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A World With Color vs. A Prisoner in Your Body

"There is no greater disability in society than the inability to see a person as more," as Robert M. Hensel once said. Throughout history, people with disabilities have always been seen as inferior to those around them. They have been given less opportunities, been discriminated against, and most importantly, they have been seen as "abnormal." The film *Emmanuel's Gift* talked about how unfair Ghanaians with disabilities were treated. Most were beggars on the streets, didn't have jobs, were abandoned by their families, and discriminated against. This is not what anyone should have to deal with. ALS, a nervous system disease that affects motor neurons in the brain and spinal cord, and synesthesia, a condition in which you experience one sense through another, are two such disabilities that cause discrimination. While they are very different, they also have some similarities in general, in the ways they affect people, in the ways they impact people around them, and in treatments. Even though ALS and synesthesia have many differences, there are also similarities between them.

ALS and synesthesia generally have things in common and things that differ. To start with, both these disabilities involve the brain. According to the Mayo Clinic, ALS is a progressive nervous system disease that affects nerve cells in the brain and spinal cord. Similarly, synesthesia causes the brain to process data in more than one sense (Live Science). As a result, the patient experiences one sense through another. Another thing they have in common is they are both rare disabilities. For ALS, there are about 12,000 to 15,000 cases in the United States, says the Centers for Disease Control and Prevention (CDC). For synesthesia, it occurs in only about 1 in 2,000 people, as noted by the American Psychological Association. Lastly, these disabilities currently have no cure. Despite ALS and synesthesia being alike, there are major differences. For example, ALS is life threatening, while synesthesia is not. Unfortunately, the life expectancy for an ALS patient is three to five years. On the other hand, synesthesia does not harm a person's life span. Another difference between these two conditions is that ALS is progressive, which means it worsens over time, unlike synesthesia. These two disabilities are alike and different in general, as well as in the effects.

Even though it may not seem obvious, ALS and synesthesia have similar effects. First of all, they both make people feel lonely and isolated, aside from everyone else. In the book <u>A Mango Shaped Space</u> by Wendy Mass, the main character, Mia, has synesthesia. "I'm going to be so normal that when people look up normal in the dictionary, my name will be there," (Mass 54). This shows that she feels abnormal and different from everyone else because of her colors. ALS patients can also feel the same way because of how they look. Although ALS and synesthesia have similar mental effects, they have major differences. For example, ALS eventually takes away the abilities to move, eat, speak, and breathe, whereas synesthesia can harm one's ability to learn. This ties into the fact that ALS mostly impacts the person physically, while synesthesia impacts mentally. In addition, ALS can be painful. According to the ALS

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Association, "Weak muscles causing extra strain on muscles and joints, immobility causing unusual skin pressure, medical treatments causing discomfort, constipation, muscle cramps, tightness, or spasms can all be painful." On the contrary, synesthesia does not cause physical pain at all. There are not only similarities and differences in the effects, but also in how the disabilities influence people around patients.

ALS and synesthesia are alike and different in the ways they affect people around patients. To begin with, a similarity is that others view the patients as "different." In synesthesia, peers may find the condition very fascinating, but also weird and quite different, to the point where they sometimes don't believe the patient. For example, in A Mango-Shaped Space, a young boy named Billy also has synesthesia, but his mother doesn't believe him when he mentions that he sees colors. "...his mother turns around and rolls her eyes. 'Don't pay any attention,' she tells me. 'He has an overactive imagination." (Mass 37). For ALS, others also see them as different because of what they look like and what they can't do. Furthermore, both conditions require encouragement. Lucy Wedemeyer's husband, Charlie Wedemeyer, passed away in 2010 from ALS. Wedemeyer said in her interview that Charlie often needed to be encouraged, because he sometimes lost hope of living his life. Even though there are similarities between ALS and synesthesia, there are various differences. For instance, ALS patients need caregivers to take care of their basic needs, while synesthetes are relatively independent. An ALS patient's family often experiences emotional problems, stress, anxiety, or depression. On the other hand, a synesthete's family usually doesn't

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go through these things. While there are similarities in differences in effects on others, there are also some in treatments.

There are a couple similarities and differences in treatments for both these conditions. The only similarity is that both ALS and synesthesia have no cure. Despite both being incurable, there are a few treatments for ALS. According to Mayo Clinic, a drug called riluzole has been shown to increase life expectancy by 3 to 6 months. Another drug that is given to ALS patients, edaravone, is known to reduce the decline in daily functioning. To help the patients physically, there is breathing care that provides ventilators and devices to address breathing problems, physical therapy to help the body's functioning, and occupational therapy which helps a patient do things despite hand and arm weakness. In the film *Breadth of Hope*, one of the ALS patients shown, Carolyn Shimek, always had a ventilator with her to aid in breathing. She had to rely on it at all times. Other therapies include speech therapy to assist in making speech more understandable and nutritional support to help with eating. In spite of there being so many treatments for ALS, there aren't any things that can effectively help synesthesia.

Even though ALS and synesthesia have many differences, there are also similarities between them. They are alike and different in general, in the ways they affect people, impact people around them, and through treatments. As author Nikki Rowe once said, "There's a remarkable amount of strength residing in those who move forward without being able to physically move. Ones that carry the weight of illness or a disability, they battle wars most know nothing about. They are the true warriors of the world, the ones who have every reason to quit but never do."

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