

# 14 years ago...

**David Askew woke up with what he thought was the flu. A few days later, he didn't recognize his own children. How do you live in a world where every moment is disconnected from the last?**

On Friday, July 9, 1993, David Askew woke up feeling nauseous with a fever and a headache. A forty-one-year old computer whiz and manager of information services for a Mississauga-based importing company, he had been installing new computer systems and putting in eighty-hour weeks. This was supposed to be his last day at work before three weeks of vacation at home with his wife and three young children, but he was too sick to go into the office. His family doctor suggested bed rest, lots of fluids and Tylenol every four hours.

David took it easy over the weekend; he had a meeting in Hamilton booked for the following Tuesday and was hoping to recover in time for it. His wife, Linda, offered to drive him and asked her mother to take care of the children.

On Tuesday morning, they got up at seven. As Linda was getting dressed, David, just out of the shower, came back into their bedroom with a towel around him and a face cloth in one hand, and sat on the end of the bed. "Aren't you going to get dressed?" Linda asked. She was rushing around to get ready, and he wasn't moving. She asked for the face cloth and reached out to take it from him. "You don't know anything about a computer disk drive," he said. "You don't know what you're doing."

"I just stopped dead in my tracks," Linda recalls. "I couldn't say anything." She rushed down to the family room on the main floor to phone their doctor, out of earshot of David. "David is hallucinating," she told the doctor, who said she should get him to the hospital immediately. She asked her mother to look after the older kids (David John was seven at the time and Karen was four). Then she brought David to the car, put her youngest (two-year-old Peter) in the backseat and arrived at the Credit Valley Hospital fifteen minutes later. Dr. Gaspar Israelian, the neurologist on call, was already waiting, having been alerted by the Askews' family doctor. He examined David and asked him a series of questions: "What is your name? What is your address? Are you married?" A CAT scan revealed an abnormality in the right hemisphere of his brain.

When Israelian finished the exam, he turned to Linda. "Your husband has a type of encephalitis," he said. "I'm about to perform a spinal tap to see if it's viral or bacterial. We'll know from the spinal fluid."

"Emergency was in an uproar," Linda recalls. "People were wearing gowns, masks

and gloves because they were concerned about infection.” But she knew nothing about encephalitis.

“I can tell by the look on your face that you don’t know how serious this is going to be,” Israelian added. “There’s an inflammation of the brain. He could die within twenty-four hours. Because we don’t know how contagious this is, I suggest that you have someone take the baby. I don’t want you to leave. At this point in time, your husband knows nothing except that you are his wife. You are his only link to reality.”

Linda called David’s father to explain the situation, and he came to the hospital to pick up Peter. “David didn’t even recognize his dad,” Linda says now. “He didn’t know his kids, or what he did for a living.”

Over the next two days, she watched her husband deteriorate. “I lost count of the number of CAT scans. The swelling wasn’t going down. He lost control of all bodily functions.”

“You could almost feel the infection (which turned out to be viral) damaging his brain.” says Israelian. He explained that David may have first contracted it through a childhood infection. “It’s a common cold sore virus, herpes simplex. Why it goes on to infect the brain is anybody’s guess. It’s very rare.” On Thursday, he told Linda that he would have to inject a corticosteroid into David’s brain. “He had to do something drastic to get the swelling down,” she says. “He said the steroid might work, or it might kill him.” Three hours after the injection, a CAT scan showed that the inflammation was finally subsiding.

Although the immediate crisis was over, David remained hooked up to an IV containing acyclovir -- a powerful anti-viral agent -- for three weeks. Linda slept on a cot in his room until the IV was removed. She remembers every detail, but for David, of course, the whole experience is a blank. “I remember being in hospital,” he says. “That’s all.” And there is the visual reminder: a huge scar on the inside of his left forearm that marks the site where the acyclovir burned into his flesh. Israelian vividly remembers the mixed emotions he felt after saving David’s life. “We ended up with a very intelligent guy, a computer man, who was well-liked by everyone. But one piece was missing. The computer had no memory. Despite early diagnosis and intervention, and the use of the antiviral agent that saved his life, he was left with no short-term memory. It was one of the most heart-wrenching things. There’s no other way to describe it.”

David Askew is not alone. Amnesia and other memory disorders affect hundreds of thousands of Canadians. The most common causes are Alzheimer’s, strokes and head injuries. But memory loss can result from Parkinson’s disease, epilepsy, alcoholism, neurosyphilis, tuberculosis, multiple sclerosis, AIDS, heavy-metal exposure, brain tumours and encephalitis, among other conditions. Although the various types of amnesia are more prevalent among older people, severe memory

problems can and do strike people at any age.

Until recently, people like David Askew were regarded as hopeless cases, unable to learn anything new and destined to live in institutions. However, memory specialists at the Baycrest Centre for Geriatric Care have developed a breakthrough program to help amnesiacs rebuild their shattered lives and achieve some personal independence. It would be two and a half years before the Askews would discover it, but there would be help for them.

Linda, David and I are sitting around their kitchen table, looking out onto a swimming pool and an expansive, heavily treed backyard. They have lived on this quiet crescent in the Deer Run subdivision of Mississauga for more than a dozen years. Linda is tall, blond, attractive – an outgoing woman with an air of self-assurance. David seems a little shy by comparison. The Askews worked hard to build a more affluent version of the close-knit family and community life they had both enjoyed as children growing up in Rexdale.

Linda describes their life before the encephalitis. “We had good jobs in management, and the house was almost paid off. Our plan was to pay off the mortgage in our forties and save money for the kids’ education. In our fifties, we were going to build a retirement home in the Bahamas.”

I asked them how they first met. “We knew of each other in high school,” says Linda. “I was two years younger. I had heard of David because he was very athletic.” David joins in: “I was a high jumper. I set the school record at five feet ten and a half inches. I also played baseball, football and did the pole vault.” As the story unfolds, they laugh and tease each other. “I was a pretty shy guy,” says David. “I thought, if she’s that good-looking, she’s probably taken.” They met officially a few years after high school at the wedding of a mutual friend. “I had gone to the wedding with my family,” says Linda. “When we came out of the church, I was about to get in the car. My eyes met his across the parking lot. It was just riveting. My sister said, “Will you stop staring at that guy and get in the car.” I was wondering, Is he going to the reception? This was so electrifying.” He did go to the reception, they danced, and they’ve been together ever since. Life was sweet for the Askews and their three children on Sawgrass Crescent – until that Tuesday morning in 1993.

David stayed at the Credit Valley Hospital for seven months. Over that time, he slowly began to heal. He regained control of his bodily functions and started walking again. But his memory was another matter. Once the brain inflammation had gone down, the CAT scans showed that the temporal lobes had been permanently damaged. That area contains the hippocampus, where the formation of new memories takes place.

Scientists first learned about the role of the hippocampus in 1953, when a twenty-seven-year-old man from Connecticut with severe epilepsy had most of his

hippocampus surgically removed in order to stop his daily seizures. Although the seizures did, in fact, end, doctors were shocked to find that his brain couldn't form new memories. If anyone was introduced to him, he would forget the person's face and name within minutes. Forty-four years later, he's a seventy-one-year-old man with no memories of events that occurred after 1953.

During David's stay at the hospital, Linda was painfully aware that each moment for her husband was disconnected from the last. "He would forget that he was about to shave," she says. "He kept repeating things over and over again." He was listless and showed no initiative. This active, intelligent guy, who was always busy doing sports, playing with the kids, fixing things around the house or working on the computer, would sit in his hospital room not moving for hours at a time. He was also confused and disoriented. He kept asking, "Why am I here?"

On TV, amnesia victims usually sustain some kind of head injury and then awaken without any memory of their identity or past life. The plot moves along until the character receives another blow to the head and is miraculously cured. This scenario doesn't have much to do with real life, but it does portray an oversimplified form of retrograde amnesia, in which a person can't recall events that occurred before the injury or illness. It also dramatizes the fact that memory is an integral part of identity. The more common form of amnesia is anterograde amnesia, in which a person can't form new memories or recall events that occur after the injury. With retrograde amnesia, the victim has no past; with anterograde, no future.

During David's acute phase of encephalitis, he had both forms: he couldn't remember anyone from his past except his wife, and he couldn't remember any new information. As certain parts of his brain began to recover from the trauma of the illness, he regained his reasoning, logic and other intellectual capacities, as well as many of his memories up until three or four years before the illness. He had no memories of the birth of his two-year-old son, Peter, and he kept thinking that his grandmother, who had died a couple of years earlier, was still alive.

After the crisis had passed, Linda repeatedly showed David pictures of Peter. She then arranged for the children to begin visiting their father at the hospital. After three weeks, she returned to her downtown marketing job, but she brought the kids in every day at 5:30 for two or three hours. These were trying times for the family. "The kids would upset him" says Linda's mother, Alice Laidler. "The least little bit of noise would upset him." A month passed before he started recognizing his youngest son; to this day he can't remember Peter's birth.

While in the hospital's rehab program, David underwent ongoing occupational therapy to assess his memory. "It didn't look like there was going to be any major change over time," says Israelian. "It didn't look very promising." Linda was frustrated because the therapist spent endless hours testing David's short-term memory, but couldn't do anything to improve it.

By Christmas, she started to take matters into her own hands. She brought him home, for four days, over the holidays. The visit was a revelation. He was more animated, more motivated than at any time since the encephalitis. “It was wonderful,” Linda says. “The therapists said he didn’t initiate tasks and had a limited attention span. I had to stop him from painting a bedroom! Don’t tell me he could only do something for a limited time.” She saw signs of the old David surfacing. “He said, ‘Let me make you a cup of tea.’ That is my true husband.”

When he returned to the hospital, his doctors recommended that he be discharged to a live-in facility like Chedoke-McMaster hospital in Hamilton, or a similar U.S. institution. But Linda was adamant. “I said, David isn’t going anywhere without me.” She intuitively recognized a truth that specialists in the new field of cognitive rehabilitation have only recently discovered. A person with memory impairment functions better in a familiar environment.

On Valentine’s Day of 1994, seven months after contracting encephalitis, David went home for good. Linda had arranged for two therapists to work with him two days a week and the kids’ nanny was there full time. But it quickly became clear that it wasn’t going to work. “David would say, ‘Why are all you strangers here? He would tell this woman in her fifties to get out. After his first week at home, I had to hand in my resignation.”

“The first year was total, constant management of David,” she says, “twenty-four hours a day. If I left the room, he didn’t know I was close by.”

She has used his disability benefits from work to make the mortgage payments and gifts of food and clothing from family, friends and their church to live on. Even with that support, though, she felt isolated: “It was all up to me to determine what was best for David. I was going by instinct – what made him happy, what made him mad. It was hard to explain to the children why he was often upset. They were frightened and embarrassed.”

Linda’s mother – who frequently took care of the children - witnessed the impact on them firsthand. “David was violent when he first got home from the hospital. I remember when he heaved the VCR up against the fireplace. This made the children scared. Yet they loved their dad so much.”

David John, who’s eleven now, missed having a dad who’d play catch or go for ice cream. “It felt very wrong. I used to have my regular dad who really had fun doing stuff, so I wasn’t used to it. I just left him alone for a while.”

In February of 1996, two years after David came home, Linda happened to see a small ad in the Mississauga News. “Morris Moscovitch at Erindale College was looking for volunteers for a study at his memory lab,” she recalls. “David got his bachelor of commerce at Erindale. Proximity is a factor I consider when putting

David into a situation. It would give him something positive to do.” She spoke with Moscovitch and agreed to bring David in the following week. In the interim, she happened to catch a segment about amnesia on 20/20. “Barbara Walters called Moscovitch North America’s most renowned expert on memory loss. That gave me confidence.” After completing the tests, Moscovitch referred Linda to Brian Richards.

Brian Richards and Guy Proulx are the memory specialists who developed Baycrest’s innovative program for amnesiacs. For Linda it was a tremendous relief: “They had seen other patients like David. One man is in his sixties and can’t remember his wife. They knew what I’d been going through.”

How do you teach a patient to learn when he can’t remember anything for more than a few minutes? “Rehabilitation is about learning,” says Proulx, a neuropsychologist who first began working with brain-damaged patients as an orderly when he was sixteen. “We teach patients to use intact parts of the brain to compensate for severe memory deficits and learn practical ways to function in daily life.”

There are two basic kinds of memory: short-term, which has limited capacity and temporary storage, and long-term, which holds information that has been processed and stored for days or decades. However, memory can be further broken down into four subtypes that more clearly illustrate David’s strengths and deficits. Episodic memory involves awareness of yourself in time and place – remembering personally experienced events like where you parked your car, what you did on your vacation, or what you ate for dinner the night before. Semantic memory involves general knowledge of principles, concepts, the meaning of words, facts and information about the world. Procedural memory involves skills and routines, such as how to drive a car, ride a bike, fix things or play the piano. And finally, prospective memory involves making a mental note of something you intend to do in the future, and then remembering to do it.

Amnesiacs like David, with damage to the temporal lobes, have great difficulty with episodic and prospective memories. But researchers have found that procedural and semantic memories acquired prior to brain damage tend to be preserved. For David, these were a valuable knowledge base and memory store that he could draw on.

Over the past decade, Proulx and Richards had developed a memory book – something like a Day-Timer – and beeper system as a practical tool to replace episodic and prospective memory. “David uses them as an external memory,” says Richards. “The beep is the cue.” The big challenge is to teach someone like David to remember when and how to use the system.

The memory book has a TODAY section, which organizes activities and appointments for a given day. David’s beeper, clipped onto the book, has settings every thirty minutes from eight in the morning to midnight. Each evening he writes

down activities planned for the following day and sets the alarm to go off at the scheduled times. He might set the beeper for an appointment with Brian Richards at nine, for example, a visit to the children's school at two, a concert at eight. When the beeper goes off, he checks the book, pushes the stop button and performs the task. "If he sees it in his handwriting," says Linda, "he will act on it." Then he checks off the activity to remind himself that he has completed it.

Richards and Linda spent months training David to respond to the beeper by opening the book. "We went over to Baycrest every morning for the first week and then twice a week for three months," Linda says. "We both knew David had to be taught the same thing, over and over again. Beeper, go to the book. It sounds easy," says Linda. "It wasn't easy. He would sleep for five hours after these sessions. We don't realize the physical energy it takes to make the brain work."

The memory book also has a CALENDAR SECTION, for scheduling future events; a DETAILS section, in which David records experiences he would like to remember; a MAP section, to help him get around; and a THINGS TO DO section, for recording plans with unspecified dates.

When he began his treatment, he was totally dependent on Linda to remind him to do everything, including take pills three times a day for colitis. This was a source of frustration and resentment. "I'll take my own pills," he would tell her. "You don't have to give them to me."

"He's an intelligent man," says Richards, "and would react poorly to being treated like an unintelligent man."

Learning to use this system gave him a degree of independence for the first time since his illness. "The memory book gives me a sense of control," he says. "I don't have as many wild mood swings as I did. I can put the brakes on." His memory hasn't improved, though, only his ability to compensate for it. A recent CAT scan shows the damage is the same.

He can also be more of a parent again. In his memory book, he'll find a note under THINGS TO DO – "Peter's bike needs a new brake line. The tire needs air." And he'll fix it. "Before", he says, "everything was a surprise. That was stressful. Why can't I remember this simple, basic stuff?" Their home was a sanctuary, but also a prison because Linda was afraid to take him out.

One of the first big milestones in David's move toward greater independence was taking his son to a Blue Jays game in June 1996. Linda was supportive but concerned: she drove them to the game, telling her son that he and his father should go to the bathroom together so they wouldn't get separated. The day went without a hitch – they even took the GO train home together – and was a great confidence-builder for David.

**“Since he started using that beeper system, he’s remembering a lot better,” says David John. “We can do a lot of things now. This summer, we went to Canada’s Wonderland, and it was really fun. He went on a lot of rides with us because Mom was too scared. I really feel that I have my dad back.”**

**Karen, a precocious and outgoing nine-year-old, says: “It isn’t scary now because he likes doing more things that are fun. He likes bike riding and swimming.” She’s also learned some strategies to deal with his moods. “We have to keep him busy, so he won’t get frustrated. When he gets frustrated, I ask him to do something. I’ll say, ‘Dad, do you want to go for a swim?’”**

**It’s a Thursday morning in May. I’m meeting Linda and David at their kids’ school, a five-minute drive from the house, so that I can watch them tutor some of the Grade 2 students. David and I shake hands. “Hi, Mark,” he says. This is our third meeting, but he doesn’t actually remember me; Linda has briefed him beforehand. He looks alert and energetic. “You seem pretty fresh today, David,” I say. He has a quick comeback: “Usually my wife accuses me of that.”**

**Every Thursday morning, David and Linda spend two hours helping Grade 2 students develop their reading skills. “I always wanted him to feel productive,” says Linda. A year and a half ago, David began going to the school himself on Thursday afternoons to help Grade 1 students with reading, math and computers. On Wednesdays he works with Grade 7 boys who need remedial help in English. He comes alone and uses a map to find his way.**

**The Askews are in the school library and computer resource centre. Children from Mrs. Philip’s Grade 2 class come in one by one with reading assignments. David and Linda each sit with a child at separate tables working through their assignments. He asks one young girl: “Do you know where Australia is?” She says no. “It’s called the land down under. We’re on the north side of the equator and Australia is on the south side of the equator, down under.”**

**Another young girl, talkative and animated, is reading a book called How Birds Live. She reads aloud: “The oyster-catcher has a long beak like a chisel for eating shellfish.”**

**“What’s a chisel?” she asks David.**

**“A chisel is a steel piece of metal,” he says. “You can hit it with a hammer to split wood or make a hole in a wall. It’s got a flat, pointed end.”**

**“My dad has thousands of tools,” the girl says. “He’s in California.”**

**As I watch this exchange and David’s obvious pleasure and satisfaction, I think of Linda’s description of him before the treatment: “He would just sit and stare, doing nothing.”**

**They get to a section about the dodo bird. The girl says, “I feel sorry for the doo-doo bird. It’s extinct.” David corrects her. “Dodo, not doo-doo. Doo-doo is something completely different.”**

**Back at Sawgrass Crescent, the Askews’ garage is filled with stuff donated by friends, neighbours and relatives for a yard sale. They need the money for car repairs and dental work for the kids. “We had a great school concert last night,” Linda says. “David John plays trombone in the junior band. Karen sings in the primary choir.” Their dad was in the audience, she says, singing, watching the kids and waving. I’m thinking about David’s progress and how great it is that he can once again enjoy being a proud parent. Then it hits me. What does he remember about the concert today?**

**“Nothing,” he says.**

**To preserve important thoughts, feelings, experiences, he writes them down in the DETAILS section of his memory book right away: “Monday, October 21. Peter got his beaver tail. November 5, 1996: What I love most about Linda. 1) Good looks; 2) Sex appeal; 3) Honesty; 4) Your love is only for me.”**

**Against the odds, David and Linda have succeeded in rebuilding a life and future for themselves and their children. Linda is both an optimist and a realist. Those qualities, and the bond she shares with David, have given her the strength and will to gradually extend the family’s life from the sanctuary and prison of their home out into the world. She knows what David can and can’t do and has gained the serenity that comes from valuing what matters most.**

**“David has taught all the children to play chess,” she says. “They have their father back. Does it matter if they have to say, ‘Dad, it’s your turn?’”**