

MAROONED IN THE MOMENT

By Carolyn Abraham



Marooned in the moment; None of them is elderly. None had accidents. Bizarre twists of fate threw each one into a perplexing, perpetual now. They can't recover the past. But as CAROLYN ABRAHAM reports, a familiar technology has offered them a future.

In an ordinary room in north Toronto, I have come to know the most extraordinary people this fall, though they may not recall meeting me.

There's Ben, the bearded former provincial judge, who has to look at vacation pictures of himself to find out if he had a good time. At 55, he can't remember his grown children as teenagers, or enough details of a court case to write decisions. He had to retire at the peak of his career.

There's Barb, a no-nonsense, corn-silk blonde who worked 25 years as a customs clerk. She used to track shipment documents on imports and exports, but now the 48-year-old can't keep track of a two-hour movie; she forgets the plot and its characters long before the credits roll.

Marty, 51, is the gifted sculptor with no memory of the first time he met his former wife at his downtown studio in 1980, dazzling her with his art, buoyant manner and Leonard Cohen looks. He did, however, recall the studio address: "666 King Street," he said proudly.

Doron was a high-octane Bay Street hotshot. The 42-year-old now stays at home, learning where the cups and saucers go in his own kitchen, a feat he mastered only after hours of practice loading and unloading the dishwasher.

Then there's Mike, 56, who travelled the globe for Canadian Tire, buying \$200-million a year in tools and equipment until 2002. "They made beautiful hammers in India," he told me a couple of times one afternoon. Remembering anything since is like clutching sand in a windstorm. Sometimes he walks the dog so many times a day that it hides when he rattles the leash.

None of them are old. They're in their primes. None of them suffer dementia, or seem the least bit debilitated. They look and sound like any of us—except that cruel, random alignments of stars, the most unfortunate slights of fate, have robbed them of their memories.



Mike had an aneurysm while watching TV. A cold-sore virus, as Barb so delicately put it, “blossomed inward and fried my brain.” Multiple sclerosis attacked Ben’s hippocampus. An apparent infection left Marty with at least 10 cerebral lesions. Doron had a cyst he mistook for a migraine.

For most of them, the clock stopped at the time of their injury, leaving them unable to acquire or retain new memories. The result is a life in the perpetual present. Modern culture might laud “living in the moment,” but these people have found nothing liberating about it. With barely an inkling of what happened last week, or even last night, what happens next is always bewildering. Even reading this article about themselves may come as a surprise.

Not long ago people with amnesia—and no one knows how common the condition is—were relegated to institutions, or housebound in the care of others. But the future looks brighter. Thanks to the study of people not unlike Ben and the others, and the boon of brain-imaging technology, experts have stepped out of a long fog and into a largely Canadian-led era they have dubbed the Modern Memory Revolution.

Through much of the 20th century, the scientific study of memory stalled under the stubborn belief that it was a single entity, a black box that was either intact or broken. No distinction was made between recollecting what you cooked for dinner and remembering how to cook it.

But over the past two decades, neurobiologists and psychologists have come to understand memory not as one unit at all, but as a fantastic network of systems in which all the facts, impressions and experiences that give us our sense of ourselves are processed, stored and retrieved by different mechanisms in different parts of the brain.

“It goes right down to the neuron,” said psychologist Morris Moscovitch, one of the great pioneers of memory research at Toronto’s Baycrest Centre for Geriatric Care. “The kind of neuron you have determines the kind of information you can process. Neurons that process visual information, for example, look different, structurally, than those for motor skills. This is why brain cells are so difficult to replace.”

Before now, no one attempted to rehabilitate or compensate for memory deficits, the way you might teach someone who is disabled to walk with crutches. But the new findings suggest one memory system might indeed be trained to offset the failings of another. In that ordinary room on Baycrest’s fourth floor, where everyone is marooned in the moment, the revolution is in full swing.

In a global first, Baycrest’s Memory-Link program is turning a version of the Palm Pilot—that ubiquitous hand-held organizer of the digital age—into nothing short of a prosthetic memory for those with amnesia.



To all outward appearances, Doron Daniels is a well-put-together man. At 42, he is tall, dark, trim and clean-shaven. Everything about him looks new—grey, ribbed V-neck, pressed jeans, fresh haircut, as if he stepped off the page of an L.L. Bean catalogue.

Even his stylish home in Toronto's tidy Allenby neighbourhood is a swank new infill, clad in the biscuit-coloured stucco and stonework that trumpets the success of Toronto's young and upwardly mobile.

It all suits a man for whom nothing is old. Doron's memory stopped in December, 2000, a year after Y2K threatened to wipe the world's technological memory clean.

On a recent Tuesday, I pulled up to Doron's home to walk with him to Baycrest. I had spent an evening there the previous week. His dog greeted me with familiarity. But Doron didn't remember that: "Did you find it okay?" he asked.

As we walked, he recounted the years he can access, when he and Debbie, a former bond specialist, bought their place in 1998, just before their daughter, Katie, was born. Then he stretched back even further to his childhood in Montreal, the city his family chose when they emigrated from Bombay in 1966.

Then he stopped short. "I can't believe you can do that," he told me. "Walk, talk and take notes all at the same time—but what am I saying? I guess I used to do things like that... before."

The word hung there for a moment like the fall leaves swirling in midair. Before, Doron had been a chemical engineer, an economist, then an equities analyst with Scotia Capital. He crisscrossed the globe investigating transport companies, and banged out multipage reports that could make or break a stock. The media, often including this newspaper, sought his opinion.

In February, 2002, *Canadian Business* magazine ranked him No. 1 in his field. Doron read the article in his hospital bed, a month after surgeons cut the cyst that nearly killed him out of his brain. At that point, he had forgotten how to use cutlery.

Now, after, he cannot tell you easily what he did yesterday, or what day yesterday was. He can't recall a dinner with friends last night, or what he had for lunch (unless he checks the chart on the fridge, which saves him from eating turkey sandwiches every day).

He doesn't drive his Audi A4 any more, or ride his bike without using the compass Katie pulled from a cereal box. So every other week for the last two years, he has made the 45-minute trip from his home to Baycrest on foot. He considers it his greatest accomplishment: "Walking... without getting lost."



When we arrived at Baycrest together, I realized that Doron literally is a poster boy for the Palm project. A Memory-Link ad tacked up in a hospital corridor features a picture of Doron brandishing his Palm. But it is a revelation whenever he sees it. “Oh, hey,” he said with surprise. “That’s me!”

Neuropsychologist Brian Richards, an affable 58-year-old with compassion and limitless patience, launched the Memory-Link program 12 years ago after spotting an astonishing gap in the medical system: If you do not have Alzheimer’s, Parkinson’s or diffuse damage after a traffic accident, but suffer only permanent memory loss with no other disability or signs of a deteriorating condition, you are, for the most part, on your own.

No one has even counted how many amnesics there might be. Last year, Dr. Richards surveyed Ontario neurologists and neurosurgeons; the 18 per cent who responded had seen collectively 2,052 patients in the previous 12 months with a diagnosis that typically results in memory impairment, 475 of them with severe memory loss.

He was surprised by the numbers, but already knew well of the need. Amnesics have come to him for help from far corners of Ontario and the United States.

In the soap-opera version of amnesia, you get bonked on the head and forget everything about yourself and your past. In reality, such episodes are exceedingly rare and usually short-lived.

Amnesia is a far more beguiling condition, stealing bits and pieces of this and that, a temperamental and often unpredictable blight. The tragedy is that, until the Modern Memory Revolution, no one paid much attention to which bits of what it stole.

Experts now tend to talk about the brain in computer terms—processing, retrieving and system failures. But for those who aren’t intimate with the circuitry of their motherboards, it might help to visualize human memory as a library.

In the basement, scattered like a Byzantine archive throughout the brain’s deepest regions, is the implicit memory. It is crammed with all the procedural information a person learns and recalls unconsciously—how to turn on a light switch or speak English, skills burned into the pages of our psyches with the hot iron of repetition.

A few floors up, in the inner regions of the mid-brain, is the massive explicit memory system, the mind-boggling trove of things we consciously remember.

One section holds semantic memory, facts and general knowledge such as the capital of France, or who your husband is.



Another holds episodic memory, the most intensely personal, most vulnerable to injury.

Episodic memory is that uniquely human ability to record the autobiographical details of our lives so that we can, on a whim, relive the thrill of our last vacation, the psychic wound of a last goodbye or reading the paper at breakfast. Like a running neural diary, it tracks what we did last week, with whom and what we thought about it.

The implicit memory system, buried deep and spread over various brain structures, tends to be protected from injury. But regions involved in episodic memory lie closer to the surface. They rely heavily on that sea-horse-shaped hippocampus to lay down new experiences.

The cells of the hippocampus are oxygen junkies—a few moments without it and they shrivel. This is why strokes, aneurysms, cysts or infections that trigger brain swelling, or encephalitis, are memory-killers.

With their implicit memories intact, most amnesics can still learn—through excruciating repetition—to use a Palm device to record information their explicit memories cannot.

Want to meet a new friend for lunch tomorrow? Snap her picture. Write down her name, how you met and why you liked her. Was it her quick laugh? Her insightful comments? Then set the Palm timer to buzz you in the morning with the details.

It's fitting that Baycrest and its Rotman Research Institute, both affiliated with the University of Toronto, are putting the new theories to the test.

The leading thinkers of the Modern Memory Revolution work here. Along with Dr. Moscovitch, there's Endel Tulving and Fergus Craik, who compiled *The Oxford Handbook of Memory* in 2000, the first book of its kind ever published. Together they are renowned as fathers of the "Toronto school of memory," from which the revolution grew.

"What we're doing is taking cutting-edge theoretical research and cutting-edge technology and putting them both together to solve a very practical problem," said Dr. Richards, whose program has trained 16 amnesics in the past three years.

"These are extremely bright, intelligent people whose conditions are limited to memory problems. If it works for people at the severe end of the spectrum, it can have much broader applications."

Perhaps, he noted, even for the memory slips of normal aging.

In the large meeting room across the hall from Dr. Richards's office there are familiar comforts—two sofas, a circle of padded chairs, a hot pot of coffee, chocolate cookies and Vachon cakes or a mountain of Timbits



(sugar can be a good memory booster). And, of course, a staple for any gathering of amnesics—name tags.

From week to week, some of them thought I was a new member. It was Christy, 47, who once took award-winning photographs until she suffered a stroke at 35, who used her Palm to snap my picture so she might know me next time.

There are often long stretches of silence in the group. There's an ever-present sense of loss, undercut by the fact that they really aren't sure what is gone. It is hard for them to pass the time. They can't drive, they can't read a book, there's little point in watching a movie and, worst for most of them, they can't work. They seem to hang sometimes in blank suspension.

In one session, it was Paula Davis, the Memory-Link social worker, who got things going: "Do you think it's an asset or a liability that strangers don't recognize you as needy?" she asked. Even using the Palm, she pointed out, makes you look just like everyone else. "Would it be easier if people knew?"

"What?" Ben asked. "You mean like wearing a big red 'A'? People will take advantage of you, to make a buck or whatever."

Ben's regret for a lost past is constant; he was the only one in the group who didn't want even his real first name used. He doesn't want strangers to know about his condition, he said. It's hard enough with his family. His parents, who were once so proud of his legal career, still don't understand why he no longer works.

"They can come to all the meetings, they can have doctorates and degrees, but they can't understand this," he said.

Mike said he lets people know right away. "I say, 'You should know I have memory problems.' But they say, 'Oh, I have them too.'"

Marty suggested Mike try the phrase "cerebral lacerations" instead. Everyone laughed. Their humour systems survived unscathed.

Unlike Doron Daniels, who says little in the group or outside it, as though careful not to reveal what he doesn't know, Marty Sheiner can speak incessantly.

When I visited him at his east-end Toronto apartment, the words streamed forth theatrically, as though he were reciting a verse from Edward Lear's *The Owl and The Pussycat*, as he frequently does. Anecdotes of the childhood bully who made him cry spill into the nice Arab man he met in hospital. From there flow reminiscences of his loyal dog, Epic, and then on to his former wife, Diane Lyn Cartwright, and her husband, who so lovingly care for his beloved whippet now. It is as though his voice itself is a tonic, assuring him of all that he still can remember.



“When you have what I have, you start to think everyone else remembers everything,” he told me. “My doctor says, ‘Marty, no one remembers what they ate in 1965.’ ”

Marty’s diagnosis remains unclear. But doctors have suspected it was Whipple’s Disease, a bacterial infection, that pummelled Marty’s brain, leaving him with little memory of the past 30 years of his life or anything else since.

Ms. Cartwright, an importer of fine teas, was on the phone discussing tea deliveries that Marty had agreed to make when his brain crashed in June, 2002: “It wasn’t gradual, it was sudden,” she said. “He started saying, ‘I don’t know what I’m supposed to do, where I am, what’s going on?’ ”

Marty grew up the son of a successful Montreal businessman. He took veterinary sciences at Ontario’s Guelph University, fell in love with art and anatomy, and then studied with the classical Egyptian sculptor Mustafa Naguib just outside Chicago.

He returned to live and work in Toronto, sculpting and supporting himself delivering pita bread, training dogs and working on the odd commission: There was the masterful statue of Pierre Trudeau for former Toronto MP Dennis Mills and a striking model of Guru Rinpoche, the seventh-century Indian saint considered to be the second Buddha.

To his father’s great disappointment, Marty never made a living at his art. If he wasn’t interested in the commission, he couldn’t complete it; if he was, he was rarely ready to let it go. He agonized over Trudeau’s pants for ages.

“I was a perfectionist,” Marty acknowledged. “As an artist, I was never good enough.”

Yet when he returned from the hospital in the fall of 2002, he looked around at the sculptures in his one-bedroom studio—the Guru cross-legged in front of the fireplace, a spectacular rendering of *The Owl and the Pussycat* nearer the book shelf—and thought, “My gosh, this is brilliant. Who did this? I did this?”

Even more shocking, he found some works smashed to pieces, particularly a statue of his father wearing a business suit, grasping desperately at a young, nude Marty struggling to escape. “It so perfectly describes how I felt about my father and how my father felt about me,” he said. “I can only think I must have thrown it.”

Marty, a thin, pale man who has lost most of the hair he used to wear to his shoulders, is one of the few in the group with little connection to the time before his injury. What’s more, in the parlance of psychology, his temporal gradient has completely melted: He doesn’t know what happened when—ever.



At the hospital, Ms. Cartwright said, Marty had no idea how old he was, the time of day or even the year. “He thought, or guessed, it might be 1920.” Friends who visited were greeted repeatedly. “If we left the room and came back, he didn’t remember that we’d been there.”

While Marty can still recognize friends, he cannot place them in context. He is often flummoxed that people he went to school with appear so much older. In his mind, they are frozen images, like photographs taken 30 years earlier. Their crow’s feet and grey hair startle him: “I think, ‘My gosh, what has happened to you?’ ”

Even personal details cannot be clocked. When Marty told the group that he remembered weeping at his father’s funeral, Dr. Richards asked him when his father had passed away. Marty’s eyes went blank. For a few moments, he fell silent.

“I have no idea,” he said finally. “Was it five years ago? No wait, I think it must have been after March.”

“It was five weeks ago,” Dr. Richards said, gently.

Yet even Marty has learned to use the Palm. Tacked to the frame of his bunk bed is a list entitled, “Each Night Before I Go to Sleep/ Are these items where they belong?” The Palm ranks No. 3, after his keys and wallet. In contrast, his glasses are Item 7.

It’s not the past that haunts amnesics so much as the future. A new friend today is a stranger tomorrow. Appointments they don’t know they made are impossible to keep.

“We haven’t put the emphasis on the past, because it’s a bit like driving in the rear-view mirror. You have to see what’s coming at you.... Otherwise you crash,” Dr. Richards said. “Not remembering the movie you saw last night is bothersome, but not remembering to meet your friend to see a movie is much worse.”

In the film *Memento*, the lead character struggles to compensate for his amnesia by etching crib notes about past events all over his body. Earlier efforts to help real-life amnesics were often just as haphazard. They tried alarm-rigged watches, calculator-like organizers and standard day-timers. Each proved impractical or too complicated to store and retrieve everything an amnesic needs in a day.

Then, in the mid-1990s, along came the Palm Pilot. Dr. Richards saw the potential immediately—a built-in alarm, camera, handwriting-recognition system and diary, with enough memory to store more than 10 Bibles.

U of T computer experts, Palm Canada staff and Memory-Link patients themselves worked with Baycrest staff to custom design a Palm for am-



nesics. It looks and works like most on the market, but also features “who-what-where-why” functions that can give an amnesic his bearings at a given moment.

The big trick was teaching amnesics how to use it.

“You have to prevent them from making any errors as they learn, and you have to teach them over and over again so that it can be committed to their implicit memories,” Dr. Richards said. “You may not remember even how to turn it on if you have a severe memory impairment, or how to take out the stylus and tap on the calendar. There’s 23 steps even before you can put in the new appointment.”

So it was that Dr. Richards and an incredibly committed support staff began teaching each group member to use the Palm one by one, in 30 to 60 one-hour sessions each, often starting from scratch week after week until it stuck.

Hardly anyone in the group remembers how they learned to use the Palm, much the same way we all forget how we first learned to walk, a phenomenon the experts call infantile amnesia.

Mike programs his Palm with his wife every Sunday for the week ahead, in part to remind him to take his medication to prevent the seizures that are common after brain injuries. Barb uses it to keep the household on its strict schedule, tracking clothes in the dryer, dinner in the oven, and her husband, Brad. Her Palm buzzes at 7 p.m. every day so she can review the chores Brad was supposed to accomplish.

“Usually he says, ‘Geez, I forgot,’ ” Barb told the group. “The biggest thing I’ve learned is that my husband’s memory sucks.”

Ben uses it to keep from getting lost. Last year, in his pre-Palm life, he emerged from a bathroom at a New Orleans casino with no clue where he was or why. He had to sit down and wait to be rescued. This year, when his wife left him for a short while at a train station in Europe, he took pictures with his Palm of the scene all around him and set it to buzz him later, fearing he might wander—which he did. This time, instead of panicking, he showed the photos he discovered in his Palm to a passerby who identified the images as the upstairs platform.

Wherever they go, the Palm is zipped in their purses, strapped to their belt loops, tucked in their pockets. They are slaves to their technology—much like the rest of us. The memory aid of the digital age has become an indispensable crutch for the mentally challenged.

The irony would not be lost on those who argue society’s over-reliance on technology makes human memory lazy. In his 2000 book *Cultural Amnesia: America’s Future and The Crisis of Memory*, Stephen Bertman, a professor of languages and culture at the University of Windsor,



blames not only technology for our collective endangered past but the culture of an instant-gratification, up-to-the-minute world.

At 59, Fritz is the oldest member of the group and its only high-tech holdout. A ruddy-complexioned PhD in native education, with a thick Dutch accent, he has yet to adopt the Palm. Most days, hanging around his neck, between the suspenders he likes to wear, is a bloated pouch of tiny maps that help him make his way around the city.

Yet Fritz is also the only group member who not only has a record of what happened yesterday, but how he felt about it. He alone keeps a detailed daily journal of his life's events and experiences.

"Things that I don't want George [his partner] to read I write in Dutch," he said. Would he be as prolific if he had to enter all that in a Palm? "Anything with more than two buttons frightens me."

Ben told the group that lately he has written notes to himself about things he doesn't like. He only remembered which things when he scrolled back in his Palm. "Here it is," he said. "On Oct. 27, I was coming back on the bus from the Hadassah Bazaar. I wrote 'No more Bazaars.'"

Ben could not recall what he didn't like about Toronto's famous one-day sale, but said he hoped to remember to check his Palm next year so he could say "no" if someone asked him to go.

Herein lies the limitation of the Palm as surrogate memory: It's only as good as the things they remember to put in it. Unless they write it down when they've grounded the kids, the kids go out. If they don't log an argument with a spouse, they don't know it happened.

Sometimes, Doron told the group, that might be an advantage. "I can tell if she's angry by the way she's walking around. But I'd have to ask her what happened."

His wife, Debbie, said Doron has actually asked, "Am I mad at you?"

"Normally when two people are angry, you can talk about it when you cool off," she said, "But with this you can't wait to cool off, because then it's gone."

The evening I visited Doron and Debbie, a straight-talking woman who looks a bit like Sigourney Weaver, she said she had kept hoping his memory would return, in the first months after his emergency surgery.

"Sometimes we'd be in the car, and he'd ask me 30 times on a five-minute drive: 'Where are we going?' I'd say, 'To Loblaw's.' Then, a few seconds later, he'd ask again: 'So where are we going?' I thought, 'I'm going to kill myself.'"



Everyone used to tell her that Doron would recover. “People kept saying, ‘He’s young, he’s always used his mind so well, it’ll come back.’ ” Near the two-year mark, she realized it wouldn’t.

“You mourn a life,” she said flatly. “I never realized how hard it would be to always live in the moment.”

She praised Doron’s post-Palm life for the independence it’s given them both. She can finally go out for a few hours on her own, confident he will remember where the medicine cabinet is if young Katie hurts herself. He can even pick Katie up from school, give her dinner and a bath.

What the Palm cannot replace is the contextual closeness couples share—no private references about a film they saw together, no common joy remembering Katie singing along to the Hairspray soundtrack or rehashing a quip a friend made at dinner the night before.

Debbie described their life as “early retirement.” But the big vacations other people enjoy in their post-work years hold little appeal.

“You can’t go somewhere, on a trip or something, and then talk about it, because it’s gone,” she said. “It’s like going to Paris by yourself. It’s hard for me after the moment has passed because I can’t talk about it. You can’t have a normal conversation.... You can’t take 100 trips to Paris.”

Doron sat quietly at the kitchen table as Debbie described her frustrations. Eventually, he mentioned that he had started a diary. Debbie had seen him leafing through it. I asked if he recorded his feelings. No, he said. Those details, rich as they are, have usually vanished by the time he makes his nightly entry.

“It would be great to be able to take a video with the Palm, you know, of Katie having dinner or something. Then I could replay it when I write in my diary, and see what happened.”

Plans are under way to include video software in the Palm devices. But Dr. Richards has even bigger hopes. Maybe, he said in his office after one session, the Palm might one day morph into a gadget that sits inside the lens of a pair of glasses. Or maybe an implant here, he said, touching a spot near his temple.

“That might have sounded really out there a while ago, but not any more,” he said.

Still, I can’t help but wonder if any device could actually remind Doron of how it felt to hear Katie sing. Would it allow Ben to relive the blast he had at an Irish nightclub the other week? Can any device return the feelings along with the factual record?



There's an intriguing physical divide between memory and emotion in the brain that seems to defy all reason. You might assume the tingling rush of your first kiss would be logged in the same book, or at least on the same shelf, as the person you kissed.

But it's not necessarily so, Dr. Moscovitch said. There are amnesics who can recall a lifetime of adventures with their partners, but lose any feeling toward them. Psychologist Elizabeth Glisky, head of the Amnesia and Cognition Unit at the University of Arizona, has found that the longer couples have been together before the amnesia, the better chance their relationship has of surviving.

People in the Baycrest group continue to care for their spouses, despite having little memory of their recent experiences together. Often, it's Marty who reminds them of all they have not lost.

"We're alive," he said emphatically in one session. "I think I'm the only one who lives alone, but we all have people who love and care for us."

Marty has retained the ability to have feelings for those close to him, despite his inability to recall all the history that made them close. It's as though the separation between memory and emotion somehow preserves the human condition.

"The people I knew and cared about, I still know and care about," Marty said. "How long I've known them? No idea. What we've done together? No idea. But how I feel about them is clear as a bell. I've kept the best part."

As he stood in his living room one evening, leafing through photos of his works when they were whole compiled by Ms. Cartwright, he said he wants to assemble enough sculptures to hold the first exhibition of his life—even those he once destroyed in a rage. The determination carries over from one fresh day to the next, so he spends his time sculpting and putting the pieces back together. He has not forgotten how.

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