

SHATTERED BRAIN: THE BRAIN BODY DISCONNECT



“When I close my eyes, I feel like my body disappears.”

~ Meaghan Buckley

The year was 1943. Lieutenant Lyova Zazetsky, just 23 years old, led his platoon of soldiers west across the banks of the frozen Vorya River in Russia. The men were tired, as they had been fighting for several months to take back the occupied town of Smolensk.¹

Before long the Nazi enemy was engaged and a barrage of machine gun bullets were flying. Zazetsky ducked down, but not soon enough to escape a bullet that penetrated his helmet, then his skull.

He survived the battle, but his life was never to be the same. He sustained a severe head wound, causing massive damage to the left occipito-parietal region of his brain, leaving him in a coma. This injury shattered his whole perceptual world.²

His right field of vision had been destroyed, as had his memory and his awareness of the entire right side of his body - all shattered into fragments, causing him to experience the world (and himself) as constantly shifting and unstable.³

Zazetsky had been a gifted student who had studied at a polytechnical institute for 3 years before war broke out in 1941. Now he had trouble remembering the names of even the simplest things. He might want a drink, but instead would ask for a *duck* or a *bird*. 4

Being asked to identify different parts of his body was a major challenge, and he was frequently forced to "hunt" for the location of his hand, foot or arm that he was trying to name. 5

The "spatial peculiarities" that Zazetsky experienced made writing a particular challenge for him. He forced himself to learn how to sit at a table and grasp a pencil properly. After weeks of rehabilitation, Zazetsky regained the ability to write, although this process was slow and exceedingly difficult, and he could neither read nor remember what he wrote.

Not only was his concept of self affected, but his grasp of language was as well. He could utter a few words but only with great difficulty and for the most part, they did not communicate what he wanted to say. He was forced to retrain his brain to make simple logical assumptions and judgment tasks. 6

Despite his devastating impairments, Zazetsky began documenting his experience in a journal.

"This strange illness I have," he wrote, "is like living without a brain." 7

"I'm in a kind of fog all the time. All that flashes through my mind are images, hazy visions that suddenly appear and disappear... I simply can't understand what these mean." 8

Zazetsky would write in his journal almost daily for the next 25 years, filling 3,000 pages in dozens of notebooks. These diaries, documenting his struggle to make sense of his fragmented life, would form the basis of a long term friendship that he established with Aleksandr Romanovich Luria, a 41 year old psychologist and physician who headed up a research team at the Russian army hospital where Zazetsky was convalescing.

As luck would have it, Luria had been fascinated all his life by the brain and, in particular, aphasia, the difficulty speaking, reading and writing that often follows traumatic brain injury or stroke. So, for him, meeting Zazetsky and reading his writings was like winning the lottery.

After Zazetsky returned home, the two men stayed in touch for thirty years. The upshot of their shared passion for understanding Zazetsky's strange mental state

was Luria's 1972 publication, The Man with a Shattered World: The History of a Brain Wound.

I am frustrated and mad at my body for not listening to my brain.

When I close my eyes, I feel like my body disappears.

Body sense, we pay so little attention to it and yet, it is perhaps the sense that has the biggest impact on our life, as Zazetsky's account demonstrates. His head wound shattered his perception of the entire right side of his body and fractured his reality for the remainder of his life. He felt like he was "living without a brain."

Vision, hearing, smell, taste and touch. If asked which of these senses we would hate to lose most, for most of us it would probably be a toss up between vision and hearing. But there is another sense that we'd probably miss even more if it were suddenly taken away from us. Because unlike the five senses that allow us to experience the outside world, proprioception enables us to understand our physical place in that world. 9

Without a functioning proprioceptive sense there is a brain body disconnect, much like Zazetsky experienced on half of his body. As Nature's Allison Abbot says: "Without it, our brains are lost." 10

Close your eyes and bring the fingertips of your right hand to touch those of your left. If everything is working properly, this shouldn't be a problem because your brain can sense your body, as well as its position and movement through space. This is proprioception at work. 11

in 1906, neurophysiologist Charles Sherrington coined the term *proprioception*, a word that literally means "one's own." Proprioception, he said, was an awareness of the body, which stems from sensory receptors or proprioceptors in the muscles, tendons and joints.¹² Proprioceptors send pressure and movement impulses to the brain that let us know where our body is in space.¹³ This movement aspect of proprioception is called Kinesthesia.

Proprioceptive receptors also work in the absence of movement, which is how we instinctively know where our hand is, even when it's still.

Sensory information about balance, equilibrium and spatial orientation is provided by the vestibular apparatus in each of our ears. Our vestibular system is part of our proprioceptive system. If one is not working properly, chances are pretty good that the other isn't either.¹⁴

And if your proprioceptive system isn't working as it should to give you voluntary control over body, you might just feel that it has control over you.

Very few people understand what autism is all about. It is not a verbal disorder. It is a sensory motor disorder. What I mean by this is that you become a slave to your body. Anything you want to do you have to think really hard about and even then your body can screw it up.

Do you lack sensation in all parts of your body, Meg, or just some?

All parts.

What about facial expressions? I know that whenever you are asked to smile you say "cheese." Is it because you cannot feel your mouth?

Yes. I cannot stretch my mouth into a smile voluntarily.

Is this lack of sensation of your mouth why you chew on things?

Yes. I chew to feel my lips. I get really good sensation back from my mouth.

So when you hit yourself?

I am frustrated at not being able to communicate. And also it helps me to feel my body.

What about your repeating?

I repeat to escape myself. Believe it or not, it creates a calm sensation when I am feeling over-stimulated or anxious, which is pretty much all the time.

I don't have good system control. Each time I am not real wild I am trying really hard to control myself. Typing helps, it gives me peace.

Bear in mind, by body movement we are not just talking about moving arms and legs, but also your head and eyes, to visually explore the world, your facial expressions to show emotion, and for articulation, your lips, tongue and mouth to communicate.

The more intricate the neural processing task, the more ways my brain finds to screw it up. My mind just can't get coherent messages through to my mouth. Not just speech. I can tell myself to smile or stick my tongue out until I am blue in the face but my mouth won't respond.

The fact is, learning to speak is impossible without the proprioceptive sense. Our mouth, vocal cords, diaphragm and lungs incorporate thousands of nerve sensors that the brain uses to control their movement and determine their position. To pronounce even a single word we need to coordinate our tongue, breathing and jaw muscles. Now multiply this complexity as sentences are constructed in rapid succession during normal conversation. 15

Imagine your dentist has just given you a shot of Novocain on both sides of your mouth to numb your nerves. And then he asks you to drink some water. You silently curse him as the water dribbles down your chin onto your shirt, but you don't say anything because you know you will garble the words if you try to talk. You have lost proprioceptive control over your lips and mouth. Fortunately for you, it is only temporary.

You can bank on the fact that kids and adults with ASD want to communicate. It frustrates them that they cannot speak as easily and normally as we do. We take for granted all that goes into speaking: thinking of words to convey our idea or message, formulating them into a proper sentence and then using our lungs, vocal cords and mouth to create complex speech sounds. 16

That's a heck of a lot of complicated neural coordination, and all systems have to be on "go" if your motor cortex is going to get the job done. It would be next to impossible if your lips and tongue were not registering any proprioceptive sensation. You could not control your mouth well enough to form precise words. 17

I want to talk but the words are stuck inside my head. It is difficult to separate them out and make sense of them, much less add sound to them.

When I type, the words flow easily. For me typing is a natural means of expression, kind of like your voice is for you.

if you don't hear yourself speak, you are not going to learn to speak. It's not even a matter of hearing others speak. If language learning were only a matter of memorization, most people with autism would talk non-stop. But it is not. There is a cog in the wheel and that is proprioception.

Simply put, the only way to properly learn spoken language is to use spoken language. And in order to use spoken language, you must be able to feel and control the movement of your mouth, tongue and lips. The sense that enables you to do that is proprioception.

Before we learn to talk, most of us learn to walk and it is proprioception that allows us to recognize and control our limbs without looking at them. Of course, most of us don't realize this. We take our effortless ability to walk for granted.

Most of us walk with our heads and eyes facing forward, watching what's ahead of us or looking at our surroundings. We don't find it necessary to look down and watch every step our feet make, and this is thanks to proprioception. Without it, we would have to rely very heavily on our vision, our gait would be unsteady and our sense of balance tenuous.¹⁸

When Meaghan walks, her head is always down, always looking at the ground. I used to keep telling her to: "Look up. Look where you are going." I didn't realize that she was, in fact, watching her legs and feet to make sure they were moving because she had no sense of this. And she couldn't tell me. Imagining how frustrated she must have felt (what she wished she could say to me!)

We assume that they are looking down because that is just a peculiarity of autism, or because their eyes are sensitive to the light, which is another factor in my daughter's case. But there is so much more to it that we just don't understand. And because we don't understand, we prod them to do things that they are actually physically incapable of doing.

Never make assumptions, because they will surprise you - all the time. When I asked Meg why she kept hesitating before she hit the keys on her iPad, she typed:

Because I can't feel my finger.

I was astounded. I had never, ever considered this. Because I was thinking with my neurotypical brain and it was not an option that was part of my reality.

If you can't feel your arms and hands, it is hard to become adept at many gross motor activities, never mind fine motor skills.

In Sensory Integration and the Child, Jean Ayres says, "If the proprioception from your hands were not sufficient to tell you what your hands were doing, it would be very difficult to button clothes, take something out of a pocket, screw a lid on a jar, or remember which way to turn on a water faucet. Without adequate proprioception from the trunk and legs, you would have a very hard time

getting in or out of an automobile, walking down steep stairs, or playing a sport.”
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Often times the problem is impulsivity. You want to do something, but your body does the exact opposite.

Picture the brain's sensory motor neurology like a garden hose. With most of us, the water power is moderated to just the right force and there is always a hand holding the hose and controlling the direction of the water flow. With the autistic brain, however, the sensory motor power is almost always on full force and most of the time there is no hand holding the hose steady, so it writhes about wildly and sprays all over the place. This is impulsivity.

Meg and others with autism can't do much to diminish their neuromuscular impulsivity, but they can, with time, come up with ways to grab hold of the hose for brief periods of time and aim it where they want it to go. Meaghan does this with her "word focus" that allows her thoughts to flow through the garden hose to her finger. But if she lets go of that focus - or something causes her to let go of it - her sensory motor hose will go wild again.

When I type my body still wants to be in control. I have to focus hard to continuously fight the impulse to hit the same key over and over again. The funny thing is, the part you doubt most about me, my facility with words, is the very least of my problems when it comes to typing. It is the visual motor part, not the mental part, that is the real challenge.

From talking to walking to the simplest things we do each day without thinking about them, proprioception is vital to our daily life. Without it, we can't feel our bodies in space. It is crucial to our sense of body ownership and forms the basis for distinguishing "self " from "non-self." Although we tend to take it for granted, **a feeling of body ownership is the foundation of our self-awareness.** 20

Lyova Zazetsky had to find this out the hard way. Only after he had his brain blown to bits was he able to truly appreciate all he had lost. Not just the ability to speak and to see properly, but a feeling of being connected and in control of his own body. However, he could still think and, with considerable effort, he could write. And it was this writing about his fragmented perception that gave purpose to the remaining years of his life.