Amnesia and the Self That Remains When Memory Is Lost

By Daniel Levitin

The tumor that erased Tom’s memory did not touch his "soul."

Tom was one of those people we all have in our lives -- someone to go out to lunch with in a large group, but not someone I ever spent time with one-on-one. We had some classes together in college and even worked in the same cognitive psychology lab for a while. But I didn't really know him. Even so, when I heard that he had brain cancer that would kill him in four months, it stopped me cold.

I was 19 when I first saw him -- in a class taught by a famous neuropsychologist, Karl Pribram. I'd see Tom at the coffee house, the library, and around campus. He seemed perennially enthusiastic, and had an exaggerated way of moving that made him seem unusually focused. I found it uncomfortable to make eye contact with him, not because he seemed threatening, but because his gaze was so intense.

Once Tom and I were sitting next to each other when Pribram told the class about a colleague of his who had just died a few days earlier. Pribram paused to look out over the classroom and told us that his
colleague had been one of the greatest neuropsychologists of all time. Pribram then lowered his head and stared at the floor for such a long time I thought he might have discovered something there. Without lifting his head, he told us that his colleague had been a close friend, and had telephoned a month earlier to say he had just been diagnosed with a brain tumor growing in his temporal lobe. The doctors said that he would gradually lose his memory -- not his ability to form new memories, but his ability to retrieve old ones ... in short, to understand who he was.

Tom's hand shot up. To my amazement, he suggested that Pribram was overstating the connection between temporal-lobe memory and overall identity. Temporal lobe or not, you still like the same things, Tom argued -- your sensory systems aren't affected. If you're patient and kind, or a jerk, he said, such personality traits aren't governed by the temporal lobes.

Pribram was unruffled. Many of us don't realize the connection between memory and self, he explained. Who you are is the sum total of all that you've experienced. Where you went to school, who your friends were, all the things you've done or -- just as importantly -- all the things you've always hoped to do. Whether you prefer chocolate ice cream or vanilla, action movies or comedies, is part of the story, but the ability to know those preferences through accumulated memory is what defines you as a person. This seemed right to me. I'm not just someone who likes chocolate ice cream, I'm someone who knows, who remembers that I like chocolate ice cream. And I remember my favorite places to eat it, and the people I've eaten it with.

Pribram walked up to the lectern and gripped it with both hands. When they had spoken last, his colleague seemed more sad than frightened. He was worried about the loss of self more than the loss of memory. He'd still have his intelligence, the doctors said, but no memories. "What good is one without the other?" his colleague had asked. That was the last time Pribram spoke to him.

From a friend, Pribram had learned that his colleague had decided to go to the Caribbean for a vacation with his wife. One day he just walked out into the ocean and never came back. He couldn't swim; he must have gone out with the intention of not coming back -- before the damage from the tumor could take hold, Pribram said.

The room was silent for 10 or 15 seconds -- stone silent. I looked over at Tom's notebook. "Neuropsychologist contemplates losing his mind," Tom had written.

If he had lived, Pribram's colleague would have experienced what neuroscientists call retrograde amnesia. This is the kind of amnesia that is most often dredged up as a plot element in bad comedies and cheap mystery stories; so-and-so gets hit on the head and then can't remember who he is anymore, wanders around aimlessly, finding himself in zany predicaments, until he gets hit on the head again and his memory remarkably returns. This almost never occurs in real life. Although retrograde
amnesia is real, it's usually the result of a tumor, stroke, or other organic brain trauma. It isn't restored by a knock on the head. Because they can still form new memories, patients with retrograde amnesia are acutely aware that they have a cognitive deficit, are painfully knowledgeable about what they are losing.

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Tom and I crossed paths years again later when we were both working for a research company. He was part of a team designing virtual musical instruments for non-musicians, like Guitar Hero or Rock Band, seeking to give customers an awesome music-playing experience after zero hours of practice. I saw Tom in the halls from time to time, said hello, saw him at a couple of company jam sessions; he was a really good keyboard player.

Sometime after I left the research company to begin my first academic job, I ran into a woman from the company who asked if I'd heard the news about Tom.

"He has an inoperable brain tumor, temporal lobe. The doctors say he has four months to live. I just visited him. You might want to drop by and say hello."

"Well I ... I don't really know him. I mean, we said hi in the halls and stuff. But, I don't know him ... I don't think we've ever had a conversation longer than two minutes."

"It doesn't matter," she said. "He doesn't really have anything to do, other than to visit with people. I think he'd really appreciate it." She gave me Tom's number, saying I should phone first, because he has good days and bad.

I phoned and a caregiver answered. We made an appointment for the following Thursday at 1:00 pm. "He's not so good first thing in the morning. The drugs. And some days aren't good at all. Call first, around 11:00 in the morning, and I'll let you know how he's doing. Apart from that, I should warn you, he doesn't remember very much -- the tumor has wiped out his memories of the past."

Retrograde amnesia.

Thursday came, and I phoned. The caregiver answered again and said I could come over at 1. I asked if I could bring anything. "He likes Abba Zabba candy, but they're hard to find, so don't worry if you can't."

I knew that the Woolworth's in town -- one of the last remaining ones -- had a huge candy counter. So I picked up a bag of Abba Zabba peanut butter-filled taffy.

Tom lived on a street full of identical apartments -- the kind of street where you'd have to count how many apartment houses from the corner yours was or you'd end up in the wrong building. When I knocked at the door, the caregiver invited me in and asked me to take my shoes off. Then he led me across a fluffy white carpet to the living room, pointed me to an old armchair, and told me that Tom would be out in a minute. I put the candies on the coffee table.
When Tom walked in, I stood up. He came over and shook my hand, and he sang, more than he spoke, "thank you for coming."

Those eyes -- the intense, gripping eyes locked onto mine and stayed locked as we shook hands, even as we both sat down. I broke the gaze to look him over -- his hair was thinning, he'd lost weight, but otherwise he looked the same as I remembered him. The same narrow face, the same guileless smile.

"I don't know if anyone told you," he started, still half-singing and cheerful, "but I have a brain tumor that affects my memory."

I nodded.

"Please forgive me for asking this, but I do this with everybody. Could you tell me your name again and how it is that I know you?"

"Um...my name is Dan. Dan Levitin."

There was neither recognition nor unrecognition. Just a calm, interested face staring back at me.

"We were students together at Stanford," I continued. "We took a couple of psychology classes together."

"Oh, yes, I have a degree in psychology."

"We were in Professor Pribram's class, and we worked in a lab together, Roger Shepard's lab."

"Who?"

"Roger Shepard. He had a music and perception lab."

"Wow. That sounds like it must have been interesting. What did I work on there?"

"I don't know. I guess ... I guess I was absorbed in my own work. I'm really sorry."

"That's okay. Did I like being in the lab?"

"Yes, I think you did. I mean, you never complained. You always seemed pretty focused."

"That's good. I'd hate to think that I was doing something I didn't enjoy." He was sitting on the edge of the old sofa and I could see that the pillows were caved in under him. "So we were students together. I guess that was many years ago. Did we stay in touch after that?"

"Well, we ended up working, a few years later, for the same company. A research corporation in Palo Alto."

"Did we work together?"
"No, we were in different divisions. You worked with Joy, and I worked with Bob. But we saw each other from time to time, and I was interested in what your group was doing. Your team gave a really good presentation during the annual roundup. I remember you had worked on a very clever new musical instrument called the 'bead box.' People could move different beads around on spindles, and the beads would play different musical licks. It was a way for non-musicians to have fun with music, without having to devote themselves to years of practice."

"Huh?" he said, looking at the ceiling, "the 'bead box.' Doesn't ring a bell. But I don't get many bells ringing these days!"

"Well it was very cool."

He looked over at me. "So, were we friends?"

I just stared. Would it be rude if I told him that I never really thought of him as a friend? I mean, if one person thought of another as a friend, and the other person denied it, that would be hurtful. But Tom had no memory of me one way or the other. As I was thinking this, he spoke.

"It's okay. There's often this . . . gray area, I guess you'd call it, in human relationships, isn't there? We meet people, we see them every day, we say hello, but we don't really know them. We say they're our friends, but really, you can't be friends with the hundreds of people you meet, can you? It's enough that we had a shared history together. We were in the same places for a time. We were part of each other's fabric." He made a rubbing gesture with his fingers and thumb.

The caregiver came over with a small Dixie cup of water and some pills.

"Excuse me a minute," Tom said. "I'm supposed to take these."

I looked around the room. There were two or three pictures on the wall and in several places, picture hooks with nothing on them, and the faded outline of frames that had once hung there but were now missing. On the wall to the left was a curio shelf with little objects -- mementos, and a collection of spoons from different states of the U.S. arranged in alphabetical order. But some were missing. Where "Maryland" and "Illinois" had been there was now just a dusty outline, and there didn't seem to be any W's at all -- no Washington, West Virginia, Wisconsin or Wyoming. Round, square, and hexagonal outlines of dust were all that remained on other shelves.

"Would you like anything?" Tom asked.

"I, uh. . ."

"I'm not going to be around in three months. I'm telling people who visit that they can take anything they like. Anything. Pictures off the wall, musical instruments. Someone took a conga yesterday. Do you play drums?"

"No, but thank you. I couldn't . . ."
"Really, it's okay. I have a nice collection of spoons from all 50 states. Please, help yourself."

"Thank you, Tom, but I wouldn't feel right. Forgive me for asking, but aren't you worried that with your memory problems someone could come in here and take advantage of you?"

"In what way?"

"Well, I mean, they could come and lie, and just take your stuff."

"That's okay. They're just things."

The phone rang. The caregiver brought it to Tom. It was his mother. Listening to his end of the call, I understood that she herself was bedridden and was not doing well. This was their daily call. I got up to leave but Tom motioned for me to stay. The caregiver took the phone away when he was done.

"It was nice of you to come. It was helpful too. It's comforting to put together the pieces of my life, to see what I've done. To know that there were kind people like you who were in it with me. Thank you."

I walked down the stairs, past the rows and rows of identical apartment buildings, back to my car. Then I sat in my car with the key in the ignition, not wanting to move. Professor Pribram felt that when we lose our memory, we lose our entire sense of self. When I saw Tom, something fundamentally Tom was still there. Some of us call it personality, or essence. Some call it the "soul." Whatever it is, the tumor that took Tom's memory had not touched it.

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