THE CATALYST

Making the Invisible Seen

MHCC & Series – Arthritis Society Canada By Debra Yearwood Welcome to the first story in the MHCC & series, designed to get to know our Health Partners membership, and learn about where our realities intersect, and how best to support each other. To mark Arthritis Awareness Month, observed every September, the Mental Health Commission.

By: Debra Yearwood | Posted: September 4, 2024

Welcome to the first story in the **MHCC &** series, designed to get to know our Health Partners membership, and learn about where our realities intersect, and how best to support each other.

To mark Arthritis Awareness Month, observed every September, the Mental Health Commission of Canada's Director of Marketing and Communications, Debra Yearwood, sat down with Arthritis Society Canada President and CEO, Trish Barbato, for a wide-ranging dialogue.

When I asked Trish what her biggest challenge is, as president and CEO of the Arthritis Society Canada, she surprised me by rhyming off a list of obstacles that sounded a lot like those we face here at the MHCC.

"You can't see arthritis; it's sneaky, one day you're fully functional, the next you're laid low by a flare; you're isolated and afraid of the judgement that comes with being labelled as unwell."

For those living with the illness, this translates to a familiar sounding refrain.

Dismissive attitudes. Check.

Difficulty planning. Check.

Dispelling myths. Check.

I nodded my head, as these realities echoed the concerns that we so often hear from people living with a mental health problem or illness.

Invisible. Episodic. Stigmatized.

A shared reality

Both arthritis and mental illness are covert tyrants. And with no cure in sight, people are often left to manage with imperfect diagnostics, limited treatments, and scarce resources.

Trish laid bare her challenge like this: "If seeing is believing, how do I make people really see arthritis for the havoc it wreaks on people's lives, so they believe it to be worthy of the funding, recognition, and research it richly needs and deserves?"

As Trish shaded in the nuances of her monumental task, I asked her how she manages her own arthritis – something she's endured in her hands for 20 years.

“We have a saying that motion is lotion,” said Trish, who defies all stereotypes as a certified fitness instructor and black belt in Kung Fu. “Movement really is the best medicine because without it, we can’t get the lubrication that eases our joint pain, or the benefits of improved strength and reduced fatigue.”

That’s an important message, because not only is there a tendency towards being sedentary when in pain, there’s also a known correlation between movement and improved mental health. Given that people who live with arthritis are more than twice as likely to face depression than the general population, I asked Trish about the relationship between chronic pain and mental health problems.

Pain is personal

She cited her mother as an example, who is debilitated by arthritis, her losses mounting until they cast a shadow on even life’s smallest pleasures.

“Pain isolates you by demanding your full attention. It wears you down to the bone – and putting on a happy façade can leave you feeling more depleted than before,” said Trish.

Describing living with chronic pain as a deeply personal and lonely journey, she went on to say, “It’s difficult to be robbed, a nickel at a time, of your mobility, your passions, your work life.”

In fact, arthritis is the leading cause of disability and workplace limitations in Canada. Yet, with knowledge and understanding, the possibility of accommodations could restore hope for those prematurely sidelined. Trish demonstrated this visually by holding up a strange-looking contraption I’d never seen before.

“It’s a vertical mouse!” she exclaimed. “Such a tiny ergonomic investment is a literal lifesaver for someone like me.”

Sadly, many younger people she’s spoken with are reticent about asking for accommodation, fearing negative reactions, or even disbelief.

The empathy gap

“There’s a huge misconception that arthritis is an older person’s disease,” explained Trish. “When in fact more than half of people affected are under 65.” And while as many as 20 percent of Canadian workers live with arthritis, there remains a lack of societal empathy about the profound nature of its impact.

Even among older adults, Trish adamantly rejects the narrative that pain and loss of mobility are the natural trajectory of aging, no different from grey hair or wrinkles.

Trish Barbato, President and CEO, Arthritis Society Canada

“This isn’t an insignificant illness,” said Trish. “You can’t just pull up your socks and get on with it. It’s complicated. Treatments, where they exist at all, come with their own downsides. Big medications equal big, sometimes scary, side effects. And for some forms of arthritis, a joint replacement is the only option.”

But wait times for surgery are often longer than the recommended six months, leaving people immobilized and in pain.

“I may go off on a tangent here,” she warned, laughing – but there’s nothing funny about the delays, which she called patently unacceptable.

“People’s lives are in suspended animation while they wait, and that has practical, financial, and mental health implications. There needs to be more accountability. Period.”

That’s one reason why Trish, together with 21 partner organizations from across the country, is grabbing the bull by the horns.

Actions speak louder than words

“We’re creating an Arthritis Action Plan, and the operative word is action!” she exclaimed. “I have zero time for dust-gathering tomes. Been there, done that. The very act of convening this group is itself an action statement, because we’re casting the net beyond the usual suspects.”

The action plan is being informed by a diversity of worldviews, because arthritis “hits different” depending on your age, race or gender, she says.

As the co-founder of the volunteer-run Menopause Foundation of Canada, Trish is an advocate for ending stigma and sparking dialogue on health areas traditionally considered taboo.

“We need to start dragging topics shrouded in stigma into the light, like the MHCC has done with mental illness,” she said, “and we need to see chronic illness through a prism of diverse experiences. We need to say, ‘Look, arthritis is experienced differently by menopausal women; by child-bearing aged women; by Black women.’ We can’t be satisfied with one-size-fits all.”

She went on to tell me a heart-breaking story of a new mother whose arthritis was so severe that she was unable to pick up her newborn. “And people say it’s no big deal?” Trish shook her head.

Joining forces

After talking at length with Trish, I am more convinced than ever that while our constituencies may identify with a particular illness, their lives could be enriched by greater access to a range of services that our current system is ill-equipped to provide.

“We have a phone line or info e-mailbox, and most often people are looking for services that fall outside our acute care system…they need mental health supports, physiotherapy or occupational therapy, expensive medications,” said Trish.

I ask her what happens when people can’t find or afford these services.

The answer – unsurprisingly – is they go without. It’s in these areas of overlap where we see the potential for shared problem-solving.

As Health Partners, we have an opportunity to amplify our collective areas of need.

And that is precisely what MHCC & intends to do.

Author: Debra Yearwood

A communications pro with more than 20 years of executive experience in the health sector, expertly navigating everything from social marketing to crisis comms. When she’s not advising on the boards of Health Partners or Top Sixty Over Sixty, she’s busy finishing her book on thriving in later life (because why stop now?). Certified Health Executive by day, diversity advocate and magazine contributor by night—Debra’s the one you call when things need fixing or explaining.