

Awareness, education and advocacy in focus for being Brain Injury Awareness Month

By Sam Odrowski

June is Brain Injury Awareness Month, and a not-for-profit organization that supports Dufferin residents impacted by the "invisible illness" is working to educate the public and advocate for the people they assist.

Mind Forward, a not-for-profit organization that supports about 150 people with serious head injuries in Dufferin County, is promoting this year's theme for Brain Injury Awareness Month: "More Than Just My Brain Injury."

Michelle Pessotto, a case manager with Mind Forward, said many people don't understand the impacts a brain injury can have on survivors and their families.

"There's that stigma surrounding the invisible nature of the injury, that creates a lot of obstacles for our clients, especially when they're trying to rebuild their lives," she said. "If someone looks okay on the outside, often people think they're functioning okay on the inside, and we know with brain injury and mental health that this is absolutely not true."

"When you've seen one brain injury, you've seen one brain injury" is another important message, Pessotto stressed, as it impacts everybody differently.

"And it doesn't define them," she said. "They just have to do things differently."

A brain injury can present behavioural and cognitive challenges, as well as change someone's personality, leading to significant losses for those impacted.

Pessotto said the personality changes that some people with brain injuries experience can lead to their family, friends and social network not connecting with them in the same way.

"There's a lot of anxiety surrounding the reaction of others to their injury," she explained. "Some clients may try to conceal their symptoms, and some may isolate themselves because they don't want to deal with that negativity or how they're going to be perceived. It can also be a reminder of the limitations that they have or the changes that have resulted in their brain injury."

The often-invisible nature of a brain injury can encourage discrimination and stigmatization of those impacted.

"For example, if someone has slowed or slurred speech, a lot of people immediately think they're intoxicated or they're on drugs, but that can be part of their brain injury," Pessotto explained.

One of her clients, who had difficulty processing information after her brain injury, was at a grocery store and had to count out change for payment. She was taking a long time, and those who had to wait behind her became impatient.

"Even the grocery clerk was making demands of her and being unkind," Pessotto recalled. "It became such a difficult experience for her just to buy a couple of groceries and she ended up just leaving."

Part of Mind Forward's mission is to help clients develop self-confidence and strategies to respond to challenging situations when out in public.

But creating awareness is vital for building a more mindful, inclusive and less judgmental society, said Pessotto.

"I believe educating others would be really helpful so that they understand what a brain injury is and the challenges that people have so that when clients and their families go out in the community, maybe it could be more welcoming, more supportive and positive," Pessotto said.

Barbara Gilchrist, program coordinator at Mind Forward, said raising awareness of the invisible nature of brain injuries is key.

"The main goal is to help create sensitivities to our fellow human beings. We all walk this journey, and some people have incredible challenges from what's happened to them," said Gilchrist. "Just be respectful, don't make judgments, quickly, like the woman in the grocery store."

Advocacy for more funding to better support people with brain injuries is an ongoing effort at Mind Forward, according to Pessotto.

"We need increased supports or resources for those who suffer from brain injury," she said. "I have clients who are in their 20s and 30s, who live in long-term care. There's no other option for them."

Being a young adult stuck in a long-term care facility with seniors can fuel feelings of sadness and hopelessness.

This is why the government needs to dedicate permanent funding and more resources towards creating residential living homes for people with severe brain injuries that need assistance with day-to-day life, said Pessotto.

"My dream is a specialized housing for young people with brain injuries that provides them with safety, 24/7 care, and socialization with people that have the same interest in the same age. They try their best with the seniors, but it just adds to their depression and their low mood because they feel that there's nothing there for them," said Pessotto.

When looking at the services Mind Forward provides, in addition to case management, they hold community events and offer day service in Orangeville at the Alder Recreation Centre.

This programming provides engagement for people with brain injuries and the opportunity to make new friends.

Participants get out for a weekly walk around Island Lake to enjoy some nature and get exercise.

Anyone interested in learning more about Mind Forward or getting added to their waitlist can contact the organization's clinical manager, Ashley Budd, by emailing Ashley.budd@mindforward.org.