

## **Breaking Sound Barriers:**

### **The Invisible Struggle by Jayelan Lee**

**Zoe:** The first voice you will hear is Jayelan Lee, the writer and sound designer of this podcast. Jayelan usually uses a letterboard to spell out his words. He's chosen a surrogate voice in Matthew Perrett to speak his written words later in this piece. Sit back and we hope you enjoy the invisible struggle.

**Jayelan:** My name is Jayelan Lee. I am an Autism advocate.

**Lou:** Hi, my name is Lou and my connection with Jayelan is through his education at Leeming Senior High School Education Support Centre. As a transition and pathways coordinator, I worked extensively with Jayelan and his family to support his aspirations to be an autism advocate, and to challenge his incredible mind with purposeful programs. If I only had three words to describe Jayelan, they would be inspirational, thought-provoking but more importantly, real. He laughs, giggles, dances and embraces life in a fabulous refreshing new way.

What most people do not know is that Jayelan has severe Ideomotor body apraxia. According to Brain Medical Journal, the type of apraxia Jayelan has is ideomotor apraxia. This is when patients cannot convert the neutral representation of an idea or goal into a precise pattern of motor activity, and so make errors on the scaling, timing and orientation of movements.

In other words, Jayelan's thoughts do not connect easily to his actions, although he is willing and able and the muscles to perform the task work correctly. They just don't communicate in harmony or as one. It is like a bad phone connection.

**Aemy:** I'm Jayelan's mum. I have no idea my son Jayelan had body apraxia from birth. I always thought he had cognitive impairment until he

communicated on a letterboard at the age of 11. He had mortal difficulties which were affecting every aspect of his daily life.

**Jayelan (Matt's voiceover):**

Sometimes I go upstairs to grab a towel but I grab a pair of socks.

**Jayelan:** It is frustrating.

**Jayelan (Matt's voiceover):**

Sometimes when I feel hot, I put on a jumper and when I feel cold, I take my clothes off.

I was seven years old. My brother Buddy arrived in this world and joined the Lee family. I was very excited about having a sibling. Buddy was a sweet-looking baby with a round face and amazing big eyes.

One sunny morning, I was helping mum to bring in a load of clean washing. I offloaded the first batch of fresh-smelling laundry onto the blue sofa as instructed by mum. I went out again to get the rest of the clothes and brought them into the house.

Mum was busy hanging the newly-washed clothes on the line, so I proceeded into the house and tipped the huge pile of clothes onto the brown sofa. If only my baby brother, who was merely two months old, wasn't under the huge pile of clothing.

I saw him sleeping soundly on the corner of the sofa, yet my body decided that that was a good spot to put the clothes. I was scared. I'm not able to deal with it. Was Buddy breathing? Was he dead? What have I done?

I panicked. My body froze. I was hoping Mum saw what happened, but she's still outside. My blood ran cold. I heard the laundry door sliding open. Mum came in, Buddy was crying, but in a muffled cry as he was under this gigantic clothes pile.

I saw Mum tuning into the sound with a puzzled look on her face. She followed and traced the sound which led her to the brown sofa, and then she frantically removed the clothes and a bright red baby appeared.

Buddy was crying at the top of his lungs now. Mum screamed hysterically. She was obviously shaken by the whole terrifying experience. I was relieved I didn't end up harming Buddy, but it was definitely a narrow escape.

Honestly, I don't know how I would have coped if something serious did happen.

**Aemy:** It is important that people know what is body apraxia, as it is quite common among non-verbal individuals with autism. Carers, families and practitioners may not be aware of this due to the individual's communication barriers.

Body apraxia can easily deceive a person in thinking the individual is cognitively impaired, which may not be the case at all. We hope that by creating awareness of ideomotor body apraxia, more research will be done in this area.

It's important that everyone presumes competency when working with people with disability in order to help them to achieve their true potential.

**Lou:** Jayelan, using your letterboard, can you please tell others how they can support you better?

**Jayelan (Matt's voiceover):**

I am spelling out B-E P-A-T-I-E-N-T. Right, be patient. D-O N-O-T U-N-D-E-R-E-S-T-I-M-A-T-E T-H-E I-N-D-I-V-I-D-U-A-L. Do not underestimate the individual with disability.

**Lou:** Jayelan, what advice would you give someone listening who may have body apraxia and does not have people around them like you?

**Jayelan (Matt's voiceover):**

P-E-R-S-E-V-E-R-E-P-E-R-S-E-V-E-R-E

**Zoe:** This podcast was written and produced by Jayelan Lee, edited by Zoe Warwick, music by Lilo Sound with thanks to Aemy Chan, Louisa Franceschini-Piil. And if you or anyone you might know would like to connect with other people with lived experience of ideomotor body

apraxia, then go to Side by Side or Kiind Families, that's with two I's, both on Facebook.