

A Mind “Surrounded by a Moat”: A First-person Account of Cognitive Impairment in Multiple Sclerosis

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Abstract: This is a first-person account of the cognitive impairments—in speaking, writing, and thinking—caused by multiple sclerosis in a professional writer. The patient explains how she has worked around her deficits in rebuilding her life over the 18 years since her diagnosis. Her personal account is woven together with her clinical history, including her neuropsychological testing and magnetic resonance imaging results.

A companion article giving perspectives on the case was written by a cognitive neuroscientist who has been studying some of the types of deficits reported by the patient.

Key Words: multiple sclerosis, cognitive impairment, working memory impairment, neuropsychological testing

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This article inaugurates what I foresee as a series of occasional first-person accounts of mental experiences. As we have done here, we will try to combine each account with commentary by an expert in at least 1 aspect of the self-report. As in this case, the experiences described may be of mental functions affected by a brain disorder. The experiences may be of mental functions that are not necessarily disordered, but are somehow extraordinary or described with remarkable insight. The critical element will be that they give the *internal* perspective on cognition and behavior, the view from the subjective consciousness actually having the experiences.

My goal in offering these accounts is to try to help correct a serious problem with the vast majority of scientific and medical studies of cognitive and behavioral disorders. By practical necessity, the viewpoint of almost all studies must be that of the outsider looking in. Yet the perspective of the consciousness actually experiencing the condition may have a great deal to offer. Although self-observation can seem to outsiders to be limited, biased, and otherwise deficient, it provides a view of cognition and behavior that cannot yet be gathered any other way. And there are strong epistemologic reasons to believe that the subjective, internal view can *never* be replaced by an external one, no matter how far science and technology advance.

Accordingly, I believe that first-person perspectives will offer several benefits. One will be to help provide closure. Cases such as the one presented here demonstrate how present-day cognitive neuroscience can unify our understanding of a patient’s seemingly disparate problems. Another benefit will be extending the science of cognition and behavior by adding more boundary conditions that the science must satisfy. A first-person account may suggest issues that cannot be explained by current scientific understanding, arguably including consciousness itself.

On a more practical level, first-person accounts may help professionals better understand the world that their patients actually inhabit, and treat them better as a result. A patient’s world may have very different challenges and very different priorities from those that professionals assume. First-person accounts may stimulate more individualized management, as this article and its companion commentary also demonstrate.

We in medicine often consider ourselves to be in a war against disease. But our patients are the ones actually doing the fighting; they are the ones on the front lines. On the front lines, even seemingly tiny victories can be momentous. It is our job to help our patients win the skirmishes and outflank their individual problems, within the greater ebbs and flows of the battles against the conditions that afflict them.

I welcome your comments on these types of articles, and your suggestions for others.

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Editor-in-Chief

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In this article, a patient whom we are calling “N.L.” (not her real initials) tells about her life and experience with multiple sclerosis (MS), and, in particular, the cognitive deficits that the condition has caused. The history covers N.L. from her childhood through the diagnosis of MS when she was in her late 30s, and the 18 years that she has lived with the disease since then.

N.L. gave permission for her story and her medical information to be published. To protect her anonymity, we have altered aspects of her history, test results, and treatment, but in ways that we feel do not interfere with understanding the fundamentals of her condition.

Much of the case history comes from N.L.’s own writings. We fill in gaps with narrative obtained from interviews with her. Wherever possible, her subjective account of her medical care is supplemented by material from her medical records.

Trained as a lawyer, N.L. spent much of her career as a successful writer, specializing in law and health care. When she turns her pen on herself, she is intelligent, insightful, articulate, often funny, and always searching for understanding. Even at her most discouraged, she manages to maintain perspective on her situation. Every doctor who sees her, remarks on her excellent writing. In fact, it was at the request of one of her doctors that, 16 years after her diagnosis, she wrote her most thorough description of the impact that MS had had on her. Her self-report forms the crux of her history. A careful reading reveals some of her deficits in word choice and grammar.

Most of N.L.’s manifestations of MS have been cognitive. She is quick to pick up on the changes in her function, and she can be zealous in seeking answers. But she lives with the diagnosis of MS for years before she comes to understand that the disease can take a cognitive as well as sensory and motor toll.

N.L.’s intelligence and writing skills have been the source of her self-esteem, professional success, and income. The impairments that MS causes to her thinking, writing, and speaking skills seem especially cruel. The article’s title comes from her own description of her cognitive impairment: “It is like the core of what I used to think of as my intelligence is surrounded by a moat, making it unreachable.” Her intellect is still there, but it is much harder for her to access. In particular, she has lost the former ease and speed of her writing, if not its quality. She spends years trying to comprehend and compensate. She pushes herself to work as hard and long as she can. Finally, her impairments force her to retire, for all practical purposes, in her mid-40s.

After 18 years with MS, N.L. has learned to accept her limits. She is grateful that her motor function remains intact and her disease is not obvious from her physical appearance. Crucial to her ability to live well with the disease is the emotional and financial support that she receives from her family. She has rebuilt her life around new activities that she can do well.

By its nature, 1 patient’s personal history cannot speak for everyone who has MS. But we believe that

N.L.’s story is valuable because she is so eloquent in describing her deficits, her worries, and her attempts to get help and to help herself.

A companion article in this issue is a commentary on N.L.’s case by cognitive neuroscientist Susan M. Courtney. Dr Courtney uses the perspective of current cognitive neuroscience research to address what can be learned from N.L.’s first-person account when integrated with her neuropsychological test results, her magnetic resonance imaging (MRI) scans, and the neuropathology underlying her clinical picture. Dr Courtney also discusses practical implications for people living with MS, and some ways that their physicians might be able to help them manage their cognitive as well as sensorimotor deficits.

CASE HISTORY

Background

N.L. (not her real initials), a right-handed woman, was born in the 1950s. She is a native speaker of American English. She is an only child. There was no family history of neurological disease.

N.L. remembers a healthy, normal childhood. Although her parents were not ambitious on her behalf and did not push her to excel academically, she pushed herself, and succeeded. On the basis of an intelligence quotient (IQ) test, she was admitted to an advanced program in middle school, and she took many advanced placement courses in high school. She was shy during high school; her friends were other academically inclined girls. She was not interested in sports or other extracurricular activities. She spent most of her free time at home, becoming a serious reader. Her high college placement test scores helped her win a full university scholarship. She earned a liberal arts degree, went to work in management, and got married.

While raising a family, she attended law school, graduating *cum laude* and passing the bar exam on the first try. She enjoyed practicing business law and did not find it unduly stressful. She credits her job with teaching her a valuable skill. During this pre-computer age, the lawyers in her firm dictated their case reports for secretaries to transcribe. Most of N.L.’s colleagues wrote themselves an outline before they began to dictate. N.L. discovered that she could see the whole “architecture” of the document in her mind, and could dictate a perfect report of as long as 15 pages on the first try.

When she had been at the law firm for several years, a situation outside work began to require much of her time and attention. Over the next several years, she became less productive and billed fewer hours. There is no way to know whether the start of her illness may have interfered with her productivity. But, finally, she had to leave the job.

She next found work not as a lawyer but as a writer about law. An education company hired her to prepare law-related newsletters for niche markets in fields like health and education. This proved to be her “dream job.”

She loved getting assignments for which she had to learn about a new field quickly—before the Internet made it easy. Her dictation experience at her previous law firm enabled her to write so fast and fluidly that her first draft was ready to publish. She was remarkably productive, almost always meeting her demanding quota of 25 pages of new material per week. She describes her work in detail under “year 16” below. She was so successful that the company had her write full-length books. In just a few years she wrote several dozen books, many of them best-sellers in their fields.

Year of Diagnosis

As a writer, N.L. spent her days typing. Soon after she began, her right hand started to “feel funny.” Within a few months, it was becoming achy and stiff. A few months later, she developed a very painful sensation around her bra band. Her family doctor, suspecting MS or a brain tumor, sent her for an MRI. The scan suggested MS.

She saw a neurologist, who started her on Avonex (interferon beta-1a). She hated the side effects, which for her were chills, sweats, and depression, and which have continued intermittently ever since. However, she dutifully kept taking her medicine. During the first few years, she had many exacerbations, treated with intravenous and oral steroids.

She continued at her job. Much as she enjoyed researching topics for her work, she did not do much initial research on her own illness. Her first symptoms of MS had been physical, and her idea of the disease was that 1 day she would be confined to a wheelchair. She had no idea that MS could affect her cognition, so she was not on the lookout for a decline in her intellectual functioning. But she did note that she sometimes had trouble finding the words that she wanted to write.

Year 3 After Diagnosis

N.L. reported a sensation of “something moving inside my hands” and a tingling or “pins and needles” in her feet. She could not walk a straight line.

MRI of the brain and cervical and thoracic spine showed several plaques in the deep white matter, particularly in the periventricular region and the inferior surface of the corpus callosum, consistent with MS. The cervical and thoracic spinal cord did not show any lesions.

Year 5

Still at her writing job, N.L. felt that she was having a harder time writing and speaking in complete sentences. She could not remember what she wanted to say from start to finish, and it was an effort to speak all the words. She also became aware that her speech had slowed, and she felt that she had to fight against “getting into ruts” in her thinking. Although she could organize and express herself better in writing than speaking, she was starting to

feel some hesitancy even in doing her written work. She was having more trouble finding words and she had lost her former easy flow of writing. She still did not understand that MS could have cognitive effects.

Brain MRI done around this time showed evidence of periventricular white matter disease and mild cortical atrophy.

Year 7

N.L. returned to a law job, this time working with psychiatrists and psychologists who treated people with disabilities. She found it difficult to learn all the new procedures, and she struggled to complete her work. Her speech had become halting. When she spoke at administrative hearings, the other lawyers would interrupt her mid-sentence, thinking that the long silences between her words meant that she had finished what she wanted to say. She kept worrying that she would be fired.

Year 8

By this time, N.L. had fully made the connection between her mental and verbal slowing and her MS. She started using the Internet to learn as much as she could about her condition. She tried to come up with new ways to deal better with her limitations. For example, rather than spreading her attention over several legal cases at a time, she tried to “unitask” on only 1 case. She started making outlines before writing up a case, something she had never needed to do before. Finally, she decided that she really could not keep up with the work, and she resigned.

She requested and underwent a neuropsychological evaluation (Table 1). The neuropsychologist estimated that her premorbid cognitive ability had been in the high average to superior range, given her academic achievement, vocational history, and neuropsychological test performance. However, on formal testing, her Full Scale IQ was in the average range (53rd percentile). Moreover, there was a significant discrepancy between her Verbal IQ (75th percentile) and her Performance IQ (25th percentile). Her verbal skills were largely “intact” by formal criteria. But her performance on tests of memory was consistent with her own observations of her memory abilities. She had severe impairments in nonverbal memory; she had moderate impairments in verbal memory and in delayed recall of verbal and nonverbal material. Testing also showed “moderate” impairments in auditory attention, complex auditory processing, and executive functioning.

The neuropsychologist scheduled a meeting with N.L. and her husband to discuss the test results. However, for some reason the meeting did not happen, and the report was sent to N.L. by mail. When she saw how badly she had scored on the tests, she was horrified. She could not bear to think of herself as the patient in that report. Most devastating of all to her was her “average” IQ. Her self-image and livelihood had always depended on her intelligence. Seeing the test results

TABLE 1. N.L.'s Neuropsychological Test Performance at Year 8 After Diagnosis

	Percentile	Range/ Interpretation
Wechsler Adult Intelligence Scale—Third Edition ¹		
Full Scale IQ	53	Average
Verbal IQ	75	High average
Performance IQ	25	Low average
Verbal Comprehension Index	88	High average
Perceptual Organization Index	12	Low average
Working Memory Index	21	Low average
Processing Speed Index	66	Average
Vocabulary	99	Superior
Information	91	Superior
Similarities	79	High average
Picture Completion	2	Impaired
Peabody Picture Vocabulary Test—Revised ²	88	High average
Wide Range Achievement Test Revision 3 ³		
Reading	91	Superior
Spelling	86	High average
Arithmetic	47	Average
Woodcock Reading Mastery Test—Revised ⁴		
Word Comprehension	NA	Within expectations
Passage Comprehension	NA	Within expectations
Wechsler Memory Test—Revised ⁵		
General Memory Index	27	Low average
Verbal Memory Index	70	Average
Visual Memory Index	1	Impaired
Delayed Recall Index	4	Borderline
California Verbal Learning Test ⁶	NA	Moderately impaired
Halstead Category Test ⁷	NA	Moderately impaired

NA indicates not available.

convinced her that she was no longer competent to work and that her future held only incapacity.

Year 9

N.L. was still suffering frequent exacerbations of her MS, and still being treated for them with steroids.

During this and the next several years, she tried a few times to do freelance writing. Working at home on her own timetable helped her somewhat, but, eventually, she took on only small projects and the occasional book chapter.

MRI of the brain and cervical spine (Fig. 1), performed without and with contrast, showed the same plaques in the periventricular regions, subcortical white matter, corpus callosum, and cerebellar white matter that had been seen on the year 5 scan. No definite new plaques were reported, and some that had been seen in the posterior fossa on the previous scan looked less prominent. Minimal punctate subcortical enhancement was found in the right occipital region. There was mild cortical atrophy. The cervical spine showed no definite new plaques, possible regression of others, and minimal progression of spondylotic changes.

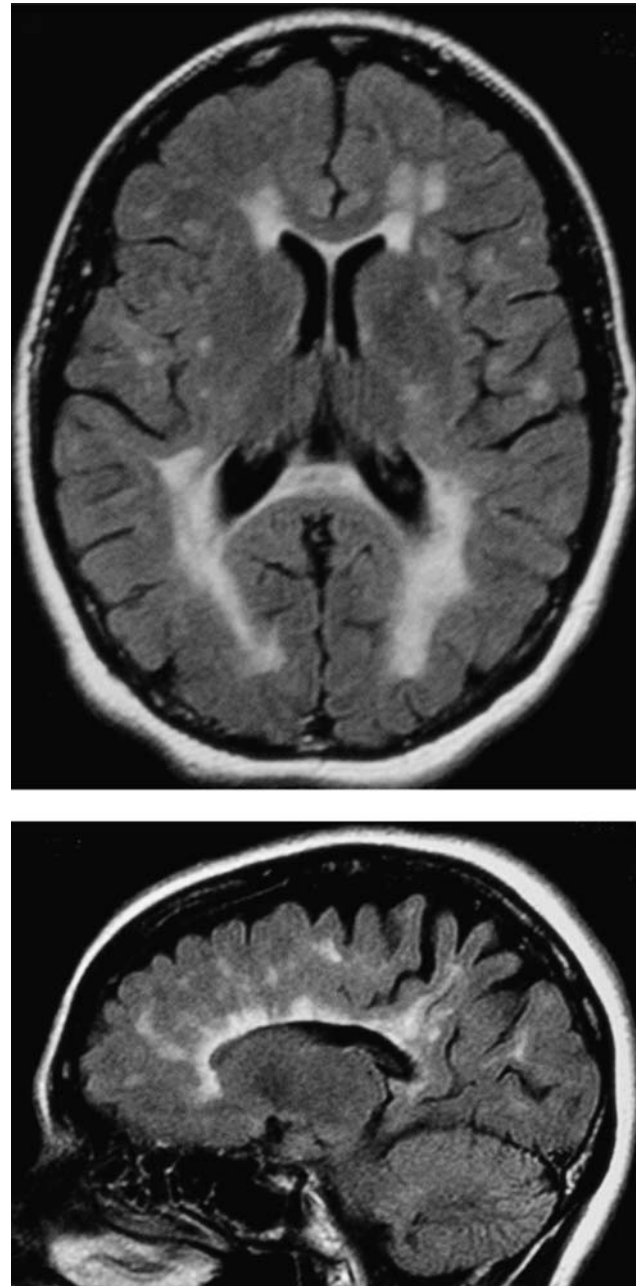


FIGURE 1. Representative images from brain magnetic resonance imaging scan performed 9 years after N.L.'s diagnosis of multiple sclerosis. Summary of the findings from this and several other scans performed at around the same time: N.L. had mild volume loss for age, and mild loss of callosal volume. There were numerous foci of increased signal intensity throughout the periventricular white matter; some of these foci were confluent, others focal. There were also numerous foci of increased signal intensity throughout the subcortical white matter, corpus callosum, white matter tracts of the corpus striatum, and cerebellum bilaterally. A few foci of increased signal intensity were found in the brainstem and deep gray matter.

N.L. sought a second opinion from a specialist in cognitive impairments. She described herself in an introductory letter:

...[I] came into my professional career relatively late in life. Once launched, that career never resulted in spectacular financial success; family and personal issues intervened. But it turned out I was a pretty good writer. I could digest masses of new, complex information; bring some insight to it; and spit it back out well in plain English for readers not inclined to go through the same process. What's more, I could do it fast. But now, as a result of multiple sclerosis, I have the cognitive problems confirmed by the testing: it is tough to make new memories and even tougher to organize my thoughts.

When I am writing something, I stay focused, in the sense that I am not consciously thinking of anything else. Even so, it takes me at least five times as long as it did to produce what I want. Sometimes, if I do not look at the clock until I'm ready to stop, I'm floored by how much time has passed. I might think an hour has passed, but I've really been at it for three. And the writing process itself is a struggle in a way it never was. I start off knowing what I want to express. I use outlines, too. But when I have to start actually putting down my thoughts one word at a time, they somehow evaporate as soon as I start typing (or even using computer dictation equipment). The process used to be so fluid it felt like transcribing someone else's speech. Now I have lost that inner voice. I don't have the competence to describe what is happening with any greater precision, but...I hope you will understand what I mean.

I am also more generally forgetful and disorganized than I ever was (I never was particularly disorganized), or that [sic] I can fairly attribute to simply getting older. Vocationally speaking, given enough time, I can still write a good legal brief, but I could not hold down a job at McDonald's. It is like the core of what I used to think of as my intelligence is surrounded by a moat, making it unreachable.

During her evaluation with the specialist, N.L. said that she thought her memory remained good for the past, but was impaired for new learning. She reported an occasional "funny feeling" around her eyes and occasional blurred vision, but no double vision. Her handwriting had deteriorated. She was aware of weakness in her right arm, especially when she tried to wash her hair. She had "funny feelings" in her feet, especially the right foot, after some walking. She did not like to exercise. She was still able to drive her automatic-transmission car. She noted that in the summertime, her symptoms worsened and she felt exhausted.

On neurological exam, she was found to have clipped and broken speech, and trouble repeating "t"

sounds quickly. Among her other most notable neurological abnormalities were pallor of 1 optic disk; slowness of fine motor functions, particularly in the right hand; mild static and intentional tremor in both hands; finger-to-nose ataxia bilaterally; bilateral Babinski signs; impaired vibration and proprioception senses in her lower extremities; and a mildly ataxic gait.

Having read one of N.L.'s recent writing samples, the specialist assured her that she was compensating successfully for her memory and executive impairments through her insight about her condition, her self-monitoring, and her allowing herself as much time as she needed to complete a task; she had retained her legal knowledge and her ability to organize and integrate ideas into clearly written text. The specialist encouraged her to keep writing at home at her own pace, and suggested that she might benefit from guidance on organization, focus, and other executive functions.

For N.L., the most memorable thing about the visit was that the specialist understood how much effort she had to expend just to get through each day, likened to running a daily marathon.

Year 10

N.L.'s flares were becoming less frequent. Around this time her periods of poor balance eased and she could walk more steadily.

Repeat MRI of the brain and cervical spine showed essentially the same changes seen on the year 9 scan.

Year 12

N.L. had been complaining of short-term memory loss and headaches. Brain MRI showed continued extensive deep white matter lesions in the periventricular area, extending to the corona radiata. Most of the lesions were perpendicular to the long axis of the lateral ventricles. The distribution of plaques was similar to that on the year 10 scan.

Year 16

N.L. was feeling well and was dealing well with her cognitive limitations. Flares of her MS had become rare.

At her neurologist's request, she wrote this detailed self-assessment:

I am not [British writer and philosopher] Iris Murdoch [, who died of Alzheimer's disease] and I do not suffer from Alzheimer's disease. But my inability to write professionally has been the most troubling of the cognitive problems I have experienced as a result of having MS. So, while I start with my mantra that I know other people have far worse to deal with, I am happy to explain the difficulties I have faced—and continue to face—as my MS, diagnosed in (around) [date] [the year she writes is 3 years later than her actual diagnosis], progresses. I'll discuss my functioning in terms of six areas: (1) memory; (2) intelligence (a broad category I'll break down into the components of fluid thinking and analytical

reasoning); (3) focus; (4) speaking; (5) social relationships; and (5) [sic] saving the best for last, writing.

But first, as [television pitchman] Billy Mays would say, I'll expand on the introductory sentence to explain two things you should understand when reading this. As for my reference to Iris Murdoch, please note that the professional writing I did was by no means extraordinary. I did write expository nonfiction, but the world has not lost another, say, [best-selling writer on the social sciences] Malcolm Gladwell. I'll briefly explain the substance of what I wrote in more detail when I describe the problems I now have. But for now the thing I want to emphasize is that I had neither brilliant ideas nor luminous prose before MS. And I think that if I could write now, the quality of both the ideas and their expression would be about the same. It is the processes of writing itself that is [sic] at issue. In addition, I realize for me (and I guess as a general matter) the impact of MS is part of a patchwork of factors and circumstances that impact functioning. By that I mean I don't feel the disease has taken over my thinking as a whole. The deficits are spotty, like the diffusion of lesions one sees on a brain MRI. While this letter is by request a description of how MS impacts me, I realize it is simplistic to discount the impact of comorbidity of other factors, such as emotional health and situational circumstances. All in all, then, this letter might be better described as a description of certain functional problems I have. I'll leave it to the professionals to decide the issue of causation more precisely....

...as I persevere in proclaiming, I consider myself an Internet-certified neurologist. My aim is to discuss how I function (or not) in concrete language. But I do have some theories about what contributes to my problems that I'm including, mainly for my own gratification. I'm going to try to keep that to a minimum.

...I'm using this letter as a writing experiment. My goal is to write this letter in the same way I used to write professionally. I'll explain the details in the section on writing. But I am happy to write now that if you are now actually reading this paragraph, I have been successful, at least to the extent of completing it.

1. Memory

I assume that pre-MS I had at least ordinary memory capacity. I believe my [year 8] (approx) neuropsychological evaluation showed a pretty piss-poor short-term memory.

Of course, at my age...everybody seems to be worried about where they put their car keys. I start, then, with the assumption that, irrespective of MS, I also have my fair share of age-related

memory loss. New names and faces are problematic; the content of casual conversations may not sink in. Over the years, though, I've learned to respect my potential for forgetting everyday things and follow the advice of [memory experts]. I have a special place to put my keys and glasses; park in the easily found handicapped spots; and write down anything in the way of appointments, chores and the like. As a result, when it counts, most of the time I work around any memory deficits I may have.

But I ran into a task in the course of my research work that let me know that I have real trouble in this area. Most of what I do [now] involves finding scholarly articles on the Internet and downloading them for review by my client. He has a particular format for [naming computer files: first author's last name and first initial, first few words of title, and year of publication]. Usually the question is broad so I've had to read through a lot of material to select those items that seem on target. In other words, by the time I get to downloading an article, I'm familiar with the content generally and the words in the title are meaningful to me, not like random letters. But I found that in the time it took me to take a final look at the author and title, download it, and give it a title in my file, which must be all of 30 seconds, I couldn't remember the author's name. If I looked again at the article, I could get the name but couldn't even remember an approximation of the title. Basically, I found that I could keep in mind the author's name, about 3 words of the title, or the year, if I did then [sic] separately. Of course, that's pretty frustrating, so I use my work-around of writing out what the file name should be on paper and looking at that to name the file after I have downloaded it.

I also have a memory oddity I've already told you about that I call the two book problem. I take books I read for pleasure out of the library, usually two at a time. At any one time the book I am not reading—either I have already read it or I have not yet read it—is between bookends on my dresser in the bedroom. I've found over the last couple of years that if someone asked me what I have been reading lately, the only way I could recall the title of the last book I finished was to mentally picture it on the dresser. Other than that, I seem to draw a blank on anything else I have recently read, if there is nothing to prime me.

2. Intelligence

I know that the concept of IQ testing as revelatory of intelligence, and the whole concept of *g* [Charles Spearman's "general intelligence factor"] being the first and last word on what a person needs to succeed are no longer the received truths

they used to be. Nevertheless, I start with what seems to have happened to my intelligence, as defined that way, after my diagnosis....I was in advanced placement classes in high school....I graduated *cum laude* from law school and aced the...Bar Exam. To put it bluntly, I considered myself smart. The IQ score on my neuropsych [evaluation 8 years ago] was a big 100. All right, that's average. But everything about my life leads me to think that it was probably significantly higher before the MS.

I have no doubt part of what made me do so well on standardized tests and in my career was my analytical thinking ability. Weirdly enough, that still seems to be intact. The research I now do is [sic], in fact, creates almost the perfect conditions for me to see that there are conditions under which I can still do demanding analytical work. I'll explain briefly below the demanding fact-checking [sic] project I did over the last couple of months. This may sound like mere bragging, but I think it illustrates the things that I do not see as causing the writing problems described in the sixth section.

My client has a contract to be the author of a popular science book. The actual operation involves a journalist writing a draft for his review and revision. My role was to fact check the journalist's draft. That involved a front-to-back reading, followed by a line-by-line reading. I have no professional experience as a fact checker, so I started without a rubric. But as I read I developed my own standards. First, I saw that the task was first to define what should be considered a fact, by which I mean a statement that had to be based on support in the scientific literature, as opposed to an opinion or a universally held truth. Then I had to identify which, if any, of the facts in the MS [manuscript] (oh, the irony!) were inaccurate. I found in this project that there were 3 basic varieties of inaccuracy: (1) the statement misstated its stated source; (2) the statement contradicted another statement in the ms; and (3) the statement's stated source was inconsistent with the literature as a whole. This last category required a review of many items outside the ms.

With respect to the element of flexible thinking in intelligence, it's hard to know how I performed in this regard before the MS, but I assume this was at least within the normal range. I experience problems at times that seem to back up the neuropsych's finding of rigidity. These are little episodes of confused thinking that I honestly don't recall and can't even imagining [sic] happening in earlier years. I have forgotten the details of most of them, but I have the strong conviction that more than the 3 I'll describe below have happened.

The first I remember [...is that] I'm driving down a street looking for a building in the 72

hundred block. My aunt's house is on the 77 hundred block. The numbers are a little hard to read and I'm not sure whether they [go] up or down in the direction I am driving. I pass my aunt's house and keep driving, and next notice that I am on the 7900 block. Do I tum [sic] around? No, I keep going through the 80's and get anxious about being lost. I tum [sic] around and go back to the intersection where I turned onto the street and go down the street again, this time looking more carefully to see which is the 7200 block. Later that day it strikes me that I should have turned around at 7900.

The second is simply inexplicable. I went into our local [supermarket] to place a special order at the meat counter for turkey burgers, an order I periodically place in a store I patronize a lot. In other words, I know the lay-out, [sic] with the fish counter in the front of the store right after the produce and the meat counter in the back. On this particular day I stop first at the fish counter. There is a line so I have to wait at [sic] bit and while I'm waiting I'm looking at the fish. Then everybody else has been served and the counter person asks how he can help me. I give him my turkey burger order! He tells me that this is the fish counter. I knew that! As I said, I have no explanation.

The last is the most recent. My [child's] wedding [will be on date X]. It has been a subject of much planning and aggravation for months. One Saturday my husband and I are walking in the downtown area of the [town] we live in and I saw a sign for a community fishing event on that date. I thought it looked like it would be a fun thing to take our granddaughter to and I ask my husband if he can take off from his usual Saturday morning work on that day. He smiles and says he thinks he can. I continue on talking about the fishing event and he asks me if I know what day [our child] is getting married. I shoot back [date X]. Then the light dawns.

3. Focus

By focus I [mean] both [sic] the ability to sustain attention, switch attention, and multitask. When it comes to sustained attention, I have always been able to concentrate. Although I read about distractibility in the literature I don't consciously experience it as a problem. For example, I can sit for hours at the computer on my research projects—or indeed, this letter—without needing to check my e-mail, celebrity gossip web pages or the like.

As for being able to switch attention and multitasking, I am going to assume I was able to do so in a normal way prior to MS. When it comes to multitasking, I have one tired story that illustrates how well I did that during the time I was diagnosed with

MS. During the years I was a full-time writer my habit was to have talk radio on during the day, both when I was doing research and when I was writing. I [was listening to the radio] with great interest... when I wrote the first in my series of... books. I knew little about the topic [of the book] before I started the research; [but] the finished book was by all accounts pretty good.

I now have experiences that makes [sic] me think I have gone downhill in those regards. I'll start with an extreme example. A couple of years ago I filled in as a [sic] assistant for two friends, a lawyer and a consultant, whose shared assistant had left suddenly. This involved tasks like answering the phone, filing, making copies and binders, and making calls to set up appointments. Not complex tasks, but a lot of items that involved a lot of pieces of papers [sic]. Towards the end of the days I felt exhausted and had increasing difficulty sorting through the paperwork. This feeling was a magnification of what happens whenever I am faced with a lot of errands to run or paperwork or other items to keep straight. While I always maintained an orderly work environment, I now feel somehow almost uncomfortable in a cluttered environment, while unable to keep things as organized as I would like.

4. Speaking

There is a lot that has changed with my speech. Most of the time I speak slowly, with what seem like long pauses for no good reason, between sentences and even words within sentences. Every so often I emit a gush of words that are tangential to whatever I was saying just prior to that. And, as you noted, something's going on with the prosody. I'll try to give an objective account of what my speech was like in those three regards prior to my having MS.

As luck has it, my client...knew me in high school!...I guess somewhere along the line I made the decision to not allow verbal tics or place savers into my speech. [My client] remembers that there was always a bit of a pause at times when someone else might have said "you know" or "um" but that my speech rate was normal and regularly paced.

As for the rush of words, I hear it myself and know it makes me sound loopy. Friends do not really call me out on this but my husband... does. He identifies it as a recent, in the course of our marriage, habit, not a lifelong way of communicating. Here is where my Internet-certified expertise comes in: I believe my brain is somehow pushing out thoughts I have that I want to say out loud as soon as I have them. Otherwise, if I wait until I articulate a better explained linkage I'll forget them.

I have even less insight into whether I sounded the same tonally prior to MS as I do now. I have to imagine that I didn't. As I wrote before, friends

thankfully don't tell you everything, but no one has ever commented on my having this problem, either before or after diagnosis.

One thing makes me think I was in every respect a far different speaker prior to having MS. When I worked as a health care lawyer and consultant...I was often selected to be a speaker at various seminars and conferences the firm gave...for clients and wished-for future clients. Other members of the firm had the same subject matter expertise but I was considered lucid, articulate and entertaining....

5. Social Relationships

I'm including this with some uncertainty because this is certainly an area rife with potentially confounding factors other than MS. Nonetheless, I'll present the before-and-after.

...I have always been comfortable in a work environment and had good female friends with whom I enjoyed socializing, both one-on-one and in groups. Naturally life got markedly quieter for me after I stopped working [8 years ago]. For a break in the routine, I used to like joining from time to time a group of... lawyers who have always eat [sic] lunch in the conference room of their office. I like them all and it is good to get out. But for the past two or three years as I'm driving back home I start to get the same feeling of mental exhaustion I described above. The same is true for holiday gatherings with my husband's family. I sometimes get the same feeling after socializing with just one friend, but not to the same extent.

6. Writing

I'll start by describing the kind of writing I did before [I retired], then relate the problem that was the coup-de-grace for my professional career, and wrap up with the current state of my writing ability.

I'm [in my 50's], so of course there were decades of employment before I became a professional writer [16 years ago]. But that was the first year my sole purpose was to produce written material about the law in varying formats and lengths for a wide professional audience. I started writing newsletter articles and went on to produce books (300-400 pages of text). I worked for a for-profit company where no one was treated as an *artiste*. Good was good; fast was just as good. Every book I wrote concerned a topic I knew next to nothing about before being assigned to write about it. But the requirement, which I was able to mostly meet, was to produce an average of 25 pages per week. The production schedule boiled down to my first draft being the final one as there was no time allowed in the production schedule for anything other than copyediting.

Despite all that, the books were well-received and sold very well. As I read them over, they all seem pretty good to me, well-organized, clearly written for my audience...and amiable.

So, to sum up: I could digest an immense amount of unknown sophisticated material, aggregate and organize that accumulated material, and produce a book whose first draft was good enough to satisfy me as the final product, all in short order and while listening to the radio. When it came to the actual writing, what made this possible was what I—and others, of course—call the “Voice.” I never used outlines. I had some general idea of where I wanted to go and then started to type out, like dictation, what I heard myself speaking, sentence after sentence.

The success of the book I wrote [while listening intently to the radio,] as I described above, resulted in the publisher’s deciding to use that format for a series of books about other topics....Thus, over time, writing in that format became, in a word, formulaic. [About 6 years into my writing career and after my MS diagnosis,] I started to have some difficulty selecting particular words I wanted to use and fell back a bit in keeping to schedule. Looking back, I think the known quality of the formula helped me keep moving and I didn’t perceive myself to be having any MS-related difficulties.

At the same time as these difficulties were appearing I decided to move to a new position as an associate lawyer in a small [specialized] law firm. One of the most crucial aspects of the job was writing legal briefs for administrative appeals. I’d never done this type of work before but it has its [sic] own formula, which I was able to learn. I turned out to be an absolutely lousy lawyer in several ways. My work was slow and I’d make a mess out of the piles of paper documents you had to assemble and keep straight for hearings. The quality of the briefs went downhill from good but slow to neither. Towards the end, I would spend hours and hours trying to write. But it felt like I was pulling teeth to get the words to come out. The last brief I wrote there was pronounced “incoherent” by the boss. The Voice had taken a hike. It has never returned.

But at least I got it done. Another assignment had been to ghost write a law review....I selected the topic and did the research. Now being fearful, I made an outline to help speed the writing. That in itself seemed to take forever. Worse, I just could not get from the outline to the draft. I’d get a paragraph or two on the page, but they weren’t what I somehow had wanted to write and they didn’t seem to be part of any whole, coherent project. I’d start to question my overall organizational plan, what information should I include and in what order should I present what I wanted to include. Then I’d start again, with the same results. Finally, after months of work, I had nothing to produce.

Since retirement I have tried to write longer pieces on several occasions without success. One time I agreed to co-author another piece for a law review with a professor. I was to do the first draft. I did research and concocted an outline, which we agreed on. Then the same falling apart made me unable to complete the draft. At one point I bought...dictation software, but I had the same problems I experienced when typing. Even using my voice, I couldn’t recapture the Voice.

When I sit down to write I feel I know in some way what I want to say. But in the same instance that I feel I know[,] I don’t know what to write (or dictate). Inevitably this process of getting nothing done takes hours. I literally lose track of time and am always amazed about how long I have been at it. And I feel like I have been out [sic] through the wringer when I get up.

So what is happening? This is the best I can understand:

What I want to write is either contained in my brain as some kind of non-verbal gestalt or I forget it at just about the same moment I think it. Or maybe it is lost in a crowd with every other thing I want to say about whatever I intend to write about to see which can get out first, with each fighting to push to the front of the line.

As for the experiment I mentioned initially, I have gotten to this point using the writing method I used for my books, with the exception of doing research and digesting new information. I consulted no documents and relied solely on my own knowledge. I thought about what I would write on-and-off (like minimizing a program on the computer) since our appointment, but made no outline. This is a first draft written pretty much from top to bottom. Aside from reading over once for typos and the like before sending, this is what you are reading. I started at 2:00 PM and am finishing at 9:30, with only short breaks. Not a sterling production rate. It felt hesitant, without the Voice.

I hope this is helpful to you. I do think it has been good for me to do it.

N.L. felt that she “could always walk well,” but at around this time she began having trouble balancing when she stood still. She also developed some new paresthesias, which were mild but unsettling. She decided that she did not want to spend her days trying to do what she could no longer do. She wanted to spend her time learning to maximize her physical strength and balance. Encouraged by her husband, she took up horseback riding. She enjoyed it and learned that it had side benefits. Her riding instructor taught her how to balance on the horse by choosing a point straight ahead of her in the far distance and focusing her gaze on it almost meditatively. This trick also helped her balance much better when she was standing. She found that riding helped her function better in general. Although the

horse threw her once and she broke a bone, she returned to riding as soon as she recovered.

It was only this year that N.L. considered herself fully retired.

Year 18

N.L. is now in her mid-50s. She feels well both physically and emotionally. She is grateful for the cognitive skills that she still has, and for her very supportive husband and family. Her appearance remains important to her. She is pleased not to have obvious signs of MS that other people would notice. She feels that she walks normally and that her speech is only slightly halting.

Looking back on the neuropsychological test results that had so shocked and distressed her 10 years earlier, she now thinks that her poor performance accurately reflected her abilities. She regrets not having been able to work longer and contribute more to her family's income. But she says that all that she lost from having to retire young was "ego and material things, and I don't think they're major." She continues to ride a horse almost daily. She is philosophical about her situation. "I didn't choose this, but it wasn't a tragedy. Other people have had it much worse. I don't think my life is bad at all.

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