These documents were written by PT over the course of several months. He sent them to me (AZ) individually. PT used the opportunity of writing these documents to record examples of his memory difficulties, as he had noticed that he tended to forget these unless he recorded them promptly. There is some repetition between the documents, but apart from putting them in a particular, somewhat arbitrary, order, and minimal editing, I have left them in their original form to preserve their flavour.

My experience of my autobiographical memory deficit

My experience of this difficulty is that my past seems like a void. My current analogy for this experience is that it is a bit like standing on the edge of a meadow at dusk. As it is getting darker, people see less and less. I stand there seeing very, very little. Yet others have difficulty too. So I begin to question myself-- how do you quantify the void, what you cannot see? How do you know what is “normal”? How do you even start to suspect you have a deficit? Maybe no one can see things. It is getting dark, after all...

In my case, I notice it most clearly when I hear others discuss events that were commonly experienced. In those cases, privately I am quite concerned that I have no recall of the events, but say nothing. With my wife, I can be a bit more candid. I’ve thought for many, many years that my wife had a “superhuman” memory. She can recall what we did last week, last month, last year. She can recall details of previous holidays, vacations, family events. I’ve found myself actually telling other people what an astounding memory she has. It didn’t occur to me until relatively recently that I was the person with the faulty memory, and that perhaps her memory was within normal limits. When I discussed my memory with her this past summer, she said “But you’ve always had a horrible memory, as long as I’ve known you.” One of the ways I experience this is that I tell stories about my life, things I “know to be true.” But I can’t remember those events. What is that like? For me, it leads me to sometimes question my own truthfulness. I do believe I am an extremely honest person. Like all of us,
I have many faults, but I am not dishonest. But I have from time to time found myself recounting one of my life stories, like the story about breaking my leg while running cross country in high school, and questioning whether it really happened, because I cannot recall details about the event. These stories lack a sense of reality, or realness.

To give you a concrete example, as I compiled my list of seizure events (see below), I've done my best to be as accurate as I can. But the fact of the matter is that there’s a modicum of “filling in the blanks” in my accounts of damned near every event from my life. I’m always afraid that any inconsistency will be viewed as dishonesty, when in fact, I am being as accurate as I can be. I frequently find myself in conversation with others recounting an event and having to say “Well, I can’t remember exactly what I said [or what someone in the story did, or how an event played out] but...” I have my emotional reactions, my conclusions about the event. But I have difficulty remembering details, even for relatively recent events. In conversations, I talk in generalities about the past.

When I do remember an event, it is usually very sketchy. I can’t remember an event that happened at a particular point in time. I’m much more likely to remember things that happened repeatedly, general things. For example, I can remember one of the guys I ran cross country with in high school, who was a pretty good friend. I can recall his silly grin, and the fact that he was a bit goofy when we’d go on long distance runs during practices. But I can’t recall any particular event involving him. I can’t really remember any particular event from running cross country.

The examples I’ve given here were recorded over a fairly long time. I would spend time trying to remember events based on the activities I know I participated in. I’d think “I know in high school I was participated in cross country and speech/debate team...” and I’d try to remember an event from those activities. I’d pick holidays I know I should have memories about. Or I’d pick life events I know I should have memories about. And I would spend time trying to think of a specific event. When I could remember something, I’d write it down. It took quite a long time to come up with all of my seizure events that I list, and I am absolutely certain there are many others. I just can’t come up with them.
When I was first asked whether I’d had any seizures as an adult, I couldn’t come up with many (if any). I slowly came up with that list over time.

It is probably a very good thing that I’m as honest as I am; I couldn’t get away with lying even if I wanted to. I wouldn’t be able to remember what I’d told people in the past. And I’m fairly sure that my ability to distance myself from previous negative encounters is related to my inability to remember previous events. I’m particularly good at “forgive and forget,” or in my case, “forget and forgive.” I’ve had disagreements with individuals over the years, but my inability to remember details probably contributes to my ability to be charitable about such things and move on. I don’t harbor a grudge, because I don’t have painful memories about previous encounters.

When I look back over my own writings from the past, I don’t have a sense of “oh yes, I wrote that when...” I’m not even sure whether that is normal, as I’ve never compared notes with another person about that. By the way, sometimes I like what I wrote-- I think “Wow, did I write that? That was well-said!” and at other times I think “Oh my God, that’s embarrassing. I can’t believe I said that.” To use my meadow-at-dusk analogy, I am most convinced of the abnormality of my memory when I’m standing there next to others who can say “I can see that tree, and the person sitting under it. And the dog on the path. And the flower bed.” Unless I have a chance to compare notes with others, I’m not entirely sure which of my symptoms are normal. Over the last few months, however, I’ve spent increasing time making lists of retrieval failures. That list making has allowed me to finally get a handle on the pattern. And every time I go back to my lists and think about the things I cannot remember, I become a bit more convinced of the abnormality of the pattern. Surely most people can recall some things they did as children, some things they did in high school, some things they did in college. Surely when they DO remember such things, they have some level of detail attached. But I don’t recall a time when I had a better memory for episodic details. I’ve stood on the edge of that metaphorical meadow mostly with members of my family.
When they remember events we’ve jointly experienced, it is troubling to me. My daughter said “Remember our trip to the Rocky Mountains? We had to get off the interstate because it was raining so hard. We stopped at the only restaurant around, and there were dozens of motorcycles out front. And there was water coming through the roof in the dining room; they had buckets catching the water.” My whole family remembered that event, but I have absolutely no recollection of it. It is during those moments when I understand that my memory isn’t normal. I also don’t have joyful memories. I don’t recall details about the birth of my children, or my wedding. I can’t tell you who we spent Christmas with last year, or the year before. I can’t tell you how we celebrated major holidays, even in the relatively recent past (last 5 years). It is as though my car’s rear view mirror is broken; I can’t see much of where I’ve been. I can see what is right behind me, but beyond that things are just gray.

A few years ago I took up the hobby of photography. I spend a lot of time taking pictures of my family. Again, I don’t know whether this is related or not, but I find myself wanting to document their childhoods. I use a program called Adobe Photoshop Lightroom, which acts as a digital photo album. I keyword all of my photos, and they are then searchable by keyword, date, etc. I love going through those pictures, often looking at collections of them based on holidays or particular family vacations. Probably as a result, most of my “memories” from family vacations are snapshots that match the photos in my digital catalog. My “memory” of our trip to Colorado includes setting up our tent—based on a photograph of me setting up the tent. Aside from the photographs, I largely have a collection of semantic information. I know the air was thin because we camped at high altitude— I’ve been telling people that story for years. But I don’t really remember what it was like to experience that.

In some sense, the events of my life have the reality of things I would have read from a biography of a historical figure. I know the information, but it is as if I wasn’t actually there. The uneven nature of my symptoms make dealing with it a challenge. In a sense, I’m utterly convinced of its presence in my life about 90% of the time. But i) there is this distinction between personal semantic and episodic memories. For someone not trained to recognize the difference, I think it would be easy to convince
one’s self “I’m o.k. There are things I can remember about my past.” I’m getting better at teasing those apart. Most of the things I remember about my past are facts, things I know but cannot actually remember. And there are just so many things that I neither remember nor know. And then ii) there is the fact that I don’t experience this as an absolute amnesia. On occasion, something DOES come to mind re: an earlier event. Those things are usually really rough “snapshots,” devoid of the temporal element to a large degree (I have to ballpark the time estimates, and am usually off by a large measure if I pursue verifying it) and the perceptual seems like more of an isolated snapshot, static in time. But when I can recall a name or a face, or when one of those snapshots pop into my head (usually not in response to an attempt to recall something), I start to think “o.k., maybe I’m o.k.” Then I counter that with the really major life events about which I have no recollection and myriad daily instances of jointly experienced events others can recall, well, you see the back and forth I go through about this. The evidential basis for my conclusion that I have memory issues just fades, unless I journal and make lists of all the things I cannot remember. It is the accumulation of those examples that convinces me there’s a real problem.

My strong hunch is that this would be difficult for many people to work through. It has been, and continues to be, difficult for me to work through. Despite all that I know about my condition and symptoms, I feel like I’m still searching for validation. The two options, in my mind, are that 1) I’m neurotically over-interpreting my retrieval failures, or 2) this is something that is recognized and that others experience. Maybe it is just my lack of self-confidence, but it feels good to think there’s a chance it is the latter, and not the former. In either case, it is something I have to deal with.

===============

It is, on a daily basis, really odd to me just how abnormal my memory can seem at times (like when I compare notes with my wife about specific family events or holidays, or when I sit down and read my journals), and yet how absolutely normal my professional life at least appears to be. I can and do essentially distance myself from all of it throughout much of my working day, despite the fact that I’m
virtually always doing something or thinking something that should ostensibly serve as a reminder of
my condition. My mental experiences seem "normal" in that they are all I know and have ever known,
except in moments like this. That duality also makes my situation somewhat perplexing to me, and
somehow harder to confront it. But distancing myself from it doesn't make it better.

My wife has expressed concern of late, that I'm more pensive now that I've started to put more of a
fine point on all of this. And I know she's right. But this is a bit of an emotional thing to come to grips
with. I don't think it has made me depressed; in fact, throughout the course of a day, there's probably
absolutely no outward sign of any of any change. But in private moments, I work through it. That
happens when I'm driving, or working out, or at night when all the kids have gone to bed. I grab some
time here and there to sift through my experiences, and try to put it all together. It is at times like that
when I allow myself to go beyond the "this is all o.k., I'm just fine" and consider the "wow, this truly
is an intriguing/interesting/abnormal/bizarre pattern of retrieval failure." Admitting to myself that I
don't have access to the life events and memories that others have is requiring a bit of work. The more
sure I allow myself to become, the more I feel like it is o.k. to admit all of this to myself and move
forward. I have actually confided in a couple of friends about this, and their reaction has been
interesting. Perhaps it is my own lack of self-confidence shining through, but I sense a bit of disbelief.
I wonder if they think I'm crazy. I've gotten "I've never noticed this before" responses. I'm working on
that one now, trying to figure out when others would have had an opportunity to glimpse this in my
words/behaviours. When I tell them about the many things I cannot remember, they give me a "holy
shit, no kidding? that's horrible" response that I think is sincere. But the pattern is more subtle in
conversation. I'm not sure how many conversations take place in which I'm expected to remember
details about a specific event that took place more than a year ago. To be honest, I haven't discussed
this in detail with them. I also get the sense that people don't want to discuss it at length (or maybe
that's just the result of my reluctance). It'd be easier to detect this if I had total amnesia for my past,
but I don't. I do know facts about some of the major life events that I don't have episodic recall about.
I know my siblings were married, in some/most cases I know where they were married. For example,
I know my brother was married outside. Yesterday, I was discussing the Super Bowl with my daughter. She said “Did you watch football with your brothers when you were a boy? When did you start watching it?” That’s the kind of question where I can’t hide my deficit, when someone asks about “when” questions about my childhood. I had absolutely no idea, and said as much.

=============

I suppose this goes without saying, but I feel extremely disconnected from my past. I suppose I mean that mostly in an emotional sense. I don’t know with certainty whether that emanates from my memory issues, but it has always been there for me. I’m not a “reunion type.” I don’t recall emotional events from my past, and I suspect that has an influence on the degree to which I feel connected to people and places from my past. My college is having a 25 year reunion this summer, and I’m just not motivated to go. I graduated summa cum laude, feel like I received a fantastic education, had a generally good experience... I’m just not motivated to go. I feel the same about the high school I went to, and even to the hometown I grew up in. I know things about them, had generally good experiences with them. But I’d bet there’s a functional aspect of being able to relive past experiences, especially those with an emotional component...probably an intensely social function.

=============

It is strange and frustrating that I cannot recall so many events about my life and that when I do hear about details, I experience no sense of familiarity. When my wife supplies a detail about a forgotten event, I frequently (usually) have no recollection for that detail at all. On a few occasions, the supplied detail does ring true (though it doesn’t usually add much in the way of episodic detail). And yet, there are times when I’ll recall fleeting bits of information about some past events, usually when I’m not really trying to remember something from a particular period- though when something has triggered the memory. For example, I have a recollection of this kind of an event from college. I met with a
member of the Economics department to get help with use of a statistics package called SAS. I can recall where I sat, at a computer near the door to his office. Nothing else about the meeting comes to mind, I just know that I met with him and where I sat. So this is akin to a photograph, not a video-- the image is frozen. Not sure what brought that image to mind. It is as though I am looking through incredibly opaque glass that eliminates all details (including colors). I cannot recount any conversation or situational information for either event. I cannot picture the professor at all. I don’t know when this event happened, other than that it happened while I was a college student. All I know is that the events took place, their general purpose, and location. I cannot picture the office itself (interior or exterior). I wrote a letter of recommendation for that professor within the last couple of years, by the way. So I’ve probably thought about that event since it happened. I feel pretty certain that these vague snippets, devoid of detail, context and colour, and that seem to float into my memory, also fade. That is, I’m not sure I’d remember them later if I attempted to do so. Maybe writing about them will help remember them later.

==

During lunch today, my secretary today mentioned plans to visit a local restaurant with her husband. I said “I haven’t been to that restaurant in years,” and recounted information about my last visit to it. I had made reservations for Mother’s Day. When we arrived, it appeared that the restaurant had “double booked,” leaving the restaurant full of disgruntled patrons. We ended up waiting for a very long time to get our table. The fact that this information came to mind so readily surprised me, and would have (in the past) contributed to wishful thinking that my memory is fine. I cannot remember what anything looked like, cannot remember any other details. I don’t know how long ago this happened-- 3 years ago, 5 years ago, 10 years ago... ? I don’t remember what ages my kids were, as I cannot picture them nor anyone else in this event. All I know is that we were very unhappy about the experience, and haven’t gone back since. This is the sort of thing that my wife, if she were here with me now, would readily embellish with all sorts of details. She’ll almost certainly be able to recall when
this happened, and fill in additional information (what we did before and after, etc.). I read the Levine (2004) Brain and Cognition paper this morning for the first time, and a couple of pages struck me as particularly apt. In particular, his discussion of teasing apart knowing and remembering seems particularly helpful. I can sometimes spontaneously retrieve knowledge of events “I know things about them.” But what I retrieve comes with very little in the way of “remembering.” What I know about that event is that on a Mother’s Day we got treated badly, apparently victims of double booking. I cannot really “see” any details in retrospect, nor supply information that would help prove that I was actually there when it happened.

=================

I have already mentioned that I feel really disconnected from my own past. I know about the people with whom I went to high school, the people with whom I worked at previous employers, etc. But once I leave a place, I virtually never stay in touch or maintain contacts. I certainly don’t need to invoke the medial temporal lobes to explain that, but I do wonder whether they are related. I’ve actually thought to myself before that I am particularly “good” at leaving people behind, distancing myself. Now my view of that has changed somewhat - I suspect that I don't really have a choice in the matter. That is, I can't remember shared experiences. Maybe one's episodic recall serves to help nurture relationships, allowing people to mentally re-experience the positive events they shared with others. That might be a fallacy; I have no idea why episodic memory developed. But I do know that I cannot remember positive events that I have shared with the people in my life, and that can't be a good thing (in terms of nurturing enduring bonds with other people). On the other hand, I can't recall bad things either. Maybe I should try to find the silver lining here, right?

=================

All of this is so very strange. The more I think about my condition, the harder it is to go back to seeing all of it as "normal," as the way I've lived my life. I can't put the genie back in the bottle, so to speak.
When I think about my condition, I now think about it as being bizarre, and it is almost hard to imagine that I'm the one experiencing all of this. It is the "normal" that I knew prior to putting all the pieces together. On the one hand, I'm finally getting to make sense of all of my experiences, including things that frustrated me, bothered me, or struck me as something I should be embarrassed about or ashamed of. On the other hand, I traded that for recognition that I have a pattern that is bizarre and almost beyond comprehension for the rest of the world (and me). And the longer I experience this new reality, the more I am convinced that I cannot meaningfully communicate with people about it. I'm just not sure most people can understand what it means to have virtually no episodic memory.

===============

I read today about reality monitoring, something I had not read about nor thought about probably since graduate school. I was reading a Conway review piece on self-memory systems, and the function of event specific knowledge. I read that ESK is the primary way we have of distinguishing between real and imagined events. That puts a pretty fine point on my observations about doubting my own memories of the past, doesn't it? Many of the facts I recall about my past have an associated level of truthfulness, or probability that they are true. Even the stories I've repeated all my life have some weird level of truthfulness... that is, I feel less than 100% about them. I factually know some event to be the case, but every once in a while I find myself sort of wondering "did that really happen?" Maybe truthfulness isn't the right descriptor... "realness" might be a better word. I know the facts are true, but they sort of seem less than real, or disconnected from me. At any rate, I keep digging into this to find out what else I'm missing. Since starting on my journey to find out about my memory problems, I've learned that a fundamental part of my mental life is flawed and abnormal... something I've lived with all my life and previously considered part of normality. Now that I'm coming to understand the nature of this condition, it does make me wonder what goes along with this, or what else about my mental life I haven't noticed or is potentially affected. What else do I consider "normal" but simply haven't noticed? My condition made me realize that some pretty fundamental elements of one's
mental life can be flawed without being aware of it. Maybe I should have known, maybe I just wasn't willing to see it. But I lived for many, many years without ever stopping and realizing just how flawed my memory is. If that's all you've ever known, who's to say what is normal and what is abnormal?

Conway discussed categories of events that most people tend to have event-specific knowledge about, including "first kiss" and first time driving a car. I don't remember either one. I know facts about them. He discusses this in the context of the visual content of such memories. I only know that my first kiss occurred when I was in junior high, and happened at a party at a local raquetball club. Can't remember the girl's name, can' remember what she looked like, what the room looked like, who I was with, etc.

I assume I first drove a car when I took driving lessons offered by the prep school I went to. I took a class that was taught by the cross country coach. I don't remember much of anything else about it. I certainly don't have any episodic memories associated with the class (can't tell you want kind of car I drove, where we drove, etc.). If I drove a care prior to that class I cannot remember it. I just have zero episodic memories from either event. When one encounters someone who has gone through something extremely emotional, one of the things we often say is something along the lines of "I can't even imagine what you must be going through [have gone through]." Whether that person has been through a death in the family, combat, or diagnosis of cancer, it seems almost rude NOT to say something like that. Because as much as we try to understand what that person has been through, we DON'T know exactly what it feels/felt like to have been in their shoes. We can't, because we weren't actually there to experience what they went through-- we don't have THEIR experiential memories (no matter how well they might convey the situation factually). I feel the same way when I think about my OWN past. As much as I try to understand what I've been through in my past, I cannot actually re-experience it. If someone says "that must have been horrible" or "you must have been so proud at that moment," I have to lie and say "yes" as if I can accurately answer the question. Honestly, I can't think about my past and relive it or re-experience it. This is true of events that one presumes must have evoked emotions of sadness, fear, elation, pride. I have no more insight into what my own past experiences were like than anyone else who hears the story of those experiences.
Three additional observations

1) A couple friends who know about my condition almost reflexively said “I’m sorry, but that is fascinating.” And I suppose that’s true, on some level. But my daily experience of this condition is extraordinarily pedestrian, because this is all I’ve ever known. There’s nothing fascinating about it at all. It can be depressing, when I sit down and allow myself time to mull it all over. But I don’t feel as though my own experience is interesting in the slightest.

2) I do, however, find some solace in the thought that I will be able to identify the impediment I’ve fought for some time. In a sense, I feel like I’ve operated cognitively with one hand tied behind my back.

3) While driving today, I had the experience of driving down the interstate lost in thought, and had one of those moments where one says “wow, I can’t remember the last 30 seconds of driving— I’ve been so lost in my thoughts that I literally cannot recall the last mile or two.” I believe everyone experiences those. That experience is what my condition feels like. On the one hand you obviously know you’ve covered that territory, and you had your eyes open and must have processed the information. But no matter how hard you try, you cannot conjure up images of that 30 second window. My condition involves the same, except that huge swaths of my past are like that. I know I was there and conscious, I might know facts about events and can make logical inferences about them, but I can’t remember what it was like to have been there.

A brief description of my memory issues

Childhood: I can recall names of teachers, schools, coaches, streets, addresses. I can recall what frequently visited places (my house, schools, etc.) looked like, but it is extremely difficult to recall particular events. When I can come up with one, the details are sketchy and vague. I can’t recall exactly when they happened, who was involved, what scenes looked like, etc. Most of my memories are things
like “We used to play kick the can in the alley behind my friend’s house.” I just cannot think of specific events. I know we went to Illinois every summer to visit relatives, but cannot think of a single event during one of those visits (nor what it looked like at the places where we stayed). I know it was often hot, and our car didn’t have air conditioning. That sort of thing.

High school: I can recall some events, but again they are pretty vague and few in number. I know the name of the restaurant where I worked, and can picture it. I know I met my wife while working at that restaurant, and have heard her tell the story of how we met, after our first year in college. But I don’t recall the actual event, cannot picture it. I broke my ankle, requiring surgery, during my freshman or sophomore year of high school running cross country. I know the name of the place where it happened, but cannot actually picture any details of that event (e.g., presumably I was brought to a hospital for x-rays, etc. I can’t recall how I got back to the school or home, etc.). I cannot remember what it was like to get the screw put in, though I do know I was in the hospital overnight. I had an MRI within the last 5-10 years, and was asked whether the screw was still in my ankle. I had to call my mom to ask, and she told me that it had been removed. I know my brother and sister-in-law visited me in the hospital, and I know he brought me food on one occasion. I cannot picture anything about any of it-- I know about what happened, but don’t really remember any details. My memory for high school consists of what the building looked like, and the faces of people I knew. But I can’t recall particular episodes.

College: I know the names of my professors, friends, buildings, etc. But again I can’t come up with a single event. When I see photographs of this time period, I recognize people and usually recognize the place. But it doesn’t bring back any memories of particular events-- I don’t have any “that was the time that we...” recollections. I don’t recall much of anything about my graduation. I know it was held outside and (from looking at pictures) I know it was sunny. I know my brother and my mom attended. I don’t recall who spoke at the ceremony, and I cannot recall anything else about that day. I don’t know whether I attended baccalaureate, nor where that was held (I’m guessing the College chapel). I
cannot actually picture my brother or mom being there. I don’t know what else we did that day, presumably we would have gone out for lunch or dinner?

Wedding: I graduated in 1987, and got married in 1988 after I’d been in graduate school for one year. I remember very little about my wedding, aside from what I’ve seen in a videotape and in pictures. I cannot recall what it looked like or felt like as my wife came down the aisle. I don’t remember the service, including who spoke or took part in the service. My wife told me recently that we took my in-laws’ car to the reception, but I have no recollection of that (I don’t know whether she meant I drove, or that someone else drove us and we sat in the back seat). I can’t recall anything about the reception itself-- where we sat, what the room looked like, what the cake looked like, who spoke... none of the usual “wedding stuff.” My wife says we took a limo to the hotel afterward-- and I have seen a picture of us sitting in the back of it-- but I don’t remember anything about it. My wife says that because the limo was rented and paid for, we asked the driver to drive around before taking us to the hotel. I can’t remember that at all.

I can’t remember the drive to our honeymoon. I can’t picture the place we stayed. When I told my wife this, she got sort of quiet and then said "Do you remember sitting on the porch of our cabin watching it rain?" I didn’t even recall that we had stayed in a cabin, let alone rain or porches. No events come to mind at all.

I have similar lapses regarding graduate school-- no recollection of my qualifying exams, nor dissertation defence (aside from who was on my committee, I’m pretty sure I can reconstruct the committee). I can’t picture it as an event, and don’t know what was asked, how long it lasted, whether it ever got contentious. I know my dissertation advisor held a party in my honor at his house at some point. I cannot picture his house at all, and I do not know who attended. I got my doctorate in 1992.

Specific examples of memories lost
This is pretty much an exercise in trying to name events in my life; that is, I can't find events from more than a year or two ago for which I have substantial episodic recall. I know in some cases what locations involved generally looked like, or what the people involved look like, etc. but cannot remember the events themselves. That is, I cannot provide details like what the event looked like, how things transpired, who was present, weather/climate, etc. I cannot "relive" the event, remembering what it was like to go through the experience. I'm generally left with only factual information, of the sort one would normally read or acquire about other people's lives.

Holidays during my childhood (Christmas, etc.)
Family reunions every summer during my childhood
The sesquicentennial of my hometown
Boys Club summer camp; a week each summer during elementary school years
Family vacations
Boston Red Sox baseball game (during one of the vacations to New England)
At least two Indianapolis 500 events
At least one Cincinnati Reds baseball game
Cross country races
Track meets
Speech and debate tournaments in high school
Rock concerts attended while in high school, college, grad school
Weddings of siblings
Weddings of college friends
Weddings of my wife's college friends
First visiting the college I attended before matriculating
Graduating from college
Visiting the grad school I attended
My wedding, wedding reception, honeymoon
Moving to our apartment during grad school
Doctoral dissertation defense
PhD graduation ceremony
Interviewing for jobs after grad school
Moving to the city where I got my first job
Interviewing for my 2nd position
Moving to the city where I got my second job
Buying our first home
Moving into our first home
Finding out my wife was pregnant
Birth of my children
Interviewing for my current position
Moving to my last and current houses
Baptism of our children
Various sporting events attended with my family
Recent vacations
I have “snapshots” (isolated images with varying degrees of detail and general knowledge of events) from some vacations taken 2005-present

Examples of my retrieval failures

- I forget my retrieval failures, in many/most cases. I recall one, and if I don’t write it down or record it, a very short time later I get frustrated because I can’t remember it. I can be in the shower, and think of 1 or 2. And then when I get a chance to write them down, I often can’t remember them. This is really frustrating. So tomorrow, I’ll walk around going “maybe I’m just not trying hard enough to remember things” and I’ll spend all the time that I’m exercising trying to recall things about my time
in elementary school, or high school. My primary symptom is the void that is my past, so it isn’t until I see written list of previously recorded retrieval failures that I again think “Oh crap, this is real. It isn’t just that I’m not trying hard enough. There are real events that I cannot recall.”

● In some cases, my problem is that I cannot remember an event AT ALL. In other cases, I have a vague recollection, but have few details-- especially perceptual/experiential details. In most cases, when I recall something I cannot pinpoint when it happened, even vaguely.

● I don’t know whether this is related or not, but I cannot recall plots of movies of books at all. I’ve read all the Harry Potter books, all the Tolkien books, etc. but I don’t remember the plots. When I watch movies, I annoy people because I have to ask about what is going on. I get lost in the plot. I’m fairly sure I couldn’t give you even a rudimentary outline of the plot of movies I’ve seen or books I’ve read. I’ve been embarrassed many times when people ask “Have you seen that movie?” and I say “no”... then my wife will say “Yes you have, we saw it together.”

● I told my wife this fall that it had been a long time since I’d been really sick with a virus. She said “remember the time last year (or two years ago, I can’t remember as I write this what she said exactly) when you had the flu, and we quarantined you upstairs in our bedroom?” I don’t remember that at all.

● I can remember, vaguely, going to my niece’s wedding (I know where it was held). I have less recall about a different niece’s wedding, not sure what church it was held in. I know it snowed that year. Don’t know who was there, or any other details about it.

● I have a large family. I have been in the wedding party of some siblings, but can’t tell you which ones. I saw a picture from one brother’s wedding, and I was wearing a tuxedo. I said to my wife “Was I in his wedding?” And she said that I was. I have no recollection of that at all. My wife remembers these events, and can share details about them (were they held inside or outside, etc.).

● I don’t remember any details about my father-in-law’s funeral -- where it was held, whether there was a procession to the cemetery, etc.
• I really don’t recall much about breaking my leg in high school. I did it while running cross country, doing hill practice at a private school near the school I attended. That’s the story I’ve told all my life. But I honestly don’t really have episodic recall about it at all... I don’t even know whether we took a bus to the hill practice or not. I completely broke the bone in my leg and had to get a screw inserted, but don’t remember walking back to the bus/car (though the story I’ve told for my entire life is that my coach made me walk back to the bus, thinking it was only sprained). I don’t remember anything else about it. I have a vague memory of my brother and sister-in-law bringing me some food to my hospital room after the surgery. And I know I was on pain meds while in a recovery room, and that my mom said I wasn’t nice to the priest when he stopped by to visit. Again, I’ve been telling those stories all my life. I have absolutely no recollection of any of those episodic details.

• My wife said recently “Do you remember when [our daughter] used to have her dance rehearsals at a bar across the street from the dance studio?” I have no recollection of that, certainly no episodic recall. Seems like a bizarre place for a rehearsal; you’d think I’d remember something like that.

• We put in a Christmas movie just before this past Christmas, and asked my mother-in-law “Have you seen ‘The Santa Clause’?” My daughter said “It has Tim Allen in it.” My mother-in-law said “Oh yeah, the one with Tim Allen in it, and his son goes with him to deliver presents...yeah, we watched it together last Christmas.” It isn’t just that I don’t remember that, it is that I cannot even fathom being able to remember what movies I watched one year ago. I was amazed that she could remember that.

• I was talking to my daughter about buying my wife a hair dryer for Christmas; my daughter said “We’ve bought her one at least two years in a row, they keep breaking. I know we got her one last year.” I asked “Did I go with you to get it?” She said “Yeah, you looked them up online, and we got it at Walmart.” I don’t recall any of that.

• My wife said “Do you remember when we purchased the t.v. and vcr in our family room (we were getting ready to buy a new tv on this occasion)?” I said “no, when?” She said “You gave them to me for our anniversary a few years ago.” My daughter piped up and said she remembered it too. I have no memory of having bought them.
• I routinely find myself afraid to ask friends about how their mom/dad/spouse/children are doing, because I cannot remember previous conversations. In some cases, I have found myself forgetting that someone has died. I will tell my wife that I ran into someone, and she’ll say “How’s their sick spouse/child/parent?” I’ll be embarrassed to admit that I’d forgotten that they’d told me that person was sick. I’ve thought for some time that this inability to remember conversations about loved ones has a real social cost, because it makes me appear callous or insensitive. I DO care about others and their lives, I just forget conversations. I ask my wife things like “Did her husband die?” etc. all the time.

• I picked up my daughter from a nearby restaurant last night [early January], it is located very close to our home. I said to her “you know, it’s funny but I’ve never been to that restaurant-- and we’ve lived here for 10 years!” She said “I’ve only been there once, with you a few years ago. You took all of us there to have lunch with a friend.” I said “who was the friend?” She said “I don’t know, but you told us he was someone you work with.” So I said “Male or female?” She said “Male.” I have no recollection of this at all. Then she said “I had pancakes... don’t know who the guy was.” This kind of thing happens to me all the time.

• With my wife, we see someone she knows. Them: “Have we met?” Me: “I don’t think so.” My wife: “Oh I think you have... at such-and-such a place [or such-and-such event, etc.]” I dread running into people because I know it is offensive when they recognize me, but I cannot recall meeting them. On New Year’s Eve, our girls had sleepovers at our house. I said to my wife “You’d better get out of the shower and get downstairs before the parents arrive, because I won’t know who’s parent they are... and in a lot of cases I’m supposed to be able to remember having met them.” This happens a lot.

• The strange thing is that I’ve been dealing with things like this for so long, feeling embarrassed about my lack of ability to remember things and covering it up, that it is just part of who I am. Up until this past year, I have never discussed this with people. I’ve worked very hard to cover it all up. I notice the retrieval failures very frequently, but do everything I can to avoid letting anyone find out. Perhaps the strange thing is that my experience of my retrieval failures is a combination of frustration and
embarrassment or shame. I experience them as personal failures, things I should feel ashamed of and cover up.

- Like most people, I like listening to music from my younger days. For me, music from my adolescence conjures up emotions, but not specific memories. It is frustrating to me that I can’t recall much about my past, but makes me feel better to listen to music from different periods of my life.

- I’m a fairly avid cook. I love to try new recipes, and I rarely eat in restaurants or eat processed food. So I cook almost every day. Unless I label the leftover food I put in the refrigerator, I cannot determine how old it is. Almost every day of my life, I look in the refrigerator and ask “What day did I make X?” And my entire family chimes in and lets me know. I’ve started labelling everything with the date using freezer tape and a marker.

- I recently told my daughter she should watch a documentary film called King Corn. She had recently watched 2-3 other films of the same genre, and I said she’d probably like it. I described the content to her. Then tonight, she was watching Netflix on t.v. I looked at the t.v. screen for a bit and said “what are you watching?” She looked at me and said “King Corn,” somewhat incredulous as I was the one to suggest it. I eventually recognized it, based much more on the content of the dialogue than what visually appeared on screen. If the volume had been down, I’m not sure how long it would have taken me to recognize it - but my hunch is that it would have taken a long while (if I ever could have recognized it).

- Conversationally, I’m also the guy making vague references to sources of information. “I can’t remember where I read/heard this, but...” I have, on occasion, said something like “Well, someone told me that...” and then have found out that source of the information was very person I was talking to. This, too, is one of the many things woven into the fabric of my life that I still am reluctant to pin on this convergence of TLE [temporal lobe epilepsy] and memory deficits. I just honestly have no idea which things I’ve noticed over the years are related, and which are not. I would have attached fairly low confidence to the connection between my ability to remember the storylines of movies and novels with this memory deficit.
I realize that everyone forgets a lot about what they’ve read, but I virtually always find myself in a position of trying to discuss a book or author and not being able to supply any information at all, almost as if I hadn’t ever read the book. My hunch is that this is especially true for fiction.

My wife was looking at a list of movies available “on demand” from our cable provider, and the title “Green Hornet” came up. I’m almost certain I watched that with my son in the very recent past (probably in the last few weeks). I said “Is that the movie I watched with [our son]?,“ thinking aloud. I could picture the lead character, but not much else. After typing all of this out and giving it more thought, a few more details come to mind. I still couldn’t recount the plot. That happens a lot-- the name of a movie comes up, and I cannot recall whether or not I’ve seen it. And even if I think I have, I cannot recall much, if anything, about it.

More along the lines of “my memory for past events is more like what it feels like to have read a biography of someone than to have lived it”: On my son’s birthday, my wife was reminiscing about his birth. She said that my mother-in-law came to visit for a week (which rang a bell), went home for a week, then came back and stayed a week because she was so upset about not being able to be with us (my mother-in-law was still dealing with the relatively recent death of her husband). All of that made sense, though I couldn’t remember her coming back, nor can I recall any details of her visits.

Another thing I know to have happened but have no episodic memory of: while I was in high school, I commuted to a private school with my brother and 1-2 other students. On one occasion, we were following the car of another student from our school. This other student driver tried to pass a car while cresting a hill, and ended up hitting an oncoming car-- all of this happening right in front of us. I “know” this to have happened. I’ve retold this story over the years too. My brother had to physically restrain the other driver, who was in shock and running around screaming. I have no real recollection of what this event looked like, details about injuries, etc., only semantic knowledge of the story. I do know that the driver required surgery on his face afterward. But I can’t tell you what kind of cars were involved (big, small, sedan?), what color the cars were, I can’t even tell you what year of high school this happened. I don’t know for a fact who I was with, other than my brother. It is possible that my brother
was driving the car I was in, but it seems more likely that someone else was driving (as we often carpooled with another student who drove us). I don’t think anyone died, but I frankly don’t recall whether anyone else was even in the car with the driver. I know that we stopped to help, and that my brother intervened. I don’t recall police or an ambulance being called, although surely they were. I assume we stayed until the authorities arrived. I just have no recollection of any of this episode, only the story that I’ve recounted on occasion in the years since it happened.

- I’m sure I visited the college I attended before choosing to attend, but don’t remember doing so. I’ve told people all my life that I visited the college on my own, but can’t really be sure my mom didn’t go with me.

- This notion of having some lack of confidence in the stories I have about my life really is a persistent theme. Without having episodic memories about them, I’m left wondering about their truthfulness. More than once I’ve recounted a story only to think “Did I witness that? Or did I merely hear about that.” There are categories of instances where I find I need to tap into my episodic memory, when I’m most likely to have retrieval failures of consequence. Musing about vacations and significant personal events is an obvious one, but there are more common categories.

- I’ve already mentioned somewhere the need to remember medical information. Appointments, illnesses, treatments, etc.

- I also find I need to remember business transactions (when did we buy this? is it still under warranty?)

- how long ago did I do some kind of routine/repetitive chore? (give the dog medicine? Get a haircut? change the oil in the car? check out those books from the library?)

- learning from past events. As an example of the latter category, Friday night my son says “my car won’t start.” It was raining, so I said we’d look at it in the morning. I told him of the short list of likely culprits, including loose or inadequate battery connections. I said “I remember having to clean corrosion off the connections in one of our cars; that could be it.” On Sat [yesterday] morning, I was trying to think more about this. I can’t remember which car I had to do that work on. And in fact, it
dawned on me that perhaps I’d had to do similar work on my son’s car at some point, but couldn’t remember details. I asked my wife “Didn’t [our son] have this sort of trouble before at some point?” She said “Yes, you’ve had to jump start his car twice with cables.” I couldn’t remember the circumstance, so I said “what was the trouble then? did we replace the battery? I don’t remember doing that.” She said “No, he left his lights on both times.” I said “When did all of this happen?” She said “Both times happened fairly soon after you bought the car for him.” Because I’m more comfortable revealing my retrieval failures, I said “When did we buy the car? I know it was winter or spring-- this last year, or the year before?” (this is the sort of thing I’d have deduced logically if I had to, by using his birthday and legal driving age). She said “You bought it last spring.” Memories for when I purchased things are prone to failure, because that’s the more incidental kind of thing I just don’t normally connect to a point in time. I routinely ask my wife when we bought things, or had work done around the house. I’ll have to try to generate more of these. They come up all the time, virtually daily.

Another example of the illness/appointments one: when I wrote up the chronology that I sent to you late last week, I actually had to spend considerable time piecing that together. I used my calendar to see when I had tests and doctors appointments, looked up email messages to see when I had sent/received email. I was surprised by the dates involved, which often happens. I would have sworn that I’d made contact with you earlier, probably by at least a month. My immediate family has a reunion every other year in summer, because I have a large family and it is hard to coordinate our visits otherwise. This started back in the mid to late 1980s or so. The location is always a state park in the state we grew up in. But it has rotated among 2-3 locations. I fairly routinely say to my wife “Is this the year we have the reunion?” And I can’t recall where it was held in the past. I have a hard time remembering much about these reunions, beyond pictures. I know the kinds of things we tend to do, but can’t attach particular activities to particular reunions.

- At dinner tonight my daughter mentioned previously seeing some people dressed up in square dancing outfits when we went to our local ice cream shop, and I DO remember that. I don’t know when it happened, can’t tell you why I was there with only one child. My wife said “Where was I?” and
I couldn’t answer that. I don’t recall much in the way of details, but I can sort of remember what these square dancers looked like. Well, to be honest, I’m not so sure about my recall for their appearance. I know they were wearing outfits, but can’t recall much other detail about them. I know they were friendly people, and that we chatted with them while in line. I remember that they told us they were in a club that danced weekly in some neighboring town (can’t remember which town either). My daughter said she thought this happened last summer. Moments like this, when someone says “do you remember this event?” and I have some vague recollection of it, always make me stop and try to determine how much I can remember. I start with the feeling “wow, there’s one I can remember!” Then as I probe and consider it further, I realize that even for events that happened 8 or 9 months ago, I’ve started to forget the sensory information, and certainly temporal information.

● My wife said that my son will be travelling to a high school speech and debate tournament this week, and he’ll have to stay overnight in a hotel for it. She said to me “when you did speech and debate in high school, did you have to stay in a hotel and travel to tournaments?” I honestly can’t recall much at all about speech and debate. I think I did it for 2-3 years; I have ribbons from the tournaments. But I can’t really remember participating, nor travelling to competitions.

● My wife gets somewhat tired of having to play the “tell me what you can remember about so-and-so’s wedding” game with me, but we spent about 15 minutes doing that again this evening, and again I’m just floored. She goes on and on about my siblings’ weddings, including weddings I apparently took part in. And I have no episodic recall about them at all. What did the wedding look like? ”It was held outside; we walked around a pond to get there. It was really hot. We rode to the wedding with your sister and her husband.” I can't remember any of it. I said “Was I in that one?” “No, I think only one person stood up with him, his best friend. We sat on a bench.” During part of the conversation, she said “we all met at your brother house”-- I said “I didn’t remember that the reception was at his house” to which she replied “It wasn’t; I meant that we all met at his house beforehand and formed a bit of a caravan to the wedding.”
Then I ask "When [our youngest child] was born, where was I standing in the room?" and she says "You were standing on my left, holding my hand." I can't remember that. I can't picture what side of the bed I stood on, how the room looked, for any of my kids' births. She says "When [our son] was born, there was a crowd of people in the room... there were no other deliveries going on in the entire hospital at the time." I can't recall any images of that.

I said "How about my college graduation?" She could name all the people who made the trip. She says "you graduated fifth in your class. It was a hot day, very sunny." She even adds "Your brother wore a plaid jacket." I can't actually picture anyone being there, though I knew my mom and brother went (she named 4 other family members who attended, which I'd also forgotten) and assumed my wife would have been there.

I have snapshots in my mind of some family vacations, which seem to usually correspond with photographs we took in a lot of cases. But it is when I try to compare notes about specific events that happened on a particular day that my deficit seems so crystal clear to me. My wife can easily recall features and finer grained events within the day that I have absolutely no recollection of. I listen to her and say “I don’t remember ANY of that.” Not only would I say there is a 0% chance I would have come up with those details, there is no sense of recognition when she talks about them.

In the years before or right after our marriage, I think my wife and I went to the state fair (more than once). On at least one of those occasions we went to a concert of some sort at the fair. Nothing else comes to mind about that, no memories.

I coached my kids teams (soccer, baseball, basketball) for a number of seasons; this would have started maybe 12 years ago, probably ended within the last 5 years or so (I can’t recall the last team I helped coach). I don’t really recall much about it. I have a vague recollection of the field where I coached most of my son’s soccer when he was started school, maybe kindergarten. I coached on the field for maybe a year or two. This is the quintessential sort of thing that my wife would normally immediately recall for me. She’d say “yeah, remember, you coached for X years. You coached with [someone’s name here], and played at [name of field here].” She’d know what sport I coached, when,
who I coached with, how many years I coached, the last sport involved, etc. She’s not here at the moment, and it is a Friday night-- I’m too tired to do the info search in my archive. I think it is safe to say that I coached for 5-7 years, in a variety of capacities.

● Talked to my brother today; he’s the brother with whom I discuss my memory issues. I mentioned that I have no memory of weddings, including my brother _____’s. He said “Oh man, it was in a big cathedral. Part of the symphony orchestra played during the service, and a children’s choir sang at the reception. I remember the enormous floral arrangements in the middle of each table at the reception, because I knew they probably each cost $500.” He could go on and on about it. I said “that’s the kind of thing I don’t have-- I can’t remember any of that.” I don’t remember what it looked like or sounded like.

● One of my brothers wrote on Facebook (for another brother and his wife) “Happy 11th Anniversary. I have fond memories of your wedding.” I don’t remember this one at all either. I travelled to another state for it. And it must have been in February (given the date of the Facebook post). But I couldn’t have told you what time of year it was otherwise. It must have been held inside, since it was winter. Can’t picture any of it. Don’t know whether I stayed in a hotel or at my brother’s house. My wife said “You were a real comfort to your mother; she told me so shortly afterward.” The only memory I have of my stay there is that a group of us went somewhere, and stopped at a bookstore. I have this sketchiest of memories of driving down the highway, a snapshot of a single moment in time. I can’t remember whether my brother’s house is big or small, whether it is a one-story or two-story, etc. My wife says “how far is it from the airport to his house?” I answered by using Google Maps, as I cannot remember.

● I bought my youngest daughter a goldfish yesterday. My older daughter quietly said to me, with a grin, “Remember what happened when we bought our first goldfish?” I said no, and just let it go. Later I said to my wife “Was I supposed to remember something about the first goldfish?” My wife said “You didn’t know that you were supposed to let the fish acclimate, or the water temperature adjust, or something. At any rate, you poured the fish right into the aquarium, and it promptly died. All three of
the kids started crying, and we ran back out and bought another one.” Probably just as well that I don’t remember the senseless slaughter of a perfectly good goldfish...

● A friend I worked with years ago in another state wrote to me this past week to say he was going to be visiting our area, because he has a job interview nearby. So I emailed my wife saying I was excited I’d get to see him. My wife wrote back “You probably won’t remember this, but he drove one of the rental moving trucks when we moved here.” She’s right, I have no recollection of that at all. I vaguely recall having to use two moving trucks, but none of this came up when I traded email with my friend. And even as I read my wife’s message, I’d put my “ring of truth” or confidence in that information at about 5-10% (of course I believe my wife; I give you the estimate to convey how much I recognize the information). I don’t really recall anything about our move here. Yet when I read those words from my wife, I recruited the image of my friend’s face and a moving truck from my memory. I can’t actually picture him driving the truck, or helping load it, or unload it, or anything else. Frankly, I don’t know what company we rented the moving trucks from... I couldn’t tell you anything about his involvement. But since I trust her recollection, I just sort of spontaneously conjured that up... it feels like I’m fabricating a memory to help piece things together. It was a 7-8 hour drive here, according to Google Maps. I can’t believe he volunteered to drive a truck here. I have no idea how we got him home... I’m guessing we paid for his airfare?

● I exchanged email with one of my brothers about childhood trips, and he mentioned going to a Boston Red Sox baseball game with our older brother during a summer vacation to the East coast. I have vague knowledge that I went to this game, but cannot recall any episodic details (nor any semantic details for that matter).

● Last night, a local television station ran a news story about a landmark restaurant in the area that went out of business. I said to my wife “Did you ever go to that restaurant?” My son was in the room, so I didn’t want to just come out and say “Have I been to that restaurant?” At any rate, my wife said “Yes, you took me there a few years ago for our anniversary. We went to an attached/nearby riverboat casino afterward, because I was curious about what the riverboat looked like inside.” I don’t
remember visiting the restaurant at all, but the notion of visiting the riverboat briefly with my wife has a ring of truth to it... I’d put that at about 30%, though I have no episodic recall of it. My wife followed that with “I think that was the year that the two teenage girls who lived down the street (who babysat our children) wrapped your car with toilet paper on our anniversary.” I don’t remember that at all, and I’d put the “truth value” of that information at about 10-15%. I suppose I have some very vague knowledge of it, but feel certain I could not have come up with that, no matter what sort of cue I was given.

More about my recall experience

I’m still thinking through the various ways I introspect about my memory, and the symptoms I experience, to more easily disentangle the various kinds of memories. Here’s what I experience, as best I can articulate at the moment. I’m still generalizing based on what I can remember and what I experience right now, but I think this is pretty accurate.

Sometimes, when I hear someone say “Do you remember [the event X]?” they mean “Are you aware that X happened in the past?” “Do you recognize the assertion that X happened in the past, now that I’m telling you about it?” “Does the event X have any familiarity for you?” The answer to those questions does not involve episodic recall for events; they are factual. I can’t spontaneously generate that kind of factual information about many events and periods of my life, especially events that happened in more distant past (I’m not sure what the cut off is). Sometimes my wife will tell me about an event that happened in our past, and my answer to the above questions is “no.” She said something once about going to see a concert at the state fair (probably late 1980s) and I assured her it wasn’t me she went with. And even when the answer to those questions is “yes” (based in some cases on logical inference) I can’t actually recall anything of an episodic nature about them. With regard to more recent events, I sometimes can retrieve factual information.

In conversation, when the answer to the above questions is “no,” I sometimes lie to save face. In some cases it isn’t really a lie, the things they’ve mentioned have some level of familiarity. Not certainty,
perhaps. But they have a ring of truth, so I reply that I do remember that event happening. I often reply “yeah, vaguely” when asked if I remember such things. At other times, the phrase “Do you remember the event X?” means “Do you have any experiential information about this event?” “Do you really remember what it was like to experience this event?” “Do you remember what things looked/sounded/felt like at the time of this event?” “Do know when this event took place?” The answers to those questions do involve episodic recall for events, my answer is almost always “no.” I know facts about events, like “I know the name of the state where I was married,” and “I was married in a Catholic church.” I even know what that church looks like. Can I actually “relive” or replay the event of my wedding in my mind? No. When I try to think about my wedding, sketchy snapshots come to mind, many of them bearing an uncanny resemblance to the posed pictures a professional photographer took afterward (I can see the color of the dresses, for example, though I don’t think I can name all of the members of the wedding party.) But when I try hard to remember my wedding, it doesn’t feel in any way like I’m reconnecting with my past.

It seems to me that, the more recently an event took place, the more I’m able to spontaneously produce personal semantic knowledge about it or answer with certainty that I know that the event happened. I know my mother-in-law visited us at Christmas time (two months ago). It is much harder for me to generate, on my own, a list of things I know to be true about events from my more distant past. On the other hand, the farther I think back into my past, the fewer of those events I can recall. But even for more recent time frames, it is extremely difficult for me to generate experiential information about my past. I had a leftover Indian dal (lentils) for lunch today, which I made. The container that held it had a date on it, because I now label leftovers before I put them in the refrigerator. The lentils I ate today were made two days ago. In order to remember making them, I had to think carefully about what day of the week it is, and work backward. It would have been on Saturday, Feb. 11. I can’t spontaneously relive the actions involved in making that dish, so that I can
visually produce what the day looked like. If I work at it for a while, snapshots come to mind. I remember reading the package the lentils came in, for example. But if you had just asked me “what day did you make that dal?” it would have been extremely difficult to work it out. That’s why I started putting dates on everything I make, because I cannot usually figure out when I made something. So when I “remember” past events, I’m usually pulling up factual information. If I can recall participants, I bring up generic memories of their faces. If I know where the event happened, in some instances I dredge up images of the places. But I didn’t know that other people can actually picture with any detail what past events looked like or felt like until recently. This really hit me when I read the appendix to one of the autobiographical recall measures, the one used with an elderly population (Levine et al.). In the appendix, there’s a description of an event from the past year written by a control participant. I laughed aloud when I read that, as it seemed bizarre to me that someone could have recall of that sort of thing so long after the event. That detailed account of a year-old event is completely foreign to me.

As an aside, I suppose one might wonder “How can he recall reading the Levine paper so long ago?” This is one of the things that has taken me a long time to make sense of. The short answer is that I can’t-- not in terms of episodic recall. What I can remember are reactions I had to that article that I have written about in several places, that I’ve shared with several people verbally. Can I remember it as an event, linked to a particular point in time? No. But I know that this was an extremely important event for me, one that I thought a lot about, wrote a lot about and shared with others as a really, really good description of what is wrong with my memory. The perceptual richness of that account, the narrative of what happened on the date, I don’t have that kind of memory for the events in my life.

So what questions make my deficit crystal clear to me? In conversations, when does this manifest itself most clearly to me?
○ Can you name an event that happened during this time frame?

○ Can you tell me [a detail about event X that would require being able to relive an earlier moment] about action or event X?

○ What day did you do action X?

○ What time did you do action X?

○ What season did you do action X?

○ Who were you with when you did action X?

○ Can you remember where you were when you did X (unless it can be logically deduced)?

○ Did you do X before or after Y on that day/week/month/year?

○ What happened on occasion X (recount the conversation, or your observations)?

○ Any questions that require recalling a particular event, things that I wouldn’t have semanticized.

  ■ Who was at the wedding?

  ■ Did we go out to eat on my last birthday? Where?

  ■ What was the weather like when we did X?

  ■ Do you remember what s/he said when we [name some specific event from the past]?

○ How many times have you done X?

○ When was the last time that you did X?

○ What was she wearing? What did he say? What happened at that meeting? Tell me about the game.

I can remember the gist of conversations, on some occasions. But I can’t recall with any certainty when the conversations took place, and in some cases, I can’t recall who was present and/or with whom I
had the conversation. I lose details pretty quickly. So conversations plague me. I find myself saying “Have you and I already talked about this?” Frankly, as I journal about my symptoms in this folder, I find myself wondering how much of my thoughts I’ve already shared with you [AZ] (“Have I already told him this one?”). Unless I’m motivated to go back and reread things, my strong hunch is that I’m repeating myself in places. This is Feb. 13, and I already have difficulty remembering exactly what we did or did not talk about in our Skype conversation. Some parts I know, because I’ve thought about them a lot and/or shared them with others.

The exception to all of this is when I know stories about my life. When I’ve thought about something long enough and told people about it, I develop a memory for the narrative or story of an event. But over time, because I lose the ability to attach any experiential details to them, they start to feel like I made them up. I will sometimes say “Didn’t we do X a couple years ago?” to my wife. I feel the need to check the veracity of my stories, because I just can’t remember them. I know the facts as if I’ve learned them by rote memorization, they lack a sense that they actually happened.

Why was it difficult to come to recognise my deficit?

There were complicating social dynamics involved in coming to the conclusion that I have an autobiographical recall deficit. The deficit is most powerfully revealed when I try to recall holidays and other jointly experienced specific events that occurred at particular points in time. At those moments, the deficit is palpable and undeniable. But when further introspecting, there are complicating factors. First, I can recall some personal semantic information. When I would recall such information, I would often try to convince myself “No, I think my memory is fine. Because I do know about things that happened earlier in my life. And in some cases I can recall repeated events; I can recall that when I was a newspaper delivery boy, I used to have to put advertisements in the middle of the papers on Wednesdays. Only later would I come to realize that while I had factual information about earlier periods of my life, I could not recall specific episodes. For example, I was a paper boy for several years, making daily deliveries; I cannot recall a single event about it, nor a single conversation. In other
instances, even when I could on occasion produce fragments about an earlier period, they were largely
devoid of perceptual and temporal information.

The social dynamic is this: I have found, thus far, that virtually every person with whom I have
discussed my deficit seems reflexively tempted to think aloud about their own episodic recall
limitations. Perhaps this is due to a natural tendency to empathize. But my experience is that almost
universally, people have responded “Well, I can’t recall a lot of things from my childhood either.” It
was not hard to make these individuals understand the severity of my problems when I shared that I
could not recall my wedding, honeymoon, etc.

So the confounding of my introspection about episodic and personal semantic information, coupled
with this fairly constantly experienced need on the part of others to encourage social comparison by
asserting that they too experience episodic recall failures, have made it difficult for me to sustain
confidence in my belief that I have a consistent, identifiable deficit. And then there is the additional
layer of standard testing that turned out normal.

When I was able to locate articles describing the difference between personal semantic and episodic
recall deficits, I experienced a “Eureka” moment. I recognized immediately that this distinction was
the key to understanding my seemingly contradictory pattern of symptoms. The pattern made sense
to me. Yet even then, I continued to experience some level of uncertainty. I continue to introspect
about what I can and cannot remember. And the most difficult part of this is that the primary symptom
involves the absence of something. Because I cannot recall a time when I didn’t experience these
deficits, there is really no way to confirm them without comparing notes with others about what they
can and cannot remember. I didn’t know what was considered “normal.” That has also been an issue,
because I do not want to openly discuss the possibility of a deficit with others. For most of my life, I’ve
assumed that my memory was perhaps toward the low end of a normal distribution of normality, but
not abnormal. That is, I don’t remember it striking me as abnormal until relatively recently. I do, however, know that I have long felt a sense of embarrassment about what I now realize are simply retrieval failures.

**Some coping strategies**

Some coping strategies

- I tape notes to steering wheel of my car so I remember to do things before leaving for work.
- I leave pill bottles on the kitchen counter after ordering a refill, so I won’t forget to pick up the refill later.
- I have to do things immediately, or I forget-- like get new printer cartridges, put things away, etc. For me, “I’ll do this later” means “I will forget.”
- I put just about everything away in a certain place so I know where to find them later: wallet, keys, laptop, ipod, earbuds, netbook, camera, etc. Everything has its place, because when I lose things I have an incredibly difficult time remembering where I might have left them (I’ve always thought this was normal, and it might be... but this is truly a question of degree: I do this for EVERYTHING.)
- I leave myself notes on my wallet so I will remember to look at the notes before leaving the house.
- I leave things I need to bring to work on top of my wallet or keys.
- I put things in the front seat of my car to remember to take them to work the next day; I hesitate to put things in the back seat, because when I do I sometimes forget to take them out (if I don’t happen to look in the back seat).
- I honestly find myself constantly thinking about how to engineer my environment to compensate for my faulty memory... and the strange thing is that I’ve never really put all this together. Even during the period where I’ve been talking to doctors about my memory issues, I haven’t done such a
comprehensive examination of all my coping strategies... until today. Now that I’m writing them all down, I’m sort of amazed at how pervasive these things have become in my life.

- I leave notes on my keyboard or screen at work at the end of the day so I will definitely see them the next day.

- I ask people to email things to me, so I have a record of the communication that I can search (since I keep all email and archive it... and search my archive throughout the day, every day). I cannot remember conversations, but I can always search my email and my documents.

- I have kept my email, ALL email, since 1998. And I have a program that indexes my hard drive so that I can search both email messages and files.

- I also search my archive of calendar events to answer questions about my past. So I make lots of calendar entries, and I can then search them to figure out what I did.

- I’ve gone through old email messages that I’ve written to others and find in most cases they have no familiarity; I don’t remember having written them, or the events I wrote about.

- I leave notes to myself a LOT. I put notes somewhere I know I’ll see them-- e.g., on doors I’ll be going through (in my office, to get to the car, etc.).

- I favor, instead of notes, audible alarms (usually via Google Calendar) that will appear on my cell phone at a specified time. I set the alarms so they’ll go off when I think I’ll be able to act on the item (if I’m supposed to remember to bring something to work the next day, I’ll set an alarm to go off with that message in the evening; when it goes off, I immediately put the item in my car. etc.). Google Calendar lets me set up to 4 alarms, and for really important events, I’ll use them all-- usually 2-3 email reminders well in advance, and then a text message reminder last).

- I have carried electronic PDAs with this alarm functionality since the Palm Pilot was first produced in the mid 1990s; I now use an iPod Touch for the same purpose... I sync it routinely with Google
Calendar. I tell people “if you make an appointment with me and don’t see me write it down, I WILL forget it. I have a memory like a sieve.” I’ve used that stock phrase for years.

● I use another, rather different, kind of strategy to carry me back, to some extent, to periods that I can’t otherwise remember. For me, the notion that music from a given era can allow me to conjure up emotions is extremely important. And it is not just emotion that is conjured up. This is really difficult to articulate, but I can bring up feelings particular to an era, associated with classes of events. There is music I can listen to that reminds me of high school. It does not remind me of any particular event, but it has a strong element of “high school-ness” associated with it, sort of emotionally re-experiencing that era. In a couple of instances, a song reminds me of a particular person. There’s a song that I heard not long ago that somehow reminded me of a guy I ran cross country with in seventh grade. At the moment, I cannot remember what the song was. But it strongly reminded me of him. It didn’t help remember anything in particular about him, no episodes. But there was something that was activated about information I’ve stored about him that was retrieved when I heard the song. So while I’m terribly frustrated by my inability to remember events, I can re-experience an element of that period by playing that music. When you’re otherwise hard-pressed to remember episodes from large chunks of your life, that’s no small thing. I have music that reminds me of college and childhood as well.

My seizures

Here’s my best recollection of seizures. I should note that I’ve done my best with dates and details here, but the fact of the matter is that my memory problems really interfere with me recalling dates or specifics about anything, including these events. I can’t recall specific dates for family events, work matters, or just about anything. I’ve done my absolute best to make logical inferences and recall things as best I can, but I have definitely had to fill in gaps with inferences. When it comes to specific episodes, I’m essentially piecing to together stories based on the facts I can recall. And yes, these are “stories,” in the sense that I don’t recall much in the way of what things looked like, etc. I’m almost certainly embellishing a bit to flesh out the stories.
Childhood:

I had three childhood events leading to my diagnosis of “psychomotor seizures” sometime in the mid to late 1970s (I was born in 1965). I can say with confidence that it was before 1981, because that’s the year I turned 16 and was legally able to drive. I know that there were discussions about whether I’d be allowed to drive.

Symptoms: I felt hot, clammy, I had a sense of fear/dread, perceptually things started to not make sense - I could still see and hear, but not understand what was going on. I vaguely recall the notion that I did not lose consciousness-- during the event in the church, a family friend who was an RN was sitting near the front of the church and knew that this was important to share with the doctor: she said “I watched his eyes, and they did not shut.” I know this only because I heard it repeated so often... it is actually one of my only memories of this whole thing. My vague recollection is that that helped lead to me visiting a neurologist, but that's really vague for me. Wish I could remember more about that whole thing. As I think I said earlier, I cannot even pinpoint how old I was when this happened, nor how long I was under my neurologist’s care. I just don’t remember. I have no episodic memory for this period... I know the story (I’ve been repeating this information as part of my medical history for my entire life) but I can’t really remember the events.

The third event led to me being on Dilantin for a period of years. I had EEGs, but have no idea what the results were. In the past year, I was able to locate information about my now-retired childhood neurologist’s former practice, but he is retired and I was told records older than 25 years have been destroyed.

Adulthood:

Later, throughout my adult life, I have experienced the above symptoms as well. I always have the same progression: I feel hot/clammy, I feel a sense of fear/dread, things I see/hear don’t make sense,
I don’t understand what is going on. I can hear people’s voices, but they don’t make sense. I don’t think I’ve ever been able to really communicate during one of these, although my wife says during the last one I repeated the phrase "I just don’t feel good." I don’t actually recall saying that. And while many of these have happened when I’ve been sitting, I have stumbled or fallen down during at least some of the ones when I was standing. I have never been hurt in any way, but I can’t recall how I fall. My wife described the last one (Feb. 2010) as "going down on all fours" as I tried to walk up a snow bank next to the car. She said I paced back and forth as I repeated "I just don’t feel good," and then went down on all fours. I knelt in the snow for a few moments at the end. I believe she told the doctor that my eyes did not shut when asked if I’d lost consciousness. I asked her if I collapsed or fell to the ground, and she said “no, you just sort of couldn’t navigate the snow bank. You didn’t pass out.” I don’t recall that part of the seizure. I didn’t learn of the pacing or what I had said until after I’d been in the hospital overnight for observation. I heard her recounting this to a nurse who was checking my vital signs, and I was really surprised.

I don’t know exactly how often these events have happened, I’ve never really kept track. Not daily or weekly, but maybe at least every few months. I have the sense that I had them to some degree with regularity, but just can’t be more specific than that. However, I have shared information about these episodes over the course of many years with my wife, and with my family doctor. I know that I’ve had more than the ones I can pinpoint in terms of time/place. I’ve had them at home, and at work, while driving, while hunting, while at my kids doctor’s appointments. I’ve had them standing, and sitting. I’ve had them in summer, and in winter. I have not really identified a pattern to them, nor a trigger. The ones I can recall and place in time: In Spring 1993, prior to moving to another state, my wife and I decided to visit relatives while we were still a reasonable drive away. We went to the beach, and I think it was too cold for anyone to go in the water. We must not have been there long, because my event happened at a restaurant around lunchtime. We were reading our menus when I had the above progression of symptoms. I was unable to speak to the waitress, and my elderly aunt who is a retired RN told me to put my head down. I don’t recall being nauseated, nor dizzy. I just didn’t “feel good.”
She seemed puzzled by what might have caused it, but it cleared up within a few minutes. [I’m doing a bit of interpretation here and filling in of blanks. I can’t recall what the beach looked like, what the restaurant looked like, who was with us, etc. But the basic story I have is intact.]

1993-95: Twice during this time frame, I had similar events while driving. My wife was with me both times, and made me pull over and let her drive. She remembers these events, and our discussion of them. I recall afterward hearing her say something like "Mark, you are scaring me!" and "Your driving really scares me." Again, I can’t really remember what things looked like, why were driving/where we were going,

Sometime after moving to our current location in 1996 (cannot be more precise): I’ve had these since moving here, and I’ve mentioned these events to my family doctor, confiding in him during appointments for other illnesses. I was still a bit embarrassed about all of this, and realized that it probably made me seem crazy, so I didn’t pursue it as aggressively as I should have. I have regular physicals, and I vaguely recall at least one occasion when I asked whether he thought maybe I had these symptoms because I was diabetic or pre-diabetic (I had gone so far as trying to make sure I had snacks with me at work, that sort of thing). He looked up my blood tests results on his computer and assured me I didn’t have low blood sugar. This was something I was just really reluctant to talk about with others, because symptoms like “the things I see and hear don’t make sense” sound crazy.

Also during this time period (prior to 2010, but within last 5 year or so), I know for a long time I carried around Gatorade bottles and water bottles because as I grasped for an explanation, I harbored a suspicion that I was feeling these things because I was dehydrated (I can even recall carrying them around during the winter months). I carried Gatorade to work, and pretty much everywhere I went. On occasions when these symptoms happened at home, I recall my wife saying “Oh, you probably got too hot mowing the lawn” or “You’re probably just tired.” I persisted a bit, saying “yeah but I’ve had them more than once.”
Since 2003: I can recall a time when I had gone duck hunting with a couple of friends. We were sitting on the boat, after setting out decoys. I believe we were waiting to start hunting, around sunrise. I should add that when we do this, we get up at 3am or so, so I am normally short on sleep. I know it was cold, because I was wearing a heavy parka. I had the same progression of symptoms as above. I loosened my parka, because I felt hot and clammy. The other symptoms were the same as above. We were just sitting on the boat, and the marsh was absolutely quiet. I must have done something that led my friend to become aware something was wrong, because I recall him looking over at me and saying “Are you o.k.?”

Sometime in last 5-6 years: I remember taking one of my daughters to an appointment at our paediatrician’s office, and I had one there. It happened as we were sitting in an exam room, just prior to the doctor coming into the exam room. When he walked in, he could tell something was wrong. I just put my head down for a short time. He asked whether I was o.k., and eventually I said I didn’t know what it was. But I said "maybe I haven’t eaten enough today, have low blood sugar." So he left the examination room and came back with a cookie for me.

February 2010: This is the event that brought me to my neurologist, and resulted in my adult diagnosis and taking Trileptal. I was driving with my wife and son, and felt the same progression of symptoms. It was very cold outside, but I started to feel very warm, so I turned off the heat and opened a window. I started to feel strange, as in previous episodes. I could see things, but everything looked unusual. Things look surreal to me, I can’t make sense of what I’m seeing and hearing. My wife and son were talking, but I couldn’t understand what they were saying. I grew clammy, and increasingly uncomfortable. All of this took place over about 2 minutes. Toward the end, I was increasingly unable to keep the car in my lane, and my wife became alarmed. She yelled my name, and I drove over a curb off the road and brought the car to a stop. I opened the car door and tried to get out-- at first, without unbuckling my seatbelt. I fumbled with the seatbelt, and headed for the curb. I can’t remember anything that happened after that. My wife reported that I walked to the curb, and paced back and
forth repeatedly, sort of rubbing my stomach with one hand and saying “I just don’t feel good.” She thought I was getting ready to throw up (nausea has never been part of my symptoms). Then I think she was afraid that I might be having a heart attack, especially when I stumbled on the snow bank next to the car. I was on all fours in the snow for a short time, and eventually got my bearings and climbed into the car. She then drove me to the hospital. I have been both troubled and embarrassed about these for years.

Even after I had my Feb. 2010 event, I persisted with the notion that this might be related to low blood sugar. I just didn’t know what else it could be, and was afraid to ask up until that time. At any rate, I asked the medical staff about this possibility at the hospital; my wife also remembers me asking for candy as we drove to the hospital... I thought maybe the candy would help. I had no idea what it was. While I was in the hospital overnight, they did heart-related tests and head CT (I’m guessing they were entertaining the notion of a stroke). It didn’t even dawn on me that these episodes might be seizures.

It wasn’t until I got home from the hospital in Feb. 2010 and looked up “psychomotor seizures” that I found out that the new name for that condition is “complex partial seizures.” I looked this up because, while talking to a doctor in the hospital, I was asked “Have you ever had symptoms like this before?” and I eventually said “Well, yes. I think I had something like this when I was a child, and was diagnosed with psychomotor seizures.” The doctor said he didn’t think it was seizures, because I hadn’t lost control of bladder, didn’t convulse, etc. At any rate, I read the symptom list of psychomotor seizures/complex partial seizures, and they (some of them) matched what I had been experiencing. I was gratified to read that other people experienced the funny feelings I’d been embarrassed to share with other people and had been trying to explain to myself for years. It wasn’t diabetes, and it wasn’t being dehydrated. That was the first time in my adult life I’d connected my childhood diagnosis with the symptoms and events I’d had. I can’t explain why it had never occurred to me that I might need to
see a neurologist for my symptoms, nor can I explain why I didn’t connect my symptoms with the symptoms I had as a child.

===============
