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Living with an 'invisible disability'

By Raveena Aulakh
Staff Reporter

Carolyn Matthews would be stuck without sticky notes.

The 43-year-old needs reminders on appointments, the time to drop off and pick up her son and which stores to stop at when shopping.

Matthews has to scribble down everything – *everything* – or risk forgetting it.

She wasn't always this forgetful. But nine years ago, when she was a detective with York Regional Police investigating child abuse cases, a car crash resulted in brain injuries, leaving her with short-term memory loss.

"Brain injury survivors are mostly invisible and forgotten in our society, yet are one of the most vulnerable populations," she told a conference organized by the Acquired Brain Injury Network yesterday. "I was lucky – many fall through the cracks. We have to change that."

There are about 500,000 brain injury survivors in Ontario. Acquired brain injury means damage to the brain after birth and it can result in temporary, prolonged or permanent impairments. The majority of brain injuries are caused by falls but also occur in car crashes and through strokes or aneurysms.

The conference is attempting to spread awareness about brain injuries and discuss ways to support survivors.

Survivors often have no physical signs of injury and so the severity of their struggles is mostly unrecognized, said Hedy Chandler of the Ontario Alliance for Action on Brain Injury. "It's an invisible disability. They are not in wheelchairs and so their needs are not automatically recognizable," Chandler said.

Matthews is the perfect example.

She can talk, walk and laugh, yet it took her four months to write yesterday's 50-minute speech. "I look the same as I did before the crash but I'm not the person I used to be," said Matthews, who lives in Lindsay, Ont.

She was driving home on Dec. 29, 1999, when she was in a three-vehicle crash on Highway 12, just north of Sunderland. It took emergency crews an hour to extricate her from the car and her family was told that she might not make it. Matthews had a fractured pelvis, five broken ribs, a punctured bowel and diaphragm, a collapsed lung and a head injury.

She recovered but instantly knew that something was wrong. "My sons would come and see me at the hospital, and half an hour later I couldn't remember that. I think it was devastating for them," Matthews said. But she still hadn't comprehended the extent of the injuries and set herself a goal of getting back to work in September, eight months after the crash.

She was still walking with a cane and had double vision when September rolled along. It took her three years to accept she would never be a police officer again. She's since been on permanent disability.

Not many people understand that, she says. "I look normal so people think everything is okay. But it's not – I can't ski, ride a bike or even focus for an extended time."

But Matthews has made extensive progress because she has a supportive family and access to services, said Chandler.

"Not everyone gets that. They (survivors) are mislabelled, misdiagnosed and misunderstood. What they need is special services – some need support for the rest of their lives." Matthews gives presentations a few times a year.

Her speech is peppered with sticky notes, reminding her when to pause and when to stop.

"I can't even write in shorthand," Matthews said. "Because chances are that I'll forget what it stands for."

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