some relief, i think i can have my life back, but its so brief.
Just when i thought you had gone for good, i wake to you screaming, i misunderstood!
So i come to terms that your never leaving , i need to keep you quiet to avoid the screaming.
I have to forget the life i had before and come to accept that if i do too much you will roar.
May one day they find a cure, so soon we wont have to endure!

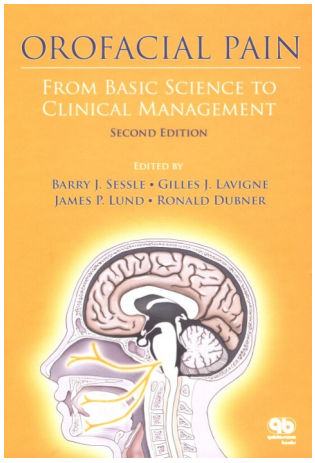
Courtesy of:
Deb Wilcox
Ankylosing Spondylitis Patient
Australia

Profile-Dr. Barry Sessle

Craniofacial pain conditions, including headaches, toothaches, temporomandibular disorders, (TMJ), are among the most common pains in the body, yet they are poorly understood and poorly managed. Dr. Barry Sessle's quest for answers into the causes of these conditions as well as the rarer, but extremely excruciating, form of neuropathic pain called trigeminal neuralgia, has propelled him to the top of his research field. "TN" can affect especially the lip, nose, teeth or jaw along one side of the face and the pain is so severe it has been nicknamed "the suicide disease."

Born in Sydney, Australia, Dr. Sessle entered dental school straight out of high school, as was the custom of the day and, after graduating in 1963, realized he didn't want to "drill and fill" teeth for the rest of his life. Because of his emerging curiosity about human body functions he took advantage of a scholarship opportunity and entered a Bachelor of Science program.

> A self-described "workaholic," it is obvious his research still "excites" him and he is planning to be a major contributor for several years to come.



At the same time he also completed a Masters of Dental Surgery, graduating from the two programs within a month of each other – the first student to accomplish this at the University of Sydney.

Dr. Sessle attributes his path to pain research to a combination of his ever growing curiosity about human body functions, good timing and supportive professors.

In the mid 1960's when little was known about pain in the face and mouth or how this pain could be controlled or managed, Dr. Sessle realized that because pain and related movements are largely functions of the brain the answers to these questions probably lay in neuroscience. In order to further his knowledge base he did a PhD in neuroscience at the University of New South Wales, in Sydney, Australia.

In 1968, Dr. Sessle made his way to the National Institute of Dental Research in the United States for post-doctoral training in dental neuroscience. He became part of a rare breed of doctors with both a dental and neuroscience background. In 1971 he accepted a position at the University of Toronto Faculty of Dentistry. He was Dean of the Faculty from 1990-2001. He is currently Professor and Canada Research Chair at the University.

Dr. Sessle has already co-authored or edited 11 books, published over 325 journal articles and book chapters and has given over 370 invited lectures in over 30 countries in North and South America, Asia, Africa, Europe and Australasia. He has been the recipient of many awards and honours during his prestigious career including President of both the International Association for the Study of Pain and the Canadian Pain Society.

Through his translational research with colleagues in Scandinavia and Australia, Dr. Sessle has been able to draw parallels between animal models with craniofacial pain and the human pain experience. A self-described "workaholic," it is obvious when speaking with Dr. Sessle that his research still "excites" him and he is planning to continue to be a major contributor to the pain and neuroscience research communities for several years to come.

"While our research itself doesn't create new pain therapies, it does explain how several of the craniofacial pain conditions may arise and how current therapies work, for example, acupuncture, tens, deep brain stimulation." He says. "We've recently developed a particular interest in exploring mechanisms underlying chronic craniofacial pain conditions and testing new neuropathic treatments for them."

Dr. Sessle's work with ACTION Ontario was a "perfect fit," a way of giving back, helping to advocate for pain patients and the pain field in general. He was and continues as a founding member and the Secretary of the ACTION Ontario Board.

Dr. Sessle and his wife, Mary, a free-lance copy-editor for the University of Toronto Press, live in downtown Toronto. They have two daughters; Claire, a school teacher in Australia, and Erica, who works at the Fred Hutchinson Institute in Seattle, Washington and coordinates clinical trials for HIV/AIDS patients in Uganda.

Having travelled to over 40 countries on business during his career, Dr. Sessle and his wife are now enjoying taking a little extra time to stop and "smell the roses," spending more time at some of their favourite destinations along the way.

Image Courtesy of:
Dr. Barry Sessle
Secretary, ACTION Ontario
www.actionontario.ca

OROFACIAL PAIN
From Basic Science To
Clinical Management
Second Edition
Edited By
Barry J. Sessle * Gilles J. Lavigne
James P. Lund * Ronald Dubner
Published by: Quintessance Books

Profile—Rachel Weisz

Rachel Weisz
ACTION PNP Committee Member

Little was known about the correlation between neuropathic pain and Shingles when I became ill with a very severe case of the virus in March 2000 after living with a very stressful situation for many years.

I had never experienced this kind of pain before in my life. My entire body was extremely sensitive to touch with a throbbing, burning, stabbing, sensation. Nothing I tried relieved the pain. I was reduced to lying in bed screaming in agony. I eventually arrived at Sunnybrook Pain Clinic in a wheelchair desperate for relief.

When a series of nerve block injections I received at Sunnybrook on an outpatient basis failed to ease the pain, I was prescribed Oxycontin.

Even though I was uneasy about taking Oxycontin, it suppressed the pain enough to allow me to walk from the bedroom to the kitchen again. A year after taking Oxycontin I decided to stop for fear of addiction and other side effects. When the doctors told me they didn't have an alternative medication for me I concluded it was time for a change for me.

As I slowly began to walk again and venture outside I was still desperate to find other options to relieve my pain.

Around this time I heard about and was referred to a Bio Feedback clinic, a technique that trains people to improve their chronic pain using signals from their own bodies. Travelling to "lessons" was both painful and expensive so, after a dozen sessions without relief I decided to look elsewhere.

Next I concentrated on finding and trying a number of conventional as well as alternative therapies. Laser therapy gave only temporary relief and self hypnosis was a great disappointment. A Naturopathic practitioner's manipulation created so much pain it caused three days of screaming again.

In 2003 I was referred to the Wasser Pain Clinic at Mount Sinai Hospital where my neuropathic pain was finally diagnosed and I was prescribed Neurontin, the predecessor of Gabapentin. Initially Neurontin caused me memory problems but the side effects from other medications were more pronounced so I returned to Gabapentin.

My most disheartening experiences came at the hands of the Ontario Health Department. As a senior, I had certain expectations of being approved for relief providing, doctor approved, Botox treatments, but this was not the case. The name "BOTOX" created instant refusal and any further explanations for different usages other than cosmetic by doctors were immediately dismissed. Our provincial government of the day thwarted me at every turn and never approved any of the requested treatments.

Today I direct my energy into positive activities such as neuropathic advocacy with ACTION PNP and volunteer work with children.

I firmly believe that anything that provides satisfaction and enjoyment keeps away depression. Best of all…
A SHINGLES VACCINE IS NOW AVAILABLE.

For more information please visit:
www.actionontario,ca

"Today I direct my energy into positive activities such as neuropathic advocacy with ACTION PNP."

A Date For Your Calendar

ACTION Ontario will host it's third Symposium on Neuropathic Pain during National Pain Awareness Week on Tuesday, November 9, 2010 with a very timely topic, *PATIENT INPUT FOR SYSTEM CHANGE.* We look forward to seeing you there!

New Friends On-Board at CPS Conference

Action Ontario/PNP Board members were on hand to increase the need for advocacy and awareness of Patients with Neuropathic Pain at the Canadian Pain Society Conference, held in Calgary, Alberta from May 12 to 15.

ACTION Ontario Chairperson and founder Dr. Angela Mailis -Gagnon, was one of many Action Ontario Board members who had been invited to present papers to the conference, that had as it's theme "Unravelling the Mystery of Pain: Nature v. Nurture". Other Board members invited to speak included Dr. Philip Peng and Dr. Barry Sessle.

ACTION PNP Chairperson, David Harlow, and Co-Chair, Janice Frampton, along with Manager, Frances Lau, headed up the group manning the ACTION booth on the conference Trade Show floor. This is the fourth year Action has had a presence at the conference, and provided the opportunity to meet new faces as well as renew connections made from previous years. "It is good for people to see us here again, with a stronger contingent and more of a presence," David Harlow said. "It renews and highlights our commitment to neuropathic pain awareness."

A large contingent of conference delegates – primary care givers and nurses practising in the field of pain - were from Ontario, and they were unaware of ACTION Ontario/PNP and the information available to neuropathic pain sufferers. Their excitement about having access to this kind of knowledge being available to assist their patients was very encouraging, especially as further information regarding the upcoming Action Ontario sponsored Pain Symposium was made available.

As David Harlow pointed out, many of the Health Care professionals who were attendees at the 2009 Patient Symposium came as a result of Action's presence at the 2009 CPS Conference in Quebec City. He is looking forward to seeing the many new acquaintances made in Calgary, and their patients at this years Pain symposium on Tuesday, November 9, at the MaRS Centre in downtown Toronto.

ACTION PNP Chairperson David Harlow
&
Co-Chair, Janice Frampton
Manning the ACTION Booth at the
CPS Conference in Calgary

The patient-focused presence at the conference was greeted with praise from the many pharmaceutical companies. The general consensus was, "Government and the entire industry itself are becoming more patient driven," and, "Patients are the face of pharma and your visibility here is very important."

Marion & Terry Bremner
ACTION Atlantic

This attitude was music to the ears of Janice Frampton who spent a great deal of time speaking with many of the companies exhibiting as well as the primary health care providers.

"A doctor from Manitoba is interested in connecting up with the work we are doing in Ontario and setting up a branch out there," she said. "As well as the nurses from Ontario that David spoke with, our presence and visibility has definitely made an impact on the awareness of neuropathic pain and promoted education."

Action Ontario was joined at the Calgary conference booth by members from ACTION Atlantic. Terry and Marion Bremner have been attending these events for the past seven years, and for Terry his attendance at these conferences is his "life passion" because he "gets to help others."

Terry was involved in a car accident in 1995 while living in Alberta. Like many neuropathic pain patients he went misdiagnosed for three years, seeing doctor after specialist before finally moving back to Nova Scotia to be around family for moral support. Eventually through multiple referrals from their family doctor he received the correct diagnosis.

His major concern when starting ACTION Atlantic 14 years ago was the "self imposed isolation many of us put ourselves into when we are trying to deal with our pain." His involvement "keeps him healthy" as he tries to assist neuropathic pain sufferers dealing with long wait lists, referrals and struggling through the many road blocks of the insurance industry.

For more information please visit:
www.actionontario.ca

"Patients are the face of pharma and your visibility here is very important."

ACTION ONTARIO
For People with Neuropathic Pain
www.actionontario.ca

ACTION Ontario is an innovative not-for-profit organization whose mandate is to advocate on behalf of people with Neuropathic Pain (resulting from injury or disease of the nerves, the spinal cord or the brain), in order to secure better and faster access to pain management. The board is comprised of university associated physicians, researchers and other health care professionals. As members of ACTION PNP each and every one of us is committed to improving the lives of People with Neuropathic Pain.

Optimism and Understanding Creates Hope

Application Form for ACTION Ontario PNP Committee Associate Membership

Please print and mail this form to the address provided below or email to: email@actionontario.ca
Membership application may also be made online at: www.actionontario.ca

Name: _____ **Gender:** M F
Surname Given Name Initial

Address: _____

City: _____ **Prov:** _____ **Postal Code:** _____

Phone: ( ) ___ - _____ home ( ) ___ - _____ work ( ) ___ - _____ cell

(Optional) Age Group: 18-35 36-55 55+

There are two types of membership on the PNP committee:
1) Regular members who are elected to serve on the PNP committee
2) Associate members who support the activities in meeting the goals and mandates of ACTION Ontario

Please check applicable designation: ( ) *people diagnosed with Neuropathic Pain

( ) *people who wish to support the initiatives of ACTION Ontario/PNP

( ) *people who work with people with Neuropathic Pain and wish to support the initiatives of ACTION Ontario/PNP

Communications and newsletters are distributed by e-mail. Please provide a valid address for this purpose.

Email: _____

Referred By: _____ (optional)

There is no fee for joining ACTION Ontario/PNP.

Privacy Statement: the information collected on this form is for ACTION Ontario/PNP membership only and will not be shared with other parties for commercial or other usage.

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