

# Home free

## How one man beat the odds to find a condo of his own

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BY DEE GIBNEY

Up at seven. Feeding at eight. Temperature taken at 3:30 p.m. When Scott McArthur was a teenager, his life was pretty much circumscribed by the walls of the institution where he lived.

Yes, there were classes during the day – like learning how to spell by moving sponge rubber blocks around on the floor, this in the days before computers.

In the mid '60s children with disabilities – like McArthur – were warehoused in a variety of institutions that adhered to a hospital model. Then at 18, if they could not be cared for at home, the most likely alternative was a home for the aged.

"They didn't think there was any point in educating us," McArthur says, "because we wouldn't be able to do anything anyway – we'd only end up 'watching TV all day'."

So who would have thought that today at 49, McArthur, who is severely disabled, would be, ironically enough, Manager of Educational Services for the Ontario Federation for Cerebral Palsy – and own his own condo in a regular building in a neighbourhood of his own choosing.

"People are really puzzled," he says, "and curious. They constantly ask me, 'Did the government pay for it?'"

It's very much an issue of personal pride for McArthur that he paid for the condo himself, that it is not subsidized and that it's in a "regular" building. It's a pride well-justified, for his route to independence was a tortuous one.

Born with severe cerebral palsy his prospects were gloomy.

McArthur has multiple physical handicaps affecting his entire body from his limbs to his speech. He cannot feed or dress himself. But he can use a computer keyboard with the aid of a mouth stick and he can kick himself backwards in his wheelchair well enough to navigate his neighbourhood streets.

CP, as it's commonly known, is a condition caused by brain damage at birth or in the womb and it can manifest itself in countless ways from mild to severe and affect any combination of physical, mental and emotional development.

It was assumed 50 or 60 years ago that people with CP had a life span of about 30 or so years.

Today, many people with CP who are living full lives well into their 60s and 70s are defying that view – as well as the restricted lifestyle that once came with the territory.

For McArthur that restriction meant off-and-on institutional living depending on his parents' circumstances. From specialized schools for "crippled" children to rule-bound hospitals, he grew up dancing to someone else's drummer.

"At Bloorview Hospital we were allowed one phone call home once a week," he says. "And we were allowed to go to the bathroom only three times a day – at 8 a.m., after lunch and again at 5 p.m."

McArthur made it to Grade 8, sponge rubber blocks notwithstanding, then at 18 moved back home. He needed five hours of care a day. The role of primary caregiver fell to his mother, but when his father fell ill, she had to find employment. So at 25, McArthur moved into Bellwoods, a college-dorm-style residence for 60 people.

Another institution. Another set of rules. But there was also the opportunity to make friends, and for McArthur, a platform to practise his burgeoning assertiveness.

"I became active on the residents' council and that's where I learned that if you really want to change things, you have to talk to the people who can do something about it rather than just whining about it," he says.

By the mid-seventies, the scope of housing arrangements for people with disabilities was beginning to diversify and expand.

McArthur took advantage of the opportunities, moving to increasingly independent living arrangements over the years, culminating in his own downtown Metro Housing apartment – which meant learning how to regulate his own time, manage his own affairs, even do his own grocery shopping.

"All my life, food had come out of a kitchen on a plate," he says. "Now I had to plan it and buy it. How much do I have to pay? What is a balanced diet? I didn't know. I had to learn to live independently."

Through a pilot program introduced by the Ministry of Health he obtained funding to hire his own attendants according to his own schedule. It's akin to running a small business: hiring, firing, planning, scheduling, payroll, tracking receipts, and is designed as an economical alternative to institutional living for those who have the ability to manage the administration.

As McArthur's lifestyle independence grew, so did other opportunities. First, there was volunteer work with TVO's Telidon project, creating a database of services for people with disabilities, which led to a similar job with the Ontario Federation for Cerebral Palsy. When funding for the project ran out, he enrolled in a two-year computer course.

Another job followed, again until funding ran out.

"I figured the only way I could get work was to create my own job," McArthur says. So in 1987, working with the police and the OFCP he developed a street-smart awareness program for people with disabilities, which is now recognized internationally. His innovative ideas led to a managerial position with the OFCP which brings us to the condo chapter of his story.

"It was really an accident," he says. "I happened to be really bored one day about six years ago, and it had been a while since I caused any trouble so I decided to challenge the Toronto Dominion Bank by applying for a mortgage. I made the appointment for a Saturday morning, never thinking they would give me a mortgage."

To his astonishment he walked out with a pre-approved mortgage.

"So then, of course, I had to go and look at condos," McArthur says with a mischievous grin. "I called up a friend who was a real estate agent and he found a listing on Maitland which was the neighbourhood where I wanted to be."

The building was buzzing with real estate agents. As luck would have it, virtually the entire building was up for sale. Built as an investment vehicle around 1980, the building was now on the block under power of sale thanks to the big thud of the recession a decade later.

Canada Mortgage and Housing had stepped in and was offloading the suites at bargain basement prices, explains McArthur's real estate agent, Rick Tremaine. "Scott came in at a good time – and I knew what he could do with that condo."

Most of the suites are about 830 square feet and shaped like a pie wedge within the round building. With only \$11,000 left for renovations after his down payment, McArthur had to plan carefully. Carpeting had to be replaced with tiles, and ramps installed. A kitchen wall was knocked down to open up the entrance hallway and the wall to the second bedroom was removed, replaced with French doors to allow wheelchair access. The ensuite Jacuzzi had to go, and a tiled shower that could be wheeled into was installed. Drapes were automated, as was the front door.

"The whole emphasis," says McArthur, "was that it not look like a disabled place. I grew up in hospitals and institutions and I don't want to be reminded of that. And I have to think of resale so I have to consider what would make it marketable as opposed to it being only a handicapped place. Although, I have absolutely no plans to move."

As with any home, it's not until you have lived in it for a while that the glitches start to become apparent. And so it was with McArthur's new condo. The ramp in the bathroom was so steep, rising to a little hillock in the centre of the floor, that he was almost tipping over sideways in his chair at the sink. The small button to activate the drapes was a constant struggle. The tiles were beginning to lift. And the kitchen was still too closed off, preventing him from communicating with his attendant during meal preparation.

So, three years later, it was back to the drawing board and another \$50,000 in renovations, this time with a greater emphasis on esthetics and convenience. Attractive ceramic tiles replaced the vinyl. The second kitchen wall came down and was replaced with suspended cupboards with glass doors that opened up the space. A large island-like counter was added that unifies the kitchen with the main living area and serves as a table. It had to be fixed and solid, McArthur explains, so that it wouldn't wobble if his knees accidentally hit it from underneath during a muscle spasm.

Old appliances were replaced with gleaming black new models. Attractive, yes, which was important to McArthur. But the big plus was the freedom that came with the new fridge. It enables McArthur to obtain a drink of water without assistance for the first time in his life. A cup with a flexible straw sits under the water dispenser lever, which he can push with his mouth to activate. The fridge also has a door handle he can operate and clear plastic bins so that he can check on supplies and plan and e-mail his shopping list to an online supermarket. Little everyday things to which most of us never give a second thought.

The slope of the bathroom floor was adjusted, foot pedals installed for the drapes and sliding patio doors and the ramp to the doors was incorporated into the overall esthetic of the living room. Finally, accessible light switches were built into the kitchen "island".

And next – voice activation. At the time of the interview McArthur was in the process of installing a fully voice-controlled set of systems, the latest in "assistive technology." He will be able to open and close doors and drapes, turn on lights, the TV and stereo, answer the phone, check e-mail, weather, stocks and so on, all through voice commands directed to any one of three microphones in the suite.

There's a built-in security system and panic buttons throughout the suite should he fall or run into any kind of problem. The system also includes emergency back-up power so that he can exit the apartment during a power failure.

And should the smoke detector go off, all the lights will come on, the front door will open, a strobe outside the hallway will flash and the security guard will be alerted.

But just in case, he's keeping the old devices such as his phone keypad control system as backup. It's all about being able to control his environment and his safety, McArthur says.

"It's the same kind of smart system that we are now installing in new homes as standard equipment," says Phil Fung of Tomorrow's Home Inc. who did the installation. "It's a rapidly growing industry in the U.S. that is now catching on here."

"And that makes it affordable for me," McArthur adds. "When anything was developed just for disabled people in the past it was always extremely expensive like my specialized TV remote. It was \$800."

McArthur isn't the only one who is benefitting from the new system. A couple of resident canine friends have caught on as well. On his way out one day, McArthur was greeted by the concierge. "I just called you," the man said, puzzled. "How does your dog answer the phone?"

That was harmless enough. But the clever pooches also learned how to break the beam of light that activates the front door. A little bit of jumping up and down and presto! The freedom to cavort about the halls in their master's absence.

"I got hell from management for that," McArthur says. "I'm working to fix it but at least they're treating me like any other resident."

Some of the people on the front desk are still a little puzzled by all the comings and goings to McArthur's suite, and refer to his attendants as his "friends."

"I'm trying to make them understand, they're employees, my attendants, not friends," McArthur says.

Still, they're very special employees. They're a link to a world he feels he missed growing up.

So he hires people who have diverse interests, who can help him broaden his own horizons. People like Ian George, a rock musician who will soon be going on an 18-month North American and European tour with the band U2. George is also an artist who painted the two large paintings in the living room.

In fact, there is artwork in every room – from a tranquil needlepoint of a country church done by McArthur's mother, to a disturbing image of a fallen soldier looming over the bed; art dominates the suite.

There are masks, mosaics, oil paintings. Images that unsettle, images that amuse and images that inspire.

Assistive technology coupled with McArthur's own ingenuity have helped him achieve a quality of life and independence he never dreamed possible.

But it's the esthetics of the space that nourish his soul.