


Inez De Florio

TO SEE OR NOT TO SEE



My  Recovery
from Blindness

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1 It is only with the heart that one can see rightly ... (Antoine de Saint-Exupéry)

Self-awareness is your awareness of the world, which you experience through the five senses (sound, touch, sight, taste, and smell). Pay attention to your sensory impressions and be aware of those five ways that the world comes to you.
Deepak Chopra

I hope readers will consider, especially in this age of the World Wide Web, that as miraculous as it is, we still need to be in the same room with all five senses if we are to empathize with each other.
Gloria Steinem

I don't remember the exact point in time because at the beginning I didn't attach much importance to this information. It must have been toward the end of the 1980s when Marco, my husband, mentioned various times that it was by then possible to correct even severe visual impairment through surgery. He had read that Russian surgeons had developed a treatment that enabled patients with complex vision problems and even blind people to see.

“And how do they reach that?”

“If I got it right”, replied Marco, “they extract the patient's own lenses with the help of particular devices and replace them by plastic lenses.”

My skepticism remained, even though the news should have given me a glimmer of hope. For outsiders, my rather hostile attitude is certainly difficult to comprehend, because I was severely visually impaired since birth. Long ago, I had reconciled myself to my blindness. Certainly, many things were awkward and time-consuming, and I was dependent on outside help, especially from Marco. But I was sufficiently compensated for this—at least in my view. My other senses, especially hearing and touch, were far more developed than with many people in possession of their sight.¹ And they still are: Even nowadays, when preparing a pizza, I don't limit myself to have a look through the window of the oven. I open it and orient myself to the smell and above all to the sizzle. I pay most attention to what I hear, that is to the heartbeat of the pizza.

The better development of the existing senses is due to the fact that parts of the brain that are actually designed for seeing take over other tasks in the neural network. Almost all persons born blind or those who went blind at an early age report this phenomenon which is confirmed by a steadily growing number of neurobiologists. For example, Beau Lotto describes the case of a blind boy who uses so-called echolocation to orient himself: He manages to identify individual surroundings and objects by clicking his tongue. Because of the echo, he knows where he is and what objects are in front of him.²

Until that time, I had not wished to be able to see. To put it clearly, I never gave it a thought. Many years later, I noticed on the basis of some inquiries that I was no excep-

tion. Most people who had been blind since birth and those who had lost their sight very early felt no shortage and were doing quite well in everyday life.³ As an example, the story of Saliya Kahawatte, a German whose father came from Senegal, may serve. In his novel *Mein Blind Date mit dem Leben* (*My Blind Date with Life*), which was turned into a movie in 2017, he tells in detail how he managed over years to hide his severe visual impairment, a retinal detachment, from his environment.⁴ For me it was easy to identify myself with his narratives, because I had developed similar behaviors. I avoided talking to outsiders—that is all those whom I had no regular contact with—about my vision problems. What for? Would they really have understood my particular difficulties? How might they have treated me after my confession? When he suffers a severe breakdown Kahawatte decides to deal overtly with his blindness. He is quite successful in arranging his private as well as his professional life. He writes that he is at peace with himself, reaches his goals and enjoys every day.⁵

A similar mindset requires will-power and perseverance. At various times well-intentioned caretakers tried to convince Saliya Kahawatte to work in the fabrication of brooms, the usual occupation of blind people. Even nowadays you can find ads on the internet that offer brushes and brooms handmade by blind people. Saliya resisted successfully. He traces similar advices back to the fact that sighted people very rarely are able to put themselves in the position of a blind person, mainly because they lack the necessary contacts.

As indicated above I can identify quite well with what he himself is telling. In his private life he keeps his vision problems even nowadays mostly to himself—for various reasons. The main reason is the insecurity most sighted people manifest when in contact with a blind person. When he says: ‘I’m visually impaired’ or ‘I’m almost blind’ they don’t know how to deal with his revelation. They react upset, full of compassion, with sadness or deeply embarrassed. They want to help, but show it in an awkward manner. Most of them are tensed up. He doesn’t want to blame them for their behavior; there are many reasons for it. It is caused by the fact that sighted and blind persons don’t have occasion to meet. They are separated since childhood; they frequent different schools, often even different nursery schools. He considers this as plain madness.⁶

Unfortunately, inclusive schooling of children who are visually impaired or suffer from an impairment of one of the other senses remains wishful thinking despite the UN Disability Rights Convention. Most schools lack the necessary preconditions or equipment. In consequence there are quite curious misjudgments of sighted people with regards to the blind. A blind blogger, a man at the beginning of his forties, tells about a memorable encounter in a subway-train in Munich.⁷ A younger woman gets seated in front of him and converses with him about his personal conditions. All at once, the lady asks him in the overcrowded train quite loud: “Tell me, please, do blind people have sex?” The other passengers seated or standing near them prick up their ears. The blind

blogger, acquainted to this type of questions, answers without reserve: “Sure, if you want to, we can try it out immediately.” No wonder that the woman does not reply, but leaves the train at the next stop.

In general, it is not astonishing that only very few people who were born blind or went blind in their early childhood consider surgery, even though quite difficult interventions have become more and more successful in the 21st century. Saliya Kahawatte, too, sees no necessity to take an operation into account. Following his feelings, an intervention would be nothing but stress. Perhaps the newly reached vision together with his extraordinarily developed touch, hearing and taste would give him the total insight. He finds this idea quite bizarre.⁸

Much further than Kahawatte goes Isaac Lidsky, the CEO of a great U.S. enterprise. At the beginning of a TED Talk, Lidsky exposes five assumptions about his person asking the public to reflect which ones are true and which ones are invented.⁹ The fourth assumption is: ‘I lost my sight caused by a rare, genetically motivated eye disease.’ As Lidsky shows no signs of blindness—he opens his blind person’s cane only later on—many of the participants are convinced that he could not be blind. Already this beginning of his talk proves the exceptional attitude of Lidsky toward his stroke of fate.

When he was diagnosed with a genetically caused eye disease for which no promising therapy existed, he was twelve years old. About ten years passed until he got totally

blind. That delay gave him time to reflect on what sight really means. For most people seeing is immediate and effortless. You open your eyes and you see the surrounding world. To see means to believe; it is equated with the truth or with reality. Many experts trace this back to the fact that the evolution has predestined us to give the priority to seeing. Encyclopedias of anatomy indicate that about 70 % of our ordinary perception is based on vision. That is right, of course, as long as you do not question these findings. Seeing is not everything. You can deduce this, as mentioned, from the fact that the brain of people born blind partly changes its functions. With me, too, parts of the neural network assumed functions which otherwise were reserved for eyesight.

Through the years, Lidsky stated that what we see is not the universal truth; it is not the objective reality. It corresponds instead to a unique and personal virtual reality constructed in an extraordinary way by our brain. From Lidsky's point of view, seeing is an illusion that was destructed by and by as his sight diminished. Everybody is creating his own reality. To confirm his convictions, he mentions Helen Keller, the deafblind American civil-rights activist. She writes that much worse than blindness is the lack of vision. By the way, the quote from *The Little Prince* of Saint-Exupéry chosen as title for this chapter continues as you know: What is essential is invisible to the eye.

There is no doubt that Lidsky is an exception. He does not consider the loss of his eyesight as a restriction; on the contrary, to him, his blindness constitutes a personal en-

richment. This attitude can be explained by the fact that his psychological immune system is extremely well developed.¹⁰ It protects an individual against the experience of negative emotions. Unconsciously, information gets ignored, transformed and reconstructed so that a disastrous event might seem more bearable for the person concerned. As visual feedback does not reach Lidsky, his environment, especially his staff members, are obliged to give him verbal feedback. His disability forces them to say what they think and to avoid ambiguity. He communicates with them on a deeper level, and above all: His team knows that their point of view really counts.

Considering the cases of Kahawatte and Lidsky which are representative for many other visually impaired people, you can state that surgery does only make sense when there is a psychological strain. The wish to gain sight, however, is not very strong with many persons born blind. Of course, there are also things that blind people would like to see. Mike May, who lost his eyesight in an accident as a child, missed nothing in his life as a blind man.¹¹ Nevertheless, he would have liked to see a landscape panorama and especially beautiful women with his own eyes. When he is successfully operated on in the middle of his life—it is a stem cell transplantation—, he has difficulties with facial recognition and perspective vision, which apparently still exist.¹² As we will see below, others have even more serious problems with their newly acquired sense of sight. In some cases, successful sur-