THE CATALYST

Room to breathe

MHCC & Series – Canadian Lung Association By Nitika Rewari Chunilall Welcome to the sixth installment in the MHCC & series, designed to get to know our HealthPartners membership, and discuss where our realities intersect, and how best to support each other. The MHCC's Director of Prevention and Promotion Initiatives, Nitika Rewari Chunilall, sat down…

By: Nitika Rewari Chunilall | Posted: November 20, 2024

Welcome to the sixth installment in the MHCC *& series, designed to get to know our HealthPartners membership, and discuss where our realities intersect, and how best to support each other.*

The MHCC's Director of Prevention and Promotion Initiatives, Nitika Rewari Chunilall, sat down with Sarah Butson, CEO of the Canadian Lung Association, to understand the massive implications that come with the inability to breathe well, and the work of the organization.

As you're reading this, take a deep breath.

Breathe in for four seconds. Hold for four. Exhale for four.

Feel the sensation of your lungs contracting and expanding. As you consciously breathe in, you may begin to relax. This technique, called box breathing, is widely used to calm stress or anxiety.

You're signalling to your parasympathetic nervous system that you're safe. And you're sending a steady stream of oxygen to the rational, thinking part of your brain.

This is just one example of the power of breath.

And it got me thinking that while health care systems may operate in stubborn silos, the brain and body do not. With this in mind, I sat down with Sarah Butson, CEO of the Canadian Lung Association (CLA), to better understand the massive implications that come with the inability to breathe well, and what the organization is doing to raise societal consciousness and much-needed funding.

On the doorstep of a 125-year legacy

CLA began as a movement in 1900 to control the spread of tuberculosis (TB) and provide better patient care. The organization has been evolving ever since, expanding their mandate to include COPD, asthma, cystic fibrosis, pulmonary fibrosis, lung cancer, and more.

"I would say our biggest strength of these last 125 years – and I can't say I was around for all of them! – is keeping pace with the world around us. From taking the fight to Big Tobacco, to pushing back against the alarming trend of vaping, we've remained relevant because we haven't taken our eye off the ball," Sarah said during a virtual interview from Toronto.

While she’s been an integral part of CLA for 15 years, Sarah has only been at the helm for a whirlwind six months.

“Our outgoing CEO of nearly a decade, Terry Dean, left big shoes to fill. But this issue is deeply important to me – both professionally and personally,” said Sarah.



Sarah Butson, CEO, Canadian Lung Association

Sarah herself lives with asthma, as does her youngest daughter.

“The visceral panic that comes from being breathless is hard to describe unless you’ve lived it. The only thing more terrifying is feeling that fear for your child. Breathing is something so many of us take for granted,” she said. “It’s part of CLA’s mission to flip the script, making us truly value our breath, and inspiring people to take action to protect it.”

Playing the long game

One of the organization’s biggest challenges is conveying the urgency of prevention.

“Prevention doesn’t have the cachet of immediacy,” Sarah emphasized. “Take wildfires, environmental pollutants – be they indoors or out – poor ventilation in workplaces…these all lead to deleterious, and even fatal, breathing concerns. Every year, 15,000 people die due to air pollution.”

But the challenge remains making that connection and getting policy makers to act on it.

One area where Sarah credits CLA for having outsized influence is the reduction of tobacco use, specifically among young people.

“It’s an uneven match – because we simply don’t have the resources or the funding of big industry. We’ve had to work doubly hard to get our message out, in response to what we now know was a covert effort to hook millions of people on one of the most addictive substances out there.”

Yet, CLA’s persistence has paid off. About 4.2 percent of people 15 to 19 smoke cigarettes, and that number continues to trend downward.

But there’s still work to be done.

More broadly, some three million Canadians smoke cigarettes. That’s about 12 percent of the population – more than double the federal government’s target of less than five percent by 2035.

Given smoking is still the leading cause of preventable death in Canada, the organization refuses to back down. “Even,” said Sarah, “as we face a constant barrage of new challenges.”

In August of 2024, CLA celebrated successful efforts to keep nicotine pouches out of the hands of children and young people.

“We have to stay vigilant,” said Sarah. “There’s no other choice.”

Living and breathing advocacy

Among the CLA’s most powerful lung health champions are those who once fell victim to Big Tobacco.

I pointed out to Sarah an interesting nuance in the language she used.

“You say ‘fell victim,’ which is a powerful way to reframe the conversation about smoking.”

Sarah agreed. “Language matters, because it can do more than change how we talk about something, it can change how we think about something. And, ultimately, how we behave.”

Today, smoking is out of sight out of mind. But that fight was hard-won.

“It used to be pervasive, well-marketed, and socially acceptable,” said Sarah. “People started and found that, even when they wanted to, they couldn’t stop.

“They [former smokers] look back with outrage, and want to see meaningful system-level change,” she explained. “This isn’t about shaming and blaming. Most people who smoke want to quit. The best way to support that is through compassion.”

We agreed that a big part of rewriting the narrative is putting the stories back into the hands of those who’ve lived them. I echoed that the MHCC similarly has found some of our most effective advocates in the lived experience community.

And their courage is a powerful antidote to stigma and its many harms.

A loss for words

To that end, CLA released a report in 2018 looking specifically at the stigma associated with lung disease. Of those surveyed, 45 percent said they had put off going to the doctor for fear of judgement.

I couldn't help but draw parallels with the experience of those living with mental illness. Health-care provider stigma is something the MHCC has been working hard to address, and our conversation reinforced the need for swift action.

"I'd love to say that we've made great strides since the release of the Stigma Report, but speaking up is still a challenge for our community. When actions may have led to a disease, it's hard to resolve. People may feel unworthy of care…and sometimes that fear materializes because the care isn't as empathetic as it could be."

Sarah goes on to explain that the addiction is so strong that even people who receive a diagnosis may not be able to quit the behaviour, which can in turn spiral into social isolation.

"On the flip side, some lung diseases are inherited, or environmental, and yet people make false assumptions."

Either way, leading with empathy is always best practice.

Just as mental illness can be perceived as a moral failing, lung disease can be maligned as the result of a lifestyle "choice," even when it may be caused by factors that have nothing to do with cigarettes.

We also found common ground when discussing substance use, such as tobacco, to self-medicate conditions like anxiety. In response, CLA has created valuable resources, particularly targeted to young people, to spotlight healthy coping behaviours that can replace tempting quick fixes – like reaching for a vape.

Research points to a link between vaping and depression, for example, with people who vape being more likely to report mental health concerns. Feelings of anxiety or low mood can trigger a desire to vape, and yet vapes and e-cigarettes contain toxins harmful to overall health.

This intersection in our work underlines the importance of raising our voices as a collective in the name of a more responsive, compassionate, and equitable health care system – one that recognizes the whole person.

"It comes back to that long game, again," said Sarah. "Helping people protect their healthy lungs – and supporting others to live well with lung disease – is part of our mission. Unfortunately, not everyone has the same resources."

Informed choices

"We need to give people the right amount of information," stressed Sarah, who pointed to various evidence-based information available on the CLA website, from "What's the big deal about Radon," to "How to protect your lungs from wildfire smoke."

"But" she cautioned, "if you overwhelm people, it can lead to paralysis."

I concurred but asked about the importance of recognizing that the burden isn't an individual's to bear alone.

Sarah quickly agreed. "Not everyone has the same opportunity to breathe freely," she said. "There are fundamental equity issues that actively work against making the desired changes. We're only as healthy as the systems we live within."

And sometimes those systems perpetuate ill health – especially among pockets of the population made vulnerable by race, socio-economic status, gender identity etc.

This reality is something CLA is highlighting in their new three-year strategic plan, proof positive of the organization's agile response to changing societal circumstances, including a better understanding of the social determinants of health.

Beyond identifying the problem, CLA is closing the gap in services.

For example, the organization has developed a virtual pulmonary rehabilitation program, Breathe Better, Stay Strong, to improve understanding of disease management, offering the kind of information that might usually be available through a family doctor – save for the 6.5 million Canadians without primary care.

As part of this program, the CLA has created virtual support groups, which offer peer-support and reduce the social anxiety and isolation often experienced by people living with lung disease.

I reflected that within our fractured system, charities play an outsized role in closing the gap between available health care and illness-specific needs. Which is why we need to band together in pursuit of shared goals.

Goals that include raising the alarm about the vaping landscape in Canada, or, what Sarah has called the new "Wild West."

Groundhog Day

When I ask Sarah what keeps her up at night, she acknowledges that Canada's high rate of vaping is like reliving the early days of cigarette promotion all over again. And she's unafraid to say that the CLA, and all health promotion organizations, need to do more.

"We don't have 60 years of evidence about the harms of vaping, as we do with cigarettes, but we do know that we shouldn't be breathing in anything that isn't (ideally clean) air, or medication as prescribed," said Sarah.

Yet vaping remains popular, and Sarah worries about not only its long-term effects, but also the potential to act as a gateway for cigarettes, which could set back the tremendous strides made to reduce the harms caused by smoking.

"We need to see strong action on flavoured vapour. That's one of our most important policy asks. We've got to nip this in the bud, so we don't end up with six decades of hard evidence of the harms of vaping, at the cost of the health and wellness of today's generation of young people."

Sarah and I reflected briefly on the prevalence of vaping shops, which I've seen sprout up in some of the remotest corners of the country, in stark contrast with the dearth of accessible health care, especially mental health care.

"I take heart though," said Sarah. "Because this time we're equipped. We've seen the playbook before. We just need to mobilize and mount strong counter measures."

When I ask what keeps her engaged after nearly two decades in lung health, she doesn't hesitate.

“You only have to experience a true inability to breathe one time for it to stay with you the rest of your life. And when you’ve experienced that, you never take a single breath for granted.”

I wrapped up the fascinating conversation with a final question.

“If you had a magic wand, and a single wish, what would it be?”

Without missing a beat, Sarah replied: “For everyone to breathe with ease.”

Until then, Sarah remains committed to CLA’s motto. “We aren’t just there for people with lung disease,” emphasized Sarah. “We’re there for people with lungs.”

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