TORONTO STAR

HEALTH & WELLNESS

Former Metro Morning host Andy Barrie battles Parkinson's with brain surgery

Parkinson's left him "like a marionette with the strings cut. You just slump there." But deep brain stimulation dialed back the clock on his disease.

By Michele Henry Staff Reporter
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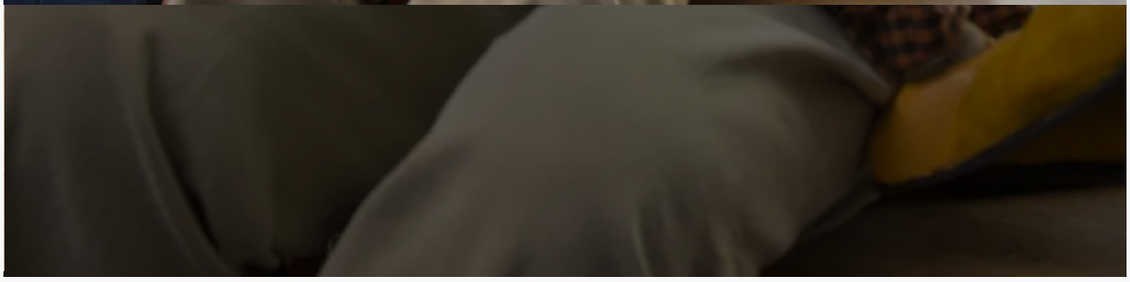

No one notices the old man who shuffles into the physiotherapy office.

“Hello,” he says to the receptionist. “I’m here!”

That voice can only belong to one man.

Even in just a few words, Andy Barrie still has that distinctive timbre that boomed into the bedrooms of Torontonians almost every dawn for 15 years with pointed questions, tell-it-like-it-is facts and wit.

But it’s weary.

Softer, gravely — far more than aging and time would explain.

For now.

In a few hours, after his body gets moving, Barrie will seem like his old self again: the robust man behind the microphone and at the helm of *Metro Morning*, which became Toronto’s top-rated morning radio show thanks to him.

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Round cheeks. Proud chest. Energetic eyes — it’s because of Deep Brain Stimulation, a surgery that, he says, dialed back the clock on his Parkinson’s Disease.

The disease that left him “like a marionette with the strings cut,” he says. “You just slump there.”

Keep that image. The marionette’s important and we’ll get back to it. Right now, there’s physiotherapy to do.

Learning how to sit

After several tries Barrie is starting to get the hang of sitting.

He bends his torso at the waist so far his plaid button down grazes his knees. He steadies his thin 6-foot-3” frame on a pair of New Balance 512s that are sturdy and look like two black bricks on his feet. Slowly he lowers his backside onto the red chair.

He’s trying to avoid that “plop” that comes with falling the last bit of the way. It’s dangerous for a patient grappling with balance — losing it is a common symptom of Parkinson’s.

The neurodegenerative disease makes basic movements much more difficult.

“It makes your head race, your body slow down and throws your coordination out of whack,” Barrie says. And it takes away your automatic behaviours — the ones you’re born with and take for granted, like standing up, rolling over in bed (Barrie bought $600 silk sheets just to make it easier); getting into a car, walking, sitting down.

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Eventually it affects mood and cognitive functioning.

Comic genius Robin Williams was diagnosed with PD just before committing suicide last month.

“Ever heard of festination?” Barrie says, from the chair.

When physiotherapist Jan Goldstein Elman goes to get her clipboard for a moment, he takes the opportunity, rises, deliberately hunches and starts to take very small, fast steps. His feet double over. He’s losing control. He looks like he’s about to topple onto his face. Goldstein Elman hears the rapid stamping, swivels around and races to his side.

Barrie halts. Stands straight. In control. He smiles.

“That’s festination,” he says. “There’s nothing festive about it.”

Since Parkinson’s Disease is all about movement, Goldstein Elman says after she recovers from Barrie’s theatre, the trick to controlling its symptoms is developing movement strategies early on.

That’s what Barrie is doing with the sitting.

He’s learning, at the One Step Ahead Mobility clinic on Bathurst St., how to break this complex action into its components: folding at the waist, bending the knees, lowering the bum onto the seat — so that as the disease worsens — and it will — he can consciously guide his body through the sequence.

It is baby steps for a giant who was admitted to the Order of Canada in 2012 for his excellence in broadcasting and raising awareness about Parkinson’s.

Tough stuff for someone who thrives on spontaneity.

He’ll have to practice these small movements — which he needs to make grand and sweeping — a lot, Goldstein Elman says. Not only to avoid the tiny motions that lead to festination, but because moving more keeps becoming stiff at bay.

The stiffer you become, she says, the harder it becomes to move, the harder it becomes to move, the less you move and the more depressed you may become. And so on.

“I was never depressed,” Barrie says, interjecting.

But he was in denial.

He refused to take physiotherapy for a long time, choosing instead a personal trainer who lived in his building. Sarah Robichaud didn’t know a thing about Parkinson’s when they met in 2007 but made it her mission to learn.

She found a school in New York City that taught PD sufferers how to dance and brought it back to Toronto, creating Dancing With Parkinson’s.

Robichaud, 39, taught Barrie to tango.

“That was our first dance together,” she says. “He doesn’t like to exercise but he likes to dance.”

It was a while before Barrie realized he needs physiotherapy, too.

Lowering into that chair at the appointment this sunny Wednesday morning is more function than fun.

Barrie tries again.

This time he gets it. No fall. Just a nice steady motion. He has to fight hard against his instinct to sit quickly — the way he’d take his seat before that microphone.

How did he get into that chair? “Plop,” he says, sticking out his tongue and splaying his hands.

Next, he and Goldstein Elman work through the sequence of getting into and out of a car.

Symptoms set in quickly

Barrie still drives, but today, he’s a passenger.

After such an appointment, he’s striding and taking big steps — not shuffling — and craving scrambled eggs. And a bagel.

He heads south along Bathurst St. and settles in on patio at What A Bagel in The Forest Hill Village on Spadina Rd. He tucks into a sandwich with egg and tomato. After a few bites he checks his iPhone.

Every three hours it beeps, signaling the time for him to pop a pill.

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It can be draining for a PD patient to figure out their medication schedule — and schedule their life around it, Barrie says.

You have to time when you eat because certain food stops the medicine from working. He's still got an hour before he has to unravel the tissue he brought with his dose of one pill, so he puts his phone away.

"This is nothing," he says. "I take far fewer pills now than before."

That's because late last year he had Deep Brain Stimulation (DBS), which neutralizes abnormally firing neuron circuits that lead to PD symptoms.

Barrie is one of the lucky 15 to 20 per cent of Parkinson's patients who qualified for the brain surgery, which is performed about 150 times a year at Toronto Western Hospital. There are about 100,000 Parkinson's patients in Canada.

His neurologist told him about the procedure a few years ago, Barrie says, but it took the former radio host a while to come around.

Why?

"It's brain surgery," he says, widening his eyes as if to say "duh!"

When he was first diagnosed in 2007 Barrie's symptoms weren't that bad, he says, but they worsened after his wife Mary died of lung cancer in February 2009.

And in 2010, when CBC moved his start time up from 6 a.m., those extra minutes on air wore him out. Having to go to bed even earlier made it impossible to stay plugged in as the ears and eyes of the diverse and growing city he presented to Torontonians in the morning. More than that, he felt he was losing his edge.

Specifically, he says, because of Parkinson's face.

Strange thing for a man who is heard and not seen, but the distinctive droop of his lips and eyes and the accompanying deadened affect made Barrie feel he couldn't relate to his guests.

Colleagues said they didn't notice anything, he says.

"For someone whose whole sense of self is based on communicating properly," it was too difficult to continue.

Barrie left his CBC swivel chair for the last time on Feb. 25, 2010, garnering a salute from a flotilla of taxis that circled in front of the downtown Toronto headquarters.

Before leaving, he reassured his fans, legions listening and tearing up in their bedrooms, that this early morning radio host planned to sleep in Monday March 1.

But he didn't.

His body woke him at 4 a.m., just as it had for so many years. That was the last time things would be the same. Symptoms set in quickly and unpredictably. He never got around to mentoring radio hosts across the country, a job he terms the "host whisperer," or becoming a visiting professor at Ryerson University, as he had planned.

He just couldn't show up.

There were good days and bad days.

During "on" periods, when the medications worked and he was "in touch" with himself, he went out — to dinner with friends and people said they couldn't tell there was anything wrong.

But during the "off" times when the dopamine drained from his system, he was seized by violent tremors or immobilized into a catatonic lump.

Worse, he got dyskinesia from the medication; those twitches and jerks that plague actor Michael J. Fox, for instance.

"It's like Dr. Jekyll and Mr. Hyde," he says. "You feel something come over you and you're terrified."

When the off times outnumbered the on times, Barrie began to retreat.

He sold the Chocolate Co. Lofts condominium he shared with Mary, an airy space on Queen St. W. and moved to his country home, a farm in Creemore, Ontario.

Barrie scrolls through photos of the 24-hectare property that offered him a slower pace of living. He adores its calm, pastoral vistas.

But after two years he was almost gone, he says. A hermit who completely withdrew from social interactions. If he once embodied the city, now he “was disembodied.”

He lost 40 pounds, deflating those big pink cheeks to sallow folds of skin.

“I was reading a lot about assisted suicide,” he says.

Here’s where that marionette comes in.

With the tremors and the immobility, the withdrawal and weight loss, Barrie didn’t have the strength or dexterity to play with Clyde — his puppet with strings attached.

As a child growing up in Baltimore, he watched the plaid-clad marionette with big eyes and clown shoes dance in black and white on a 1950s television show (he can’t remember the name). And he spent 40 years tracking him down.

Finally, he found him in the hands of an eccentric New York City collector in 2011 and, after haggling, brought him home. But the timing was wrong.

Clyde, of wooden face and eyelids that open and shut, was heavy and had so many strings.

“If I tremored, he tremored,” Barrie says. “If I couldn’t move, he couldn’t move. I had to put him away for a while.” Into a shrine in the TV room at the farm.

With Clyde asleep near him, Barrie mustered the strength to fight his symptoms, but like a petulant adolescent — refusing to go to physiotherapy and even take his pills sometimes — which only made the symptoms worse.

“When you have a chronic disease it can run your life. ‘Do this, don’t do that; eat this, don’t eat that,’ and the only way to put the disease in its place is to ignore its demands,” he says.

“It’s perverse and ridiculous, but you have to be there to understand why.”

Then his medications — a handful of pills every few hours — stopped doing their thing. Looking at the odds and certainty of incapacity, Barrie decided to go ahead with the DBS.

“It was either put my life in the hands of a brain surgeon,” he says, “or put my life in the hands of Parkinson’s.”

Brain surgery

Barrie swipes his finger across the iPhone screen to scroll through a photo album and stops on a gruesome image.

It’s the bird’s eye view of a head.

Soft white hair is shaved back far along the skull. Just at the pitch of the cranium is a long, red and black Frankenstein smile punctuated along its middle by staples.

“That,” he says, with an amused look, “is brain surgery.”

There’s no sign of it left now.

On Dec. 13, 2013, Barrie sat wide awake in a Toronto Western Hospital operating room ready for the four-hour surgery.

He felt the drill penetrate his skull and remembers the noise of it cutting down to his gray matter.

“My brain felt like it was shrieking,” he says. “Not from pain but it was saying to the surgeon ‘hold on, there’s only room in here for one person!’”

Dr. Andres Lozano planted minuscule electrodes in Barrie’s head, the thinness of a single spaghetti strand, at certain trigger points. The electrodes are controlled from the outside, like a pacemaker, and, with electric currents, block the bad impulses that lead to Parkinson’s symptoms.

“We seek out the trouble-making neurons in the brain and use electricity to prevent them from doing so,” says the neurosurgeon, also senior scientist at the Toronto Western’s Krembil Neuroscience Centre, who has performed the procedure more than 1,000 times.

Once it was over — there’s very little recovery — Barrie felt like a new man. But he had to wait two months for the honeymoon period to end — just putting in the electrodes provides relief, Lozano says. Once Barrie’s symptoms resumed full force the doctors would turn on the electricity.

Barrie went back to Toronto Western in late February where neurologist Dr. Alfonso

Fasano did just that. He adjusted the currents on the many electrodes, just like fine tuning the volume on different radio stations.

That's when Barrie came back to life.

The tremors stopped. The off periods stopped. His voice, which could have been more affected by the surgery, Lozano says, has retained that boom, even if it is a bit — a tiny bit — softer and Barrie still feels it's not quite the same.

He needs far less medication. And he got his spontaneity back.

Mornings may be a bit slower for Barrie as he wakes up. But as the day progresses, his movements become faster and grander.

Is his face fuller, too? He turns back into that "pull up your socks and do it" host we all know: probing inquirer, charming humourist, on-the-mark observer.

"I used to be someone who said no to everything," he says. "Now I say yes."

The only danger of this "miracle," says Susan Kastner, a documentary researcher and former journalist (who Barrie describes as his vibrant, bombshell lover) is that he compares himself to normal — to the self he was 10 years ago, rather than a Parkinson's patient.

"He doesn't remember how bad it was," she says, from the downtown Toronto home she shares with Barrie. "It's the joy of being given your life back."

But the disease isn't gone. Far from it.

It is still progressing in the background. It is still chronic and degenerative. The surgery is a tool. Not a cure.

For now, however, he has a reprieve. The marionette strings have been reattached. Sort of.

Barrie is looking forward to playing with the grandchild he's expecting soon, he says. His daughter Jess Barrie, an educator who lives in Albuquerque, N.M., is pregnant.

And he's started physiotherapy. Does he want to get back to radio? Maybe. There are possibilities again.

What's he going to do for sure?

Play with Clyde.

At his downtown Toronto flat on a recent morning, Barrie holds the crossed wooden sticks that bear the limbs of this child-sized doll. It was created by American puppeteer Bil Baird for a 1940s Broadway show called *Flahooley* and Barrie delights in watching clips of it on Youtube and comparing it to the real thing now within arms reach.

It smiles and winks and tips its little hat at Barrie's command.

The former radio host once sent his mother to New York City with $3,000 to buy Clyde at auction (she was far outbid) and spent years mining the puppeteering world in his search.

Being able to move those strings is like a homecoming.

"As long as I had Parkinson's, he had Parkinson's," Barrie says, of the yellow-haired toy. "Now that I don't have it anymore, he doesn't have it anymore. I want to get back to that again."

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