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## My Memory Returned to Me

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Three years ago, after a decade-long series of illnesses, my mother developed symptoms of dementia. They came with devastating severity, and we were not prepared for them. She almost completely lost her connection with the world of objects and with the everyday practices and procedures of life. That kind of knowledge evaporated out of her, and suddenly she had no answers to any questions. She was only sure of one thing: she knew who the people beside her were. She knew that she had her husband, my father; her daughter, me; and Maja, my partner.

Since then, we have been observing together what memory and knowledge can mean when it is no longer about growing and developing but about the shedding of layers and finding what foundations still remain. But of course, we don't know anything about these amazingly rich and complex structures.

We are still in my mother's most stable and—for now—unshakable memory, but every time we meet, even when we spend more time with each other, again and again I have to reassure her: you are my daughter, she says. Yes, and you are my

mother. Maybe it makes her happy to say this, happy that she still fully remembers one of the most important things about life, and she is happy that we can communicate with each other. It makes me happy, too.

The most incomprehensible complexity of memory presented itself to me when, for a few nights, her memory returned. Suddenly, in the dark of night, she began to remember and to speak. She needs twenty-four hour supervision, day and night, and I was next to her at that moment, listening, asking. Everything came back: who she was, how she lived, what she did and when, how she had felt, and what her plans had been. Her life story was not disfigured by self-censorship or self-blame, nor was it infiltrated by neurotic revision. With brilliant clarity, she remembered.

Later, I learned that many people who live with dementia experience something similar, and lucidity always comes at night. I don't know why—how the blood flows or how the inactive parts of the brain become reanimated—but what is clear is that in these tracts of time, when I thought that her memory was lost, the truth was that it still existed; it had only been paused. And then, for a few nights, it returned.

She was so happy to have her memories back. The timbre of her voice, the pace of her sentences all came back. It's because of her that I know that remembering is joy. I've always known that it is important, but that it is joy, a happiness tied to the very core of existence, that I know because of her.

“Ko mne vernulas pamyat.” “My Memory Returned to Me.” This will be the title of our book, she says. She chose this. And I must write about her, about her sickness, her life, and about all of us, she says. It’s important to her; she still remembers that she used to love books, and that I love them, too. She knows that it will give us both a purpose during this time. And so we cling to it, both of us.

My mother learns what is truly important: that her father’s grave has been found, that her best friend has had an accident, that her nephew’s son was born. She has learned to say that if her own mother were still alive, then she would be a great-grandmother by now. If we would tell her about important events, she would memorize most of them. But which verb should I use? It’s not right to say that she “memorizes.” We toss that word around, as if we expect her brain to be able to memorize. But it’s also not right to say that these things become “etched into her mind” because it’s not possible to etch something into that sporadically-functioning instrument from which anything and anyone can spill out at any given moment. Truly, she is learning these new pieces of information. She is working. And I am working with her, too. I am learning how to pass along information; I am teaching her new essential knowledge. Again and again I explain things, contextualizing with emotion. I repeat every piece of information until she herself begins repeating it. So that the information becomes ingrained, I’ll ask her it about several times over until we can be certain that she has mastered her own knowledge and learned these memories.

What else has she learned? That it's not okay to touch her stool. That she should not chew her medicine before swallowing it. In both situations, she had to fight her strongest instinctual compulsions. My father taught her both of these things. I don't know how he did it, but he didn't back down, and he didn't give up.

My mother learned, in her own manner of learning, how to navigate a completely new and complicated space: a new house and a new garden after she and my father moved. She quickly found her own places—her room, her bed, her chair at the dining table—in this new space. She could adapt, and she could delineate what was hers.

That kind of knowledge is the strongest because it is automatic: it becomes a feature of the body. But then again, what kind of knowledge isn't a thing of the body? It is not a retained knowledge; my mother can no longer retain information. What remains is the kind of knowledge that has permeated the body to such an extent that the knowledge, itself, becomes movement. It manifests in her compulsive repetitions, in the unconscious movement of her hands, and in the way her legs simply take her somewhere. Just as she knows what to do with a spoon and a fork, her hand and her mouth know, too.

Like many with dementia, she learns quickly what it is that she does not have to do and what her aides do instead. She herds us persistently. She would hand over all responsibilities for getting dressed just so that she wouldn't have to put on anything by herself. She would hand us every task

that becomes complicated and to which she can no longer adapt her movements. She hands over the spoon when it hits the bottom of the plate; that last dip is already insurmountable. We take the spoon, but we cling, resolutely and desperately, to her every shred of knowledge and to every functioning reflex. And she does, too. She does not want to give up on knowing and remembering, and she does not want to feel the all-pervading disappointment of becoming helpless.

A person living with dementia is like a poet. They have to be like poets, in the way they twist their words. Only now am I able to write about this, two and half years after my mother was diagnosed with moderately-severe stage dementia. Since then, we have all found a common language. But when dementia, with its wrung-out words, suddenly came crashing down on us like an avalanche, I wrote this about my mother:

She's forgotten the names of things; she's forgotten the times of day. But she wants to talk, to communicate, to be in constant contact. Over and over, she repeats the sentences that she forms on the nights when her memory returned to her, and she is stuck with them. Now, these have become her new memories: twenty sentences. The other repeated sentences are about her anxieties. If something is black, if it is afternoon now, if there is water, if there is toilet paper, and when are we eating already. She feels as though she cannot answer the question:

“why did you do this?” And we also repeat ourselves. Every day, two hundred times a day, we ask: Why did you pour out the water? Why didn’t you shut off the faucet? Why didn’t you put on your slippers? She feels as though there is a disconnect between the action and the question—that’s all. Even if she forgets her present embarrassment, the profound frustration she feels at herself is gathering inside her. So, too, is the anxiety. Sometimes she rebels, and she becomes sharply defiant. The only thing she repeats in Hungarian is *vállalom*. I admit it. Her second language, the one she learned as a wife and a parent—Hungarian—she has forgotten.

Now, she is like a poet, and once again a bilingual one. My father, who never let her lose her language skills, was right about this, too. Meeting the Hungarian-speaking helpers reawakened the language in my mother when we had thought that it was almost completely lost. The encounters stimulated her. She has difficulty recognizing when she is using Russian or Hungarian, but for the most part, she still chooses her words correctly.

She never spoke Hungarian flawlessly, but beyond accent and literal translations, her style was unmistakable. Already, then, she was playing with the language.

For us, Russian used to be the language of our home, and all three of us spoke it. My father flawlessly, and I with mistakes and falteringly, but

Russian, too, was mine. Meanwhile, Hungarian became the substance of and vehicle for my thoughts. With Maja, I speak English, though with mixed feelings. Would this be an impediment to intimacy? We hoped to compose our own private language. Instead, multilingualism is now our norm with English, Russian, and also Slovenian. Hungarian words flying through the air, with a few Serbian ones, too. And we know a little German. We speak in a carnival patchwork.

Maybe because by now we all have more or less found a common language with my mother, which she primarily creates and shapes; or maybe we've found common ground because, as she says, she got "used to this illness — but I hear her differently. I pay attention to how she switches words, when in place of an important word she cannot recall, she offers another. These changes can extend across entire turns of phrase and sentences. It's as if a strong and indelible word has dragged another into its forcefield because one resembles the other (perhaps in function or in sound). Nowadays, she feels as though her walking stick is necessary for every step, which is why a fork or a spoon will sometimes become a stick, too: "palka." Sometimes the word with which she replaces the other resembles its tone, its mood. For a time, she liked to take a molecule of perfume out of an old bottle, one of the last drops in the vial, and she would call it: "igrayu na skripke." Playing the violin. When I first heard this, I didn't understand. She had never been able to play the violin, but I was certain that the connection between the two would become clear. Maybe it was in the so-

phistication of using perfume. Neither in Hungarian nor Russian is there a good verb to describe this.

Maybe we've learned to hear her distress in the accumulating repetitions, and so we try to alleviate it. Maybe we've also learned how to repeat things well, more slowly and more loudly, if necessary, so that she can understand what we are saying. Our language has also evolved; we use simpler words, and we rely on figurative meaning and abstract metaphor less and less. Maybe we already better understand that we have to make eye contact when speaking—she has to see us. Conversation is situational, and we have to be present for her.

I've also adopted some of her new turns of phrase. For example, anything good is “delicious.” In Russian, as in Hungarian, that adjective applies to everything from tastes to smells. And it didn't stop there for her: “Mnye eto vkusno.” “It's delicious to me.” We say this about whatever brings us happiness and we enjoy. In Hungarian, too. In my mother's manner of speaking, it becomes *FI-nom*; the stress is on the first syllable, and the second collapses into the first, almost sliding away.

She had to relearn how to wash her hands, and even now, she is not always successful in completing the complicated series of steps: turn on the faucet, soap, rinse with water, turn off the faucet, dry with a towel. But sometimes, when she gets to the end of the sequence, she says triumphantly: “ya vit'erla kazhdiy pal'chik!” I dried off every little finger! And I say this to her, too, and we laugh. There is nothing better than this.



I can't describe how my mother speaks Russian. All I can say is that as it was before her illness, now too, her own style is evident in every word choice. But it's possible that the reason I describe it this way is because she is the Russian-speaker to whom I am closest. And because it's my mother's tongue, so it is my mother-tongue. When dementia suddenly came crashing down on us like an avalanche, for a long time after the jolt, we lived with the certainty of her impending death. At the time, I wrote:

How easily I talk about her death, but what will happen to me once she dies? With her will also die the soft consonants, the *nezhnost'*, the Russian, where "tenderness" is said so that three times your tongue touches your palate. I fear that what remains after will be rigid and prescriptive, and the language will run dry. I don't even want to finish writing this sentence, just as I do not want her to die.

### **About the Author**

Teri Szűcs is a literary historian, critic and writer. Over the past decade she has been involved in homecare, and in the last few years, in dementia care. She has started her blog titled "Visszatért hozzám az emlékezet" — "My Memory Returned to Me" to collect and recount the experiences and adventures of caring for her mother who is living with dementia. Email: [szucs.teri1@gmail.com](mailto:szucs.teri1@gmail.com)

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