



The Lady from Down Under : by Pam Cole

Kim is a lady from Down Under, and I want to share her story. She has Rett Syndrome, which is considered an Autism Spectrum Disorder in the DSM-IV. I came into contact with her family from the Deal Communication Center's website, deal.org.au, while researching communication and disability. She and her mother Jill have been kind enough to allow me to interview them on the topic of Rett Syndrome and how it affects Kim's life. So, here she is!

Riding the surf in a blow-up boat, exploring unusual places, horse-back riding, hot-air-ballooning, going out with friends for some coffee, or staying in with a good read... Sounds like a list of activities of someone with quite a sense of adventure. It is, actually, and this person is Kim. She has Rett Syndrome, a condition which didn't stop her from going airborne in a helicopter for her fortieth birthday. Rett Syndrome is a developmental condition that affects oneself pervasively and inhibits intended movement, including speech and mobility. It often renders the hands next to useless. Sometimes it causes breathing irregularities, namely hyperventilation with apneas.

So, what's it like to have Rett's? Kim answers: "I feel that love has lessened (the) damning effects of Rett Syndrome. I feel my terror mostly at night. I feel sad that I do not live with my husband in my own city apartment with expansive views." She also needs around-the-clock care, as well as help with activities of daily living, such as feeding, dressing, and walking. While irregular breathing may cause anxiety in some, Kim says that it helps her to "gain control."

Rett Syndrome also affects sensory processing, the way we collect and process information about "the world." Jill explains, "Kim doesn't have touch perception over most of her body – just head, hands, toes, and a few joints. She feels pain and temperature, and is very sensitive to both, but not much to touch." Also, Kim needs to be seated no more than several feet away from the television – or else her visual perception breaks into "bits." In order to see the whole picture, she has to be close. She enjoys concerts, live shows and films, but needs to sit close to her TV set for her view of the screen to be unified – beyond a couple of meters she sees the scene "in bits".



Her sensory issues also influence her taste. Kim writes, “I feel lulled by dominant melody and strong rhythm. I love quivering drumming music – lively and energetic, but not too loud.” Jill adds that baroque is one of Kim’s favorite musical styles. At home, they greatly enjoy listening to classical, because “pop...is so pervasive.” Also, “Kim loves to dance to lively music – we hold her, and she rocks from foot to foot.”

Kim communicates with a head-pointer attached to a small keyboard, which is linked to her laptop, because she is nonverbal. The program she uses has a word-prediction program to ease typing. In the past, she used to need Jill to hold her head a bit to type. Now, though, Jill makes contact with her back for some sensory input. When she is not near her laptop, she uses her Cannon Communicator, which prints out slips of paper with typed words. When speech is expected, she has her Lightwriter, which holds phrases and speaks typed words aloud.

Kim’s education is a major aspect of her life. She taught herself to read as a child by watching Sesame Street and through interactions with her family. When her family contacted Dr. Rosemary Crossley, at the DEAL Communication Center, in Australia, it was discovered that Kim was not “profoundly mentally retarded,” but already understood the intricacies of the written English language. At age 22, Kim became communicative. She went on to earn her Victorian Certificates in English, History of Revolutions – French and Russian, Australian History, and Psychology. She completed her 11th grade math exam without facilitation and earned a score of 82%. Math is one of her favorite subjects, but she couldn’t continue due to not being able to use the required programmable calculator because of its small buttons and screen. She chose to study the arts at university for this reason.

Kim’s interest in politics has refined into a desire to help those with Rett Syndrome. Like a true leader, Kim leads by example. She decided to get her degree for herself and to show people with Rett’s that they can advance their education. Kim was the first person

with Rett Syndrome to be considered to have intelligence via Rettnet, a world-wide email network for families with a person with Retts. This was groundbreaking, because before then and even now, Retts has been associated with intellectual disability. In her own words, “Justice means nobody gets left behind and I try to help those I can.” She also wants to encourage Rett Syndrome people and their parents by her example to gain an education. As she said “I once toyed with the idea of writing a book, but then thought getting a degree better,” because a book could be discarded and forgotten about, but her education records are permanent. However, they did write that book and are currently looking into getting it published.

Currently, she is attending a day program and lives in a residency for severely disabled adults. What she wants to share with the community is this: “Talk with the people. Just because they don’t answer, doesn’t mean they don’t understand.” Certainly, this is poignant, as many people are afflicted with communication impairments. As is often the case with people who have trouble communicating, they can perceive a lot better than they can express, so it is always good to talk to people. Certainly, the ability to communicate does not equate intelligence.

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