On Losing My Memory

Introduction

Most of us don't think much about how memory works, except when it lets us down. When we misplace our keys, or can't remember someone's name or find ourselves in the den but can't remember why we're there, we chalk it up having a "senior moment". I, too, have senior moments, and like everyone else they're increased as I've aged, but my unusual memory loss is much more dramatic.

About ten years ago, in 2007, when I was 68, I was bewildered and horrified to discover that I had lost the ability to retrieve memories of the previous forty years of my life. These were memories that I had earlier had no difficulty in retrieving, as my friends and family can attest to. The memories in effect just disappeared as if I had never had them. I simply could not recall any of the life I had lived in those years; no sounds, smells, tastes, feelings, conversations---nothing.

I couldn't remember my wedding to my wife Sara in 1980, nor my wedding to my first wife in 1970, nor an untold number of other well-documented events that have happened to me in between that I know I have experienced, because of photographs or documents written earlier or the memories of others.
That is how, in fact, I am able to write this essay. I don't really remember all the events described here, which is based simply on facts that I \textit{know} or records that I kept at the time, or on the memory of Sara, my wife of 32 years.

I just couldn't bring to mind the memories of these events, their descriptions, the feelings that I had had when I experienced them. To varying degrees I still could remember the general outline of places I had been and people I had known, but no events involving those places and people.

This disability has totally colored and dominated my life ever since. I can't reminisce about the events in my life with myself or with others, and I feel cheated and angry at this stroke of bad-luck that will now diminish the quality of the remaining years of my life, and about which no-one can do anything.

Losing those memories happened more or less overnight, as if I had had a stroke\textsuperscript{1}. But I hadn't had a stroke, and was and am in good physical health.

\textbf{Memory Loss Revealed}

The first sign of my memory loss came when I was rummaging through my email files, pulling together
material for a personal memoir. I came across an email dated about a year earlier, from a woman named Diane, effusing about how much she liked Sara and me.

She wondered whether I could be related to another close friend who was also doing genealogical research in The Ukraine, and whom she also liked very much. My email reply to her at that time was also warm. Since I had indeed been very involved in genealogical research that included searching for my maternal side in The Ukraine, Diane was describing a totally plausible encounter with her that I almost certainly had.

However, I couldn't recall having had the warm conversations she referred to, nor could I recall who Diane was. Because her email was filed under a folder with the name of the Mexican spa Sara and I go to occasionally, I knew the incident had probably happened, and that the lapse was mine.

Sara was not concerned about my forgetfulness; she said the men and the women often went to different exercise classes, so probably I hadn't spent much time with Diane. Still, according to Sara and implicitly from the email, we had had frequent lunches together, including discussing genealogy. It was bizarre that I couldn't recall our conversations or Diane, especially as our comments to each other were so warm and friendly.
So, I wrote to her, and in order not to embarrass either of us, I didn’t say anything about not remembering her. I simply asked how were they doing etc., attached a recent picture of us, and asked her for a picture of her and her husband, as if to “catch up on each other.” I hoped that by seeing a picture of her, my mind would be prodded to remember her, or at least the general flavor of our experience of spending time together.

When the picture arrived I didn’t remember her at all! As far as I was concerned, I’d never seen her before in my life! Her husband’s face was vaguely familiar, and I recalled he had a foreign accent (confirmed by Sara). Still, without the email exchanges, I would never have recalled him to my mind, nor where I had met him had I encountered him again.

We exchanged a few more polite emails after that, but the exchange upset me. The memory lapse did not feel like the forgetfulness that comes with aging. I have that, too, like others my age, but this felt different.

Shortly after this incident, Sara and I visited a friend in Snowmass, Colorado. There, Victor fell into reminiscing about a “guys only” ski weekend about 12 years earlier in Utah, where apparently five friends rented a cabin. As much as I tried to recall such a week-
end, and as much as Victor tried to prompt me, I could recall no memory whatsoever of being on such a trip.

According to Victor there had been a blinding snowstorm on the second day; the roads were closed and no one was allowed to drive. My friends all skied but apparently I chose not to ski. Although I liked skiing I must have thought I was not good enough to handle and enjoy steep terrain in a whiteout.

While everyone else was skiing, I realized we wouldn't be able to drive anywhere for dinner. So, I slogged through the snowstorm on foot to and from a nearby restaurant, bought five meals and persuaded them to sell them to me uncooked.

I listened to Victor's recounting of the anecdote in total disbelief. I had no recall of anything he was saying. He might just as well have been talking about someone else, not me.

Victor told me that everyone had repeatedly made jokes in good humor about my (English) pronunciation of my aching calves ("carves"), but I didn't remember that, either. I didn't remember the skiing itself. In fact, I could recall absolutely nothing about the week-end.
Victor also reminded me that we all stopped in a Patagonia discount store, where I bought a colorful Patagonia fleece sweater. In fact, I've seen that sweater every day in my closet since the day I bought it, but it was just a sweater. My mind seemed to have no automatic recall memory or natural curiosity or pleasure about how I acquired it.

Again, my failure to recall the memories that Victor was describing felt different from the forgetfulness of aging.

Victor, as many people might be, was skeptical of my lack of recall. I, on the other hand, was privately beginning to really be concerned.

After this conversation, Sara said “surely you remember the father-son ski trip in Utah you took with Mischa, about ten years ago, when he was 15 or 16?” Well, it was not a complete surprise to me by now that I had absolutely no memories of such a trip, even with my own son.

Mischa subsequently told me we had had a really memorable time on the trip. Something “clicked” that I had told him about how to make a weight-change to turn his skis, and he remembered that that was when he had his skiing breakthrough.
He recalled that we chitchatted with waitresses and other young girls, and that I taught him ways to charm girls, by noticing something special about them, such as the color of their eyes, or hair, but nothing too suggestive.

We stayed in a hotel, and I rented an “adult” film called “Showgirls” which he watched and I fell asleep!

The next night, he told me, I described my childhood to him, and he recalled it was the first time he had seen me cry. (Sara said that he actually had seen me cry once before, listening to Shostakovich, years earlier).

Again, I remembered nothing of this trip: not the air flight, the hotel, the meals, the waitresses, the movie, the skiing: nothing!

By now, I was seriously concerned about what seemed to be happening to me, and I shared my anxiety and these earlier anecdotes with my sister. She is two years older than me, and we feel free to share our concerns with each other.

At first she was naturally very skeptical. She tested me by asking whether I remembered my visit to her in Philadelphia for her son’s bar-mitzvah in 1969.
She told me that I arrived there with a hurt index finger on my left hand; then, the finger had become so infected that I had to be taken to the emergency room on the morning of the bar-mitzvah. She told me she has a picture of me sitting in the synagogue service with a big white bandage on my hand.

Surely, I couldn’t have forgotten that? Yes, I had. I don’t remember a thing about having made such a visit or having been in an emergency room, nor the bar mitzvah. She tested me with other incidents involving her, that she thought would be memorable, and again I had no memory of them.

(Sara recalls that I had told her that I had once trapped it in the door of a squash court. I was fortunate since those doors are heavy, not to have lost the finger entirely. )

I now had an explanation for the scar on my left index finger and the slightly misshapen fingernail, but I was frantic with worry about what was happening to my memory; where would this lead?

Sara and I had recently rented the film Urban Cowboy, which we thought would be fun, and it was.
Somehow I knew all the songs, as did Sara, though I didn’t remember how and where I learned them.

Well, Sara said, it was “our” music that we played and played driving to the local town for groceries during our extended honeymoon in Maine in 1980, while our apartment in New York was being remodeled. She asked “Don’t you remember?” No, I was very sad but I didn’t remember.

A stanza from a hymn, “Oh, God Our Help in Ages Past” a hymn that I must have sung at my High School, came to my mind:

Time, like an ever-rolling stream,
Bears all its sons away;
They fly, forgotten, as a dream
Dies at the opening day.

How could I remember that hymn, I wondered, and not recall the sentimental times listening to songs that my wife and I enjoyed together?

To gather more information and reassure myself that these were just a few isolated memories that I had lost and not something more serious, I asked Sara and my children to test me, by asking whether I could recall important events that were truly memorable to them and
should have been equally memory to me. When they did so, I couldn’t recall those events either. I clearly had a serious problem.

**An unforgettable trip to Israel**

I flipped through my passport to see if I remembered the foreign trips I had taken. I also thought this might be another way to help bracket the dates of events remembered and events forgotten.

There was an Israeli stamp dated August 1967 in my passport. It’s possible or even probable that my first wife Holly was with me, but I had no memory of the trip itself, so none of Holly on it.

It still surprised me that I had no memory of visiting Israel, because my trip must have been incredibly memorable and vivid, since it was just after the end of the six-day war that dramatically changed the history of the Middle East.

I could imagine what a truly fascinating trip it must have been and what I must have seen; a united Jerusalem, Israelis and Arabs mingling in the streets; a war torn country; a population excited by its victory. Again, it was plausible that I would have visited Israel, being Jewish and having a good friend who lived there.
I wrote to my friend who lives in Israel, to see if I’d stayed with him, to see if he could “jog” my memory. His reply was that no, I didn’t stay with him, because he hadn’t moved to Israel until 1973. He then added, because it was such a momentous time in Israel’s history, “Boy, if you’d been in Israel in 1967, you’d remember it!” Well, he was wrong. My passport showed that I had been in Israel in 1967 and yet I didn’t remember the experience at all.

When I told another friend that about that particular trip, he asked rhetorically and sympathetically “Yes, why do you have a stamp in your passport that you went to Israel, but no stamp in your soul?”

That comment stopped me in my tracks. My soul should have been filled with an infinite number of memories or events great and small, but it apparently did not; it had been wiped clean, like a tabula rasa.

This was more than forgetfulness; I felt I was losing my mind.

What happens when I try to remember an experience

Whenever I try or am prompted by others to remember something, no memory comes to the forefront of
my mind; all I can try to do is imagine what the experience might have been like. I can’t reminisce alone or with others about experiences that I had alone or with others.

I could imagine an event, based on whatever I knew about it—such as a picture, a description, the location—but imagining an event is far different from actually recalling it as a genuine memory.

I am like someone who can play the piano, knows where and from whom he learned, but cannot evoke the memories of the countless piano lessons he undoubtedly experienced.

To all intents and purposes, for me, it is simply as if I had not been present at all the events, big and small, that I have experienced in my life. I am forced to live in a Zen-like present, though my giving up the past is involuntary, rather than a philosophic or religious choice.

It was unfortunate and confusing that in addition to the memory loss, this is also the time when I, like many people my age, also experience increasing number of “senior moments” of forgetfulness.

Right now, I’m able to distinguish between the two. A “senior moment” can usually be rectified with prompting; no amount of prompting can produce an irretrievable episodic memory in my head.
Maybe Some Pictures Would Jog My Memory

In order to gather more information to find out what the scope of my problem was, I decided to try some independent research on my own. I reviewed photograph albums, scrapbooks, passports, medical records and employment records and other similar factual material hoping to find experiences of which I might have clear and vivid memories. I was also hoping to establish some kind of date range when my “forgetfulness” began.

The simple rule of thumb “test” I used to discover whether I really remembered an incident or merely remembered the photograph of an incident, was whether I could describe any other related events that occurred a short time before or after the moment the photograph depicted? Did the photograph evoke any feelings?

The photographs confirmed what I feared. Often the snapshots themselves were familiar, but I could not recall the events the photographs depicted. I had what the brain experts call “screen memories” of events, just not the events themselves.

Sara, on the other hand, could relate to me almost unerringly where a picture was taken, approximately when, what the event was, what happened before and
after, or other incidental information, such as the names of other people was at the event, even if they weren't in the photographs. That's because she has normal memory recall. She reeled off memories triggered by the photographs, and I was dumbfounded at not being able to recall even one incident she was recalling.

**I can't remember my life with Sara**

There were hundreds of pictures of events in the more than thirty years of marriage with Sara; wedding pictures from 1980, honeymoon pictures, pictures of Sara being pregnant, pictures with the children, pictures on trips, pictures at school events, summer camp, friends parties, and so on.

I was stunned to discover I couldn't independently describe any of these events of our lives together. It was both impossible, but apparently true that I couldn't recall any of the individual experiences that have gone into making a marriage of more than 30 years.

After looking at a photograph of me or Sara in the lobby of a hotel, I would ask myself whether I could say what event it depicted, and whether I could describe the entrance to the hotel or any related events that occurred that day or week. Sara not only could answer
most of those questions in a flash, but could also add even more details.

In fact, Sara, on the other hand, could describe the event and circumstances of practically every picture of our married years. Oh she would say, that was taken in London airport while we were waiting for a plane to go to Paris, that time we took the children to France to a house we rented in the Dordogne.

I would look at Sara blankly. A similar thing happened with picture after picture. How could she remember hundreds of details while I remembered none of them? Is this what normal memory recall is like?

Forgetting events in our marriage is the loss that is the saddest of all; to know I couldn’t recall the memories of more than thirty happy years I have spent together with Sara.

Still, if I don’t remember our lives together, how do I know it’s been happy. I seem to have some kind of muscle memory that tells me that has been a happy marriage. I just can’t describe the happy events we have shared, even though I may know from conversations and pictures something about those experiences. She reminds me that we have had our differences, but never anything major and indeed this has been a happy marriage.
I can't remember my children's childhood

As I reviewed photographs and video of the children's school events, holidays, camps and other children's events, I confirmed I had also lost all memories that I once had had of bringing up our children, now 28 and 30 years old, even though I was a stay-at-home father.

I had no recall of my own of playing with or comforting them, games in the park, teaching them to ride bikes; family dinners, ski trips, hiking trips, tourist trips, even though pictures and passport stamps prove that I was there and involved.

A video of me playing with my daughter Chloe, aged about 3, another of her reading to me, aged about 6, were just as if a stranger were there, not me. I could see I was there, happy and very involved, but I couldn't have told you anything about being there, absent this evidence.

There was a picture of our children in a playground which Sara told me was taken (in about 1987), the day our son Mischa fell off his bike and tore his chin open. We had to take him to the doctor, who just happened to be in her office even though it was a Sunday.
I didn’t have any memory of this event, either, even though I’d seen the picture and heard the story many times. I just couldn’t actually independently recall the event itself.

Sometimes, from the evidence in a picture, e.g., my daughter in front of a row of tents, I would infer that she was at summer camp, but I couldn’t remember having been to the camp on visitor’s day when I presumably took the picture.

On the other hand, Sara could remember visitor’s day. She would say that the picture was taken around 1994 when Chloe was ten. That was the year Chloe didn’t want to go to camp, Sara would add, but then once there never wanted to leave.

This loss also makes me very sad; not to have memories of helping to bring up my children.

I can’t remember My 50th Birthday Party

I came across pictures of my 50th birthday party that Sara had organized, in 1988, about 19 years earlier. There were pictures of a well-known pianist, who played romantic songs, and who Sara had hired for the day to make the day very memorable for me. However, seeing
his picture didn’t bring to my mind any memories of the party.

Other pictures depicted certain friends who lived abroad, and I assumed hadn’t been at the party. Then, I realized I didn’t really remember the party; I could only recall the photographs not the event itself.

I can’t remember my first marriage

I reviewed pictures of my wedding day with Holly, my first wife, in 1970, but again I had only screen memories. I couldn’t recall the day at all in any, even though I’m smiling and being sociable in most of the pictures. I didn’t remember our honeymoon or even if we had one.

There were photographs of me and Holly taken on vacation on a beach somewhere, driving together in a sports car with desert-like scenery, snapshots with friends, snapshots in the courtyard where we had lived, on hikes, and so forth; but again I had no memories of those experiences, either good or bad!

I couldn’t recall any personal memories about my life with Holly---dinners at home, dinners out, birthday parties, sentimental times, trips, fights, what it felt like
to be with her, on any occasion whatsoever, intimate moments. Nothing came to mind!

I know from the marriage certificate that we married in San Francisco in 1970; we separated in 1974 (a guesstimate); the divorce certificate is dated 1978.

I also knew as a fact that we had met in 1965, in Frankfurt, where she worked at the German office of the company I was working for in the U.S. I recalled that my company had transferred me to Frankfurt in 1965 for a one-year computer consulting project.

Oddly, I did remember the name of the restaurant where we signed the “no contest” divorce settlement papers, though not of the experience of being there---I think because I must have recounted the anecdote of our amicable parting several times. But I didn't remember how I felt or she felt, or what the atmosphere was like between us; and I remembered nothing else, no lawyer, no judge, no court proceedings etc.

In short, in a bizarre way, except for photographs, the testimony of friends, and marriage and divorce papers, if I had to rely on my own memory, it was as if the marriage to Holly had simply never happened.
I had related some memories of my marriage to Holly to Sara, and she can relate them back to me. This is just one of many ways I can verify that I once had had been able to recall memories that I now can no longer recall.

**I also can't retrieve *new* memories**

During the discovery process, my worst fears were confirmed: When I suddenly lost the ability to retrieve the memories of the past forty years, whatever brain function was damaged meant that the condition also affected the retrieval of *new* memories that I was making.

I do make a short-term memory of an event normally, because I can still recall recent events, but as soon as time progresses and my memories are transferred into longer-term memory, in a relatively short time, I can no longer retrieve them. They're as lost as the memories of the previous forty years.

**I also can't retrieve others' recounted experiences**

It should have been no surprise, but not only could I not retrieve memories of events in my own life, I couldn't retrieve memories that other people had recounted to me that they had had. Even though I might extract and
retain some knowledge from such interactions, I just won’t be able for very long to recall where I learned it.

**I also can’t retrieve Movies and Novels**

The memory loss applied also to movies, one of the great pleasures in life. Even though I recognize movie titles, and may even know I’ve seen a movie before, and possibly even the names of the stars, I can’t retrieve---or, in everyday language, remember---the experience of the movie (that is, I can’t evoke the movie plot itself).

So, I can re-see a movie again, a few weeks after seeing it for the first time, without being able to predict the plot as the movie unfolds, just as if I’d never seen it before. The same is also true of reading novels.

Reading non-fiction, I can learn the information the writer is providing me, and I might incorporate that knowledge in my personal database of knowledge, but in the absence of that knowledge being reinforced by repetition, I find I also “lose” even non-fiction books.

**Maybe, I dreamed about past events?**

I wondered whether my experiences were really absent from my brain or just not accessible to my conscious mind. So, I tried to explore whether such
experiences ever occurred in my dreams, even if in contorted form. I hypothesized that if a dream included some version of a past experience that I knew I had had (but couldn't recall), then that experience must be stored somewhere in my brain, even though I couldn't consciously recall it.

From time to time, I have weird, confusing dreams like most of us, but I don't recall ever having one that even remotely resembled an experience I might have had. I never dreamed of past experiences.

This wasn't completely conclusive evidence, of course. Since I don't consciously remember experiences, I can't categorically say I've never dreamt about a real past experience, since I might not be able to identify it as such the next morning.

The evidence could mean that the memories don't exist in my brain or that the mechanism that the brain uses to retrieve old memories is similarly unable to retrieve those memories in the dream state.

If these lost experiences exist anywhere in my brain, they seem to be securely locked away forever.
My Memory is a black void

I initially characterized each of the various memory lapses I had discovered as a “Black Hole” in my memory. I really thought that that’s what I had, a few isolated incidents that, for some reason, I had somehow forgotten, but that the memories of events in between those events were still recallable.

However, as I looked more thoroughly through picture albums, and discussed past events with Sara and my children, it seemed was that there was dozens, hundreds, thousands of separate black holes in my brain. My brain was like gruyere cheese!

I was discovering new black holes daily, many by what started off with an apparently casual conversation about the past with friends or acquaintances.

I was trying to be analytic and objective, but I seemed to have stumbled across the beginning of something devastating. I wanted to know everything, to be ready to prepare myself, and others, for what could lie ahead. I was determined to find a kind of explanation and also hoping to find reassurance.

I had been concentrating only on a set of specific events that I didn’t recall but others did. What about
the events surrounding those events, as well, events for which there would be no evidence?

Of course no one discussed the Thursday before or a Monday after an exciting weekend some years earlier. If they had, I would have found that I had no memories of those more prosaic days either! Nor the days before or after that; nor the weeks, nor the months!

Based on the evidence I had gathered, I didn’t have isolated black holes of forgetfulness. The black holes were continuous: my past life was a vacuum, as black and as empty as outer space. That’s why I feel lost and hopeless when groping for a memory. I’m trying to explore a void!

I’m scared and depressed and sad

I became demoralized and depressed at the discovery that so much of my life had been taken away from me, and all I had as a substitute were boxes of screen memories.

What is life going to be like when I can’t conjure up the who, where, what, and how of thousands of events or conversations or incidents happened that I had had; if I couldn’t know whether I enjoyed them, disliked them, found them fascinating or dull, or what happened before
or after them. How would I be able to live with this condition?

**My Sense of Privacy**

Out of privacy and to avoid confusion and possible ridicule, I have generally kept my memory condition very private, not sharing it with many others, except close family.

I felt embarrassed to ask friends for their memories of me, when it was almost certain I wasn’t going to remember their anecdotes. This disability is bizarre and is difficult to explain, and for others to believe. It’s proved hard for others to really comprehend and accept it.

Because I retain other kinds of compensatory memories and capabilities, from the outside I seem to be functioning normally in daily life to most people I come in casual contact with. I have friends who were and are bemused by my apparent need to learn what they remember about a certain event when I was present.

**What I learned about Memory**

From my own research, I learned that different parts of the brain deal with different kinds of memories. The brain recognizes two distinct kinds of memories: Declarative
memory and Procedural memory (for skills like riding a bike).

Declarative memory is further subdivided into episodic and semantic memory. I seemed to have lost decades of "episodic memory", autobiographical events at which I had been present. Semantic memory is the knowledge extracted from our life experiences---such as fire is hot, it gets cold in winter, and so forth---and knowledge explicitly learned (such as schooling).

I can still recall my personal biography, my time-line

My personal biography is stored in semantic memory. I've recounted it frequently---different parts at different times---to other people---which somehow reinforces and strengthen my knowledge of my personal biography, even though I can't recall so many individual episodes.

Retelling and recalling the facts of my biography, don't bring back the lost episodic details of the experiences and related feelings that went into building that biography, which are gone forever.

How my memory of places is affected

Because I can't recall events that took place at those places, I have noticed that my knowledge of places that I
have known in the world, both casual and intense, is less vivid in my head. This seems to be another instance of semantic memory not being reinforced by experience in the natural way.

**How my relationships are affected**

I also somehow retain information, a sort of muscle memory, about my emotional relationships---who I am close to and who I feel distant from---so I still remember the people in my circle of friends.

I can still make and retrieve knowledge about my relationships as husband, father and friend. These seem to be stable because they are automatically refreshed each time I interact with the people involved.

Without consciously knowing it, it appears that our relationships are informed by our own past and by those parts of the past we share with others. I have noticed that the quality of my friendships and relationships is affected in subtle ways by my not be able to evoke memories of the experiences I had that went into building those relationships.

As a result of losing the common past I shared with friends and family, in some mysterious way a barrier has come down between us, a barrier that can't ever really be
overcome. Because I can no longer recall that shared past I have in common with others, I feel less “connected” to them, as if somewhat forced to live in a world of my own, as a deaf person might.

Still, I become very frustrated and don’t know how to answer when someone asks me a question along the lines of “Do you remember when?” Of course, I can’t, though they don’t know that. I may realize or infer that I was likely at the event they are describing and, if I can, I try to stay in the conversation by trying to remember relevant pictures or facts that by inference are probably related to the experience being discussed. Or, if necessary, I try to use my imagination to picture to myself what the event was probably like. But my imaginings are not the same as real memories.

Still, when I have absolutely nothing to add, it is painful and frustrating to listen to others’ stories about events in my own life, though I try to be as graceful as I can be and not make a fuss. Unless I am with people I really know well and trust, I don’t explain my disability. What is depressing is that without the original question, I wouldn’t even have realized I’m missing a memory of something.

Unlike a physical disability, there’s very little others can do to assist me. They can make allowances when I can’t reminisce with them, but that’s all. They can’t prompt me
and hope it will evoke a memory. Still, being prompted can sometimes be useful to help me bring a picture to my mind’s eye of what the event might have looked like, maybe even help me imagine something about the event.

However, being prompted and encouraged too much, in an attempt at being helpful to me, is counter-productive; too much prompting becomes frustrating and annoying.

I’m also reluctant to tell or remind many others about my disability because I’m worried that they will then assign me, even unconsciously, into a lesser category of friendship; that they will respect, admire or like me less as a result. I worry that my disability will inhibit them from behaving normally when they’re around me, treating me not as an equal but someone they have to make allowances for, to pity me.

I don’t want to be pitied, just accepted for who I am, with all my strengths and weaknesses, someone who is affectionate and loyal to friends and loving to family; a human being like everyone else.

In reaction to all these complicated feelings, I notice that I have a tendency to want to withdraw from social interactions to avoid any embarrassment at my shortcoming.
Ear Worms

Similarly, without past memories to fill in an idle mind, I notice that my mind gets filled instead with “ear worms” such as repetitive songs, the first words of songs that just keep recurring in my mind, absent anything that would push them aside. I try to combat these with meditation, but what is best is over-riding the worms by listening to other, competing music, or pro-active work for my empty brain: journaling, writing, reading, conversations with others, and physical activity.

What the Memory Specialists Said

Memory specialists I consulted confirmed my own research that our memory mechanism consists of Declarative (divided into episodic and semantic) memory and procedural memory.

They explained that as a result, it’s definitely possible for me to have lost my ability to recall memories of my experiences, but still retain other kinds of knowledge,

They had to accept my assertion that I had lost years of “episodic memory”, autobiographical events at which I had been present. (In theory, I could have been pretending to have lost these memories, for whatever peculiar motive.)
Their tests seemed to show that my semantic memory didn’t appear to have been involved in whatever had happened to my episodic memory, and seems to be relatively intact for my age. Fortunately, everything else about my cognition was also relatively normal for my age.

They presumed the damage or fault was localized in one area of my brain, the temporal lobe, the area that deals with episodic memory.

They reassured me that they did not think I was en route to getting Alzheimer’s disease or any other dementia. They had various theories to explain my loss; the one that fits the evidence most closely is that, unfelt by me, I had suffered some kind of trauma to my temporal lobe.

Not by coincidence, my temporal lobe was the focus of two grand-mal seizures I had had thirty and twenty-five years ago---a condition that has been controlled by medication ever since.

The specialists’ theory was that my temporal lobe might have been weakened by the two earlier seizures, and possibly also by ongoing sub-seizure-level epileptic activity since then, until the damage reached some threshold point in 2007, and something “broke”. There was no way to repair whatever damage had been done.
It was likely, the specialists thought, that I made short-term memories just as others do. In a normal person, a selection of our daily memories gets converted into long-term memories. I may or may not be creating long term memories normally, but that was irrelevant because, regardless of the quality of the memories I made, I would never be able to retrieve them because something was faulty in my retrieval mechanism.

The specialist tried to make me face the reality of my situation; unlike a physical injury, a brain injury of the kind I seemed to have cannot be repaired; there was no cure for my condition. They recommended that I should accept the condition; "just move on, and not look back."

Yet, for my own emotional and intellectual satisfaction, I chose to scrutinize my past, to explore photograph albums, passports, security clearance, journals, and other documents and the memories of others to at least refresh the facts of my life even if I could not evoke the experiences that went into it.

I still retain other semantic memories

Memory specialists have discovered that the apparent “shelf-life” of an experience can be extended by conscious and explicit recounting of the experience,
and by viewing pictures of it, thus creating a “screen” or reported memory of it, what I called “second-hand” memory. These kinds of memories become part of semantic memory. Thereafter, it’s possible to “remember” the event by recalling a “second-hand” memory. My semantic memory contains many screen memories of photographs of various events.

“Second-hand memories” seem to be created in numerous different ways ---by seeing photographs or movies of a past scene (“screen memories”); by participating in repeated discussions of a past event (“reported” or “hearsay” memories); by intellectual interpretation of the evidence about an event from a current discussion (“inferential memories”); from viewing data from an objective sources such as a passport or wedding certificate (“evidentiary memory”); an article of clothing or jewelry, say, worn or viewed repeatedly (“artifact memory”), and so on.

Once created, second-hand memories take on a life of their own; they can get fleshed out with one’s own imagination by describing or visualizing a scene or event.

However, these other kinds of memories don’t contain or evoke the “feelings” that were experienced during the event itself.
Semantic Memory needs to be reinforced periodically

I once thought that my inability to retrieve memories would be very confined to experiential memory. However, I was surprised and dismayed to discover that indirectly the loss seems to affect semantic memory as well.

It’s not really a surprise that we strengthen our knowledge base, our semantic memories, by periodically recalling the experiences that went into building it, just as we needed to repeat our “times table,” when we were learning multiplication.

As a result, my knowledge base, my semantic memory, is also being somewhat atrophied from not being refreshed.

So, since I can’t think about the seventies, say, and memories of Bob Dylan or Joni Mitchell don’t come up in my mind, then my knowledge about them degrades as well.

In fact, knowledge I once had about the past that I now can’t and don’t recall has become increasingly harder to recall as time progresses.
What if my condition were to get worse?

I have to admit that I get scared every time I forget something, which might indicate that my condition could be getting worse. I was fearful that if one part of my brain could fail, why not another? In fact, if my brain structure is damaged, I tell myself, then obviously it’s more likely to lead to other failures.

My fear makes me very self-conscious and very aware of how fragile my hold is on my brain faculties. I often poll myself, to check whether I seem to be losing other faculties as well. What would my life be like if I also lost other kinds of memories, not just episodic memory; what if this degenerates into dementia?

Well, I try to remind myself, the specialists say that I'm cognitively OK now (based on my testing). No one has said anything to the contrary. I know that now is the only time I can experience my life, but I can't stop myself from worrying about the future, especially when I forget something important. Is this a trend, I ask myself?

Yes, I could get dementia, as many others do, but until I do, I have to move on, just as they told me. I should try to live as normal a life as possible, given that one dimension of time and recall is missing from it. I should try to enjoy my present life, and truly give up hopes of retrieving the past,
Grieving My Loss

After absorbing the depressing news that my loss was permanent, I went into a period of grieving for my loss. Poetry and haunting music would remind me of “time” since the very thing that I had lost was the ability to look back in time; my grief became a paroxysm of tears.

Typically, a mention of a particular evocative word would then bring up a line or two of poetry, which would then trigger a paroxysm of tears of sadness and of grief for a minute or two until I pulled myself together. I wept, I cried, I felt helpless and hopeless.

I cried at my own losses, at what I have forgotten, and because I can't recall the details of my own life. Something very deep inside of me was being released: I was grieving.

Underneath my tears of loss were also tears of frustration; and underneath those was my anger. I was angry at being robbed of one of the basic features that makes people human, memories of their past; the past which enriches and informs everyone's life, no matter what their circumstances, rich or poor.
Here is some of the poetry that I recalled. They all clearly involve the passage of time.

And so we beat on, boats against the current
Borne back ceaselessly into the Past
(The Great Gatsby by Scott Fitzgerald:)

(It is especially moving to me that the past is so important in The Great Gatsby, a favorite book of mine since I first read it as teenager).

Today we have naming of parts.
(The WWII poem The naming of Parts, by Henry Reed)

That is no country for old men. The young
In one another's arms, birds in the trees -
Those dying generations - at their song,
(The poem "Sailing to Byzantium", by W. B. Yeats)

Tomorrow, and tomorrow, and tomorrow
Creeps in its petty pace from day to day
(The famous speech from Shakespeare’s Macbeth)

Go and catch a falling star,
Get with child a mandrake root,
Tell me where all past years are,
(Poem by John Donne)
Poetry, ah poetry, mostly about time and loss, which can evoke sadness so economically and swiftly. I wondered when this state would pass because otherwise there's no end of poetry in the world and no end to my sadness.

Eventually, after some months, the grieving ended and I cried a lot less. I turned towards the practical side of learning to live with the loss.

Now, I'm back to "normal" although I can sometimes sense---when a poignant word pops up in conversation, ---the risk of being sucked back and prepare myself for the ride ahead.

Living with the Condition

Until I suffered this loss, I didn't realize to what extent our lives are informed by the past, whether we think consciously or unconsciously about it. Making any kind of informed decisions in the present is much harder when it's not possible to recall what was satisfying in the past.

How do I cope with this condition? Even though I try to lead as normal a life as possible, and not dwell on my disability, it's impossible not to be confronted by daily reminders of what others have and what I lack---the ability
to enjoy the pleasure of evoking past memories with friends and family or privately to oneself.

In practically every conversation, someone evokes memories, reminiscing in some way. If it's a close friend or family member, I might say, “Oh, rats, you know I can’t recall memories”, and then we can move on. It is so frustrating to be so apparently normal, and yet at the same time so disabled; to be on the edge of so much human interaction that I can’t contribute to or enjoy, just sitting on the sidelines of life.

I feel starved of this kind of self-nourishment. I feel deprived and depressed at the thought I am going to have to go through the rest of my life without this source of renewal that others have as automatically as breathing, but that I totally lack.

I just know, though don’t have a memory of my own that I can recall, that everyone without my disability is experiencing interesting and satisfying random memories when they hear a particular song, see a friend, smell an aroma, or feel the sun on their face. But I don’t.

Sara is my muse and my memory

Sara has become my muse and my memory. Even though it initially made her incredibly sad, and continues to be a
sadness for us both, that I wouldn’t be able evoke any memories of our more than 30 happy years together, she has learned not to say “Remember when…?”

Instead, she’ll say something like “You won’t remember this, but what just happened reminds me of that time when….” And then she’ll patiently describe an experience we shared or something she remembers about our children, or a place we visited together.

My mind tries to find a memory of the experience Sara is describing, but I become incredibly frustrated at the brick wall I keep hitting. I try to imagine the scenes she’s describing, and ask relevant questions, try to participate somewhat, but my involvement is based solely on my imagination, not on any tangible memory that I am able to retrieve.

Sara can even describe back to me events that I had described to her before my memory loss, about experiences I had had before we met but which I now can no longer retrieve.

I know Sara and I know my children and their relationships with me, but without them and other family members and friends and the memories they have of me and relate to me from time to time, I wouldn’t have real
memories of what I did for more than half of my life, just knowledge.

Journaling

I've tried numerous times to keep a journal of my days, but when I re-read it, it doesn't teach me anything or make me feel more satisfied. It's a dry recounting of events that when re-read I no longer have a real memory of, a recounting without feelings. Even if I record those feelings, those feelings don't return when I re-read the journal but can't really independently recall the experience I describe in the journal.

"Oh," I say to myself, "I recorded that we went to a particular movie with Jane. I'd forgotten. Apparently, according to what I wrote, the movie made me feel sad." However, reading about my sadness, doesn't evoke the sadness I felt while watching the movie.

Also, the journal entry doesn't cue my memory. All I can do is to imagine the evening with Sara and Jane, probably dining together before or afterwards and discussing the movie we've just seen or what we are about to see, but I can't evoke an authentic memory, including my feelings, and none of the details of the evening itself, such as the table we all sat at.
Cheated

I can pretend otherwise, but I feel robbed and cheated in an exquisite way; to experience my life in the present, and then see it sail away over the horizon never to be seen again, to become part of an irretrievable past; never to be recalled in tranquility and pleasure.

Altogether, I find that living in a Zen-like present is a difficult art to master, although I must.