

the spin

SPINAL CORD INJURY BC

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Live Plan ~~A~~ Be

Is chronic pain making you feel like you're losing control of your life? Dr. Michael Negraeff, who speaks from the experience of being a pain specialist and living with his own SCI neuropathic pain, says an important technique to bring pain under control is self-management—and explains how Pain BC's new self-management online tool, *Live Plan Be*, can help you regain the upper hand.

During our recent annual SCI Forum, attendees had the rare experience of listening to the unique perspective of a physician and researcher who, like many of those in the audience, deals with SCI neuropathic pain every day of his life. Dr. Michael Negraeff's presentation was so powerful that we followed up with him in this issue of *The Spin* to give a wider audience a chance to hear his views on chronic pain, and to find out more about a subject close to his heart—Pain BC's *Live Plan Be* online self-management tool.

"The problem with chronic pain is you never expect you'll get it," says Negraeff, who lives and works in Vancouver. "After my SCI in 1995, it took about a year to feel like I had put my life back together. So I was feeling pretty good after a year being

back in (medical) training, getting active, and socializing. Then I needed one more surgery, and for whatever reason, the pain didn't go away after it."

Negraeff admits that, at first, he was deep in denial. But he already had a good knowledge of chronic pain thanks to his medical training, and one day he finally accepted that the pain wasn't ever going to go away.

"This was my 'You've got to be kidding me!' moment," he says. "After all this figuring out of mobility, bladder, bowel, spasms, sex, work, sleep and just getting back to my new normal, and now you're telling me I will have chronic pain on top of all that to deal with? I was very upset about that for quite a while, to put it mildly. It nearly ruined my honeymoon. I was not fun to be around. It was too much. I remember thinking in

the hospital right after my SCI, 'I can do this. I'm up for this.' But this pain wasn't part of the bargain."

And, he adds, this hammer blow happens to everyone who gets chronic pain unexpectedly after an injury, surgery, or illness—they simply can't believe it at first, and when they finally come to accept that their pain is permanent, it's a bitter pill to swallow.

At the time, Negraeff was already a physician, and was training as an anesthesiologist at UBC. After coming to terms with his pain, he decided to meet the challenge of life with neuropathic pain head on via a significant career alteration—he set his sights on becoming a pain specialist.

"My pain was definitely an influence on my decision to become a pain specialist," he says. "I had already developed an interest in pain management during my anesthesiology residency, but now I wanted to understand why some people get chronic pain and some don't, what causes it, and what can be done about it."

After completing his anesthesiology residency at UBC, he signed on for a Pain Fellowship at the Australian and New Zealand College of Anaesthetists, which he completed in 2001. In 2003, he moved to BC to take on a position at Vancouver General Hospital, where he's been ever since. Today, he's an associate member at ICORD, and a clinical associate profes-

sor and Head of Pain Management in the Department of Anesthesiology, Pharmacology & Therapeutics at UBC.

He's also a founding member and the current chair of the board of directors for Pain BC. Composed of people in pain, health care providers, and leaders from universities, government, business and the non-profit sector, Pain BC is a collaborative non-profit organization established in 2006 to improve the lives of pain sufferers through education, empowerment and innovation.

As one of BC's leading pain specialists, Negraeff has treated thousands of people with chronic pain, contributed to a growing body of research into chronic pain as it's increasingly been recognized for the devastating health problem that it is, and learned many lessons about neuropathic pain—his own, and that of others—and what can be done to manage it.

Among the most important pieces of knowledge that he's gleaned is that, while there's no total cure for anyone, most people can find some relief via a multitude of approaches that go well beyond simply getting a prescription.

"Research has shown that multiple solutions are definitely needed to help people live better with chronic pain, because chronic pain affects more than just our bodies," he says. "The traditional medical model doesn't address all the facets of complex pain—for example, the effects on close relationships, that people in pain are dealing with a super sensitized nervous system, the need for movement, and so on."

Among the strategies that he's found to be successful when employed in tandem are traditional pharmaceuticals, exercise, cannabis, mindfulness and meditation, counselling, and, perhaps most importantly, taking responsibility for your pain management—self-management, in other words. And that's the reason why, under his stewardship, Pain BC created the *Live*

Plan Be interactive online self-management tool.

"The seed for the idea of *Live Plan Be* was planted at Pain BC's Pain Summit in 2011, where much of the discussion was around strengthening the continuum of self-management support, especially as most pain self-management training is either location-based or short-term," says Negraeff. "After hearing from patients about their needs, and considering how we could support health care providers to better help patients, Pain BC saw the need for a tool that removed many of the barriers chronic pain patients face—for example, distance from resources, accessibility, financial issues, a lack of peer support, and a need to manage pain in their own manner. We also wanted to focus on evidence-based research and on making this information easy to understand and apply."

Negraeff stresses that, in the context of chronic pain, the term "self-management" is far from being a nebulous, untested concept—it's actually a strategy that's been validated through considerable research.

"We studied why some people live well with pain and others don't, even though their pain may be similar in severity," explains Negraeff. "We turned to the expertise of Dr. Bronwyn Thompson, a psychologist who conducted a literature review for us and contributed material for *Live Plan Be* around the biopsychosocial model of pain—a broad view that recognizes that pain and pain relief involve an interaction of biological factors, psychological factors and social factors. Different people have different paths on their journey with chronic pain. Dr. Thompson's research has shown that some people are able to move beyond a pain-focused life—although they're still in pain, it doesn't occupy the very centre of their lives. We looked into how these people in pain were able to do this, and

"We looked into how these people in pain were able to (move beyond a pain-focused life), and Live Plan Be is the result."

– Dr. Michael Negraeff





We know your pain is real.
 We know every day can be a challenge.

- Learn about the science behind chronic pain.
- Keep track of your symptoms and their impacts.
- Develop a plan for better pain management and quality of life.
- Connect with a like-minded community of others who live with pain.

Open and Honest Discussions



Share your story, strategies, and questions in a safe, private discussion forum with people who've been there and understand what you are going through.

DISCUSS PAIN

Powerful Pain Science



Learn about the science of chronic pain, along with other topics such as sleep, mental health, medications, and treatment options. This practical knowledge will help you better understand your condition and how to manage it.

LEARN ABOUT PAIN

Personal Action Plan

Take action towards your wellness. The Pain Plan is an online tool that helps you set meaningful, realistic goals, and supports you in seeing them through.

CREATE YOUR PAIN PLAN

thanks to the framework provided by Dr. Thompson, *Live Plan Be* is the result.”

Negraeff stresses that, because research has demonstrated that those who take control of managing their pain have better outcomes, *Live Plan Be* is primarily about putting people back in charge of their lives.

“Regaining a sense of self after trauma or change, which are both components of chronic pain, is vital to wellness,” he says. “When you get back to living well, you find your identity again. We wanted to create a customizable tool to support people along the journey to reoccupy that sense of self—what is known as ‘flexibly persisting’ with pain. This means you still have pain flareups and setbacks, but you’re able to draw on a large bank of resources that enable you to live better and overcome those setbacks. We also want people to feel more empowered to communicate their needs and self management plans to their healthcare provider team so they are truly working together.”

So what can you do on the *Live Plan*

Be website? (And yes, in case you’re wondering, the name is an intentional play on words.) When you visit the *Live Plan Be* website for the first time, you’re greeted with some simple text:

We know your pain is real.
 We know every day can be a challenge.

- Learn about the science behind chronic pain.
- Keep track of your symptoms and their impacts.
- Develop a plan for better pain management and quality of life.
- Connect with a like-minded community of others who live with pain.

Negraeff says that there’s no particular order or sequence when it comes to engaging in the website’s four primary functions.

“One of the key things we wanted to achieve with *Live Plan Be* was to create a tool that could meet people wherever they might be on their journey with pain. So there is no right or wrong way to move through *Live Plan Be*. For example, you might have just experienced a life-changing injury and need more information, so you would benefit from starting with learning more about pain science. If you’ve been living with pain

for many years, you may be ready to set more goals around exercise, for example, so you could start with the Action Plan section. The benefit of *Live Plan Be* is that you can choose your own entry point and tailor it to your needs.”

He’s particularly enthusiastic about the Assessment module. “This is definitely a vital part of the site where we’ve created an interactive version of the Brief Pain Inventory. This allows you, on your own, to track and compare your pain and your ability to function over time. This not only helps you see how your pain changes, but you can also show these results to your health care providers. Because the data is shareable, the advantage is that everyone in your health system can work from the same results.”

Another important component of the site is the Pain Action Plan. “This section employs a method of SMART goal-setting that puts you in the driver’s seat,” he says. “Self-efficacy is a major component of self-management, and an action plan supports you to set realistic goals. It provides clear structure, and allows you to

get specific about when, where, and how you'll achieve the goals. You can also rate your confidence levels and reflect on these—this allows you to take a step back as needed and readjust if you aren't in the right place yet. There is also the important element of accountability—the plans are meant to be shared, down to including a place for you to name who you'll share your goals with.”

Live Plan Be also allows users to check in and reflect on their path and strive for continuous improvement. “It's not about success or failure,” says Negraeff, “but about reflecting on the experience and really looking at why things worked or didn't. Maybe you just weren't ready, so you can take a look at that, and *Live Plan Be* can then support you to get ready.”

A great deal of effort was also made during development to make it easy and rewarding for site visitors to share their stories and learn from others.

“Our Real Stories section is particularly powerful as we showcase the stories of those coping well with pain. We've in-

cluded these real experiences of people with different types of chronic pain, from those who have grown up with it or experienced it later in life. These stories also present different strategies for coping. We have not sanitized what people have said and feel that the stories are impactful, relatable and helpful. They encourage people to see that they're not alone.

“Meanwhile, the Forum is also an important 'sharing' component of the site. Pain BC has a wonderfully supportive Facebook community, but the *Live Plan Be* Forum answers the need for anonymity. The idea of the Forum is definitely to let people see they aren't alone—but also to provide an opportunity for peer leaders to share what's worked for them and how they've handled different situations. People in pain are experts in their own experience. This peer support and sharing is vital to self-management, because everybody's story is so different. People need to see lots of different ideas and suggestions so they can find

what works for them. The Forum creates a safe, moderated space to share these stories, ideas, experiences, and questions. Creating a network of coping strategies, opening your mind to different ideas, and taking an active role where you can—all of this helps you take back control of your life. Sharing your own experience and questions is in turn valuable for others.”

Negraeff concedes that *Live Plan Be* is not intended to replace expert medical advice. If you're completely overwhelmed by your pain, particularly to the point where you find yourself in a state of depression or withdrawing from the world around you, don't hesitate to seek help from your medical team. But Negraeff has witnessed firsthand—and experienced for himself—that those who become an active participant in their personal pain management are usually those who are the most successful with easing pain out of the centre of their lives. And to that end, *Live Plan Be* is a great way to regain this control. ■

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