

Technology helps amnesiacs with memory

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So you think your smartphone's your lifeline, that you couldn't do without it?

Try talking to David Dorey.

From the minute he wakes up until the second he closes his eyes at night, his hand-held device is at his side; he doesn't know where he'd be without it. Literally.

"I wouldn't know where to go or what to do. It would feel like I was ..." the Markham resident pauses, searching for the right word, "floating."

That's because Mr. Dorey has amnesia. Seven years ago, he had a brain aneurysm and can remember some things, but can't retrieve new memories.

Mr. Dorey is also one of 45 people with severe memory loss who has found a new, life-changing use for hand-held devices, such as smartphones and iPods. The technology has become their memory substitute and it's an approach, developed at Baycrest, that is garnering attention around the world.

In the movies, amnesia is getting bumped on the head, forgetting everything, getting another bump and it all comes back again.

But that's Hollywood. This is real life.

The men and women with amnesia sit in a circle upstairs at Baycrest's main campus in North York. They hail from across the GTA — several, such as Mr. Dorey, from York Region — and as far away as a southwestern Ontario. They meet biweekly because they have finally found a group of people who understand what it's like to be missing memory.

TOUGH ON FAMILIES

"You know what I hate? You tell people you have no memory and they say, 'yeah, happens to me all the time. My memory's failing too.'"

Rick, who asked that his real name not be used, is one of the more expressive members of the group. He had an aneurysm in 2006 and has given up trying to tell people what's wrong.

They all nod, quietly agreeing and finding rare empathy and even humour in their shared experiences. They laugh at how they drive their families crazy with misplaced items, taps left running, starting to speak and then forgetting what they were going to say.

Throughout this hour-long meeting, their handhelds ding and beep reminders and no one minds, because if it weren't for this new technology, and Baycrest's pioneering Memory Link program, they could be institutionalized, as amnesia patients had been in the past.

Just 10 to 15 years ago, those with severe memory disorders were often placed in care facilities for their own safety, despite the fact they have otherwise intact intellectual ability, says psychologist Dr. Brian Richards, who developed this ground-breaking method to help amnesiacs track and retrieve information.

"It was an absolute tragedy."

A survey nine years ago found more than 1,000 new such cases were being diagnosed in Ontario every year, he says. It is a difficult condition to describe.



STAFF PHOTOS/JOERD WITTEVEEN

David Dorey with his wife, Gail, and his iPod Touch. Before being diagnosed with amnesia, Mr. Dorey worked as a radio frequency design engineer. Now, his iPod replaces lost memory and helps him gain more independence.

Many are no longer able to follow a book or movie plot. They forget what they did 15 minutes ago and rely on checklists, sticky notes and their families' reminders.

Those who have it say it's not the same as forgetting — it's more like constant bewilderment. Memories flit in and out of view similar to balls in a bingo machine.

They may still know the capital of Paris or how many legs a zebra has, but aren't able to access new memories. In their minds, George Bush might still be president or their teenager is five years old. Older memories remain strong; it's the new experiences that are lost.

For a while, Mr. Dorey thought his wife was 58 and his son was eight years old. They were actually 44 and 18. He gets it right now, but there is still plenty he gets wrong.

He told his wife, Gail, he felt sick that morning, back in 2004. She found him on the floor, lamp knocked over, talking in slow motion. By the time he got to Markham Stouffville Hospital, he was having seizures. For two months, he was in ICU in a coma.

Gail watched the room fill up, empty out, while she wondered if her husband of 18 years would survive. When he awoke, he didn't even know what a toothbrush was.

Someone said they're like two people with one brain now. She fills in his blanks and finishes his sentences. They laugh a lot. You get the sense they have been through hell and come out the other side stronger. Not every marriage does. Some in their support group were abandoned while in hospital.

But the toughest part may be career loss. Gerald, a quiet, bearded man, who sits silent at the edge of the group, was a lawyer who fought cases all the way to the Supreme Court.

Many in the Baycrest program were professionals. Now, they struggle to fill their time.

Tim, who worked in manufacturing and lost his memory nine years ago in a skydiving accident, volunteered at the OSPCA in Whitchurch-Stouffville.

Mr. Dorey was a radio frequency design engineer. When discharged from Baycrest, he was still in diapers; they didn't know how they'd cope. After time in rehab, he lived in an "old folks home" for 18 months, but that wasn't the right place for him. With trepidation, Gail brought him home, gave him a little bell, thinking he'd call her when he needed her.

"I don't need no stinking bell" he told her — and he just sat there. Initiative is one of the areas of the brain that was affected by the aneurysm.

LOSS OF CAREERS

His iPod has made a world of difference.

Learning to work the device, when you can't make new memories, is a painstaking process. Lessons must be structured, with no errors, tapping into the undamaged procedural memory (the place where riding a bike is stored). But it can be done.

Mr. Dorey taps his iPod all day long. His iPod 'dings' reminders at him all day long. Together, they get through the day.

"He's feeling more in control of his life. It's not mommy's looking after him anymore," Gail says.

He used to ask her 100 times a day the same question. Now, he just checks his iPod Touch.

He keeps his memory there and jots down what happened in the day so he will know about it later. Some clients take photographs or videos so they can remember people or events.

Mr. Dorey still does some things the old-fashioned way. Taped to the washroom wall is a list — teeth, face, hair, deodorant, shave — and a place for his check marks.

But most everything else he needs to know is in his wife's brain or his trusty iPod, revealing the kind of resilience and resourcefulness that inspires Dr. Richards.

"I have been struck by the dignity and courage of some of these families ... Like pioneers, they have that kind of strength and persistence."

GOOD TO KNOW

For more about Baycrest's Memory Link and other programs, go to: www.baycrest.org, click on Care Programs and follow the links to the Centre for Memory and Cognition

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