

Adjudicator's Comments. This is a sensitive imagining of what it might be like for an adolescent to be living with a terminal illness. The writer skilfully evokes Zero's (the protagonist's) sense of isolation and otherness, along with the guilt of feeling themselves to be a burden on carers. The register of the language suits the thinking of an insightful adolescent – at once fairly informal and well-articulated.

That is not to say that the writing is without faults that would need to be addressed if it were to be published. For example, at one point we are told that the disease has left Zero unable to move or speak, but later we are told that they inject themselves and tell their aunt that they love her. More careful proof-reading would pick these and some punctuation issues up.

Overall, though, this is a courageous and well-written piece.

The Distant Light

On my first day of primary school, the teachers noticed I was a bit slower than the rest of the kids around me. Not just in intelligence, but in movement, speech, and even eating. It was also written in my report that I, "preferred to play alone" and, "showed annoyance to my peers." Once my aunt had read that, she decided to take me to a doctor.

I remember walking into that waiting room, which was just the first of many to come. Sick children surrounded me, coughing, crying, begging to get help. You could hear the shushing of worried mothers and fathers, and the doctors calling out names every so often. The first call was Thomas, then it was Elizabeth, and after what felt like a decade to little five-year-old me, my name was called. My aunt picked me up and took me to a brightly colored room.

I was grateful for the quietness of this room (unlike the waiting room). Although I was not so grateful for the bright colors. There was a play mat laid across the floor. The ones that were covered in roads so you could drive toy cars on them. On top of the playmat, was a small, round table. The table held a couple of small stacks of paper, and a tub filled with toys. Around the table, were two big chairs and a little chair, presumably for me. In the corner of the room were some more small chairs, with a packet of anti-bacterial wipes on top. The walls were covered in colorful shapes. It was all a bit too much.

The doctor told us to take a seat. My aunt sat me down in the little chair and sat herself down in the big chair next to me. I remember looking at her, and wondering what she was feeling. Maybe she was thinking about me. Even though I was just a five-year-old, I understood why I was there. It was easy to tell I was different from the rest of my class. Maybe even the rest of the world. The doctor took a seat opposite me. "Hey, Zero, I am Doctor Zachery, but you can call me Doc. Zach if you'd like." He gave me a warm smile, then turned to my aunt. "I am Andrea, thank you so much for seeing us, I'm just so worried about him" My aunt sounded a bit shaky. After she had said that Doc. Zach

started to ask her questions. First it was about when I was born, then he went onto questions about my early development.

I don't remember the rest. Except for up until Doc. Zach asked if I'd like to play with some toys he'd brought for me. I nodded my head and picked up some bricks from the tub. As I was playing, every so often Doc. Zach would ask me questions. "Do you like going to school?" and "Do you have many friends?" Most were about my social life, until he asked my aunt to step out of the room. Then the questions shifted to being about my her. "Do you get on well with your auntie, Zero?" or "Does your auntie ever do things you don't like?" I told him that I loved her, and that sometimes she makes me eat vegetables which would make me upset, but I knew that I had to eat them anyway. I could feel Doc. Zach's eyes on me the entire time. I decided then that I didn't like him.

Once that appointment was over with, my aunt sat me down and told me we were going to have a 'serious talk'. I didn't like the sound of it, but I sat anyway. She told me about how I would be taken out of school for a while and would have to go back to the hospital more than I would have wanted. I wanted to ask her why, but I could see the tears forming in her eyes. Instead, I let her take me upstairs and put me to bed.

Then came the next appointment, this time I didn't have to wait in the waiting room for as long as last time. Instead, it was about five minutes before I was called in. They took me to this room with a massive machine in it. I remember the doctors telling me I was very special, and that little kids like me didn't usually get to go in the machine. They also told me that I might find it a bit scary, but all I would have to do is sit still and listen to them through my headphones. It wasn't as if I could move much anyway.

After the scan, it was about four days later until we got the results. The next day, I had to go to hospital again. I was told that my brain was slowly shutting down, and that they would need another scan to see what they could do to help. Also on that day, we moved in with my uncle, probably since my aunt was struggling to cope with a dying child on her own. I felt bad, guilty even. I didn't want to watch my aunt be sad because of me.

A few months later, after many trips to the hospital and definitely many waiting rooms, I was diagnosed with Huntington's Disease (HD). That's when I learnt I wasn't going to live as long as everybody else was. That's when I learnt that in my final years, I would be stuck at hospital while everyone else was enjoying their teenage years. I didn't find it very fair. I cried a lot to my aunt and uncle after my diagnosis. I told them I wanted to be normal, and I can't imagine how that must've made them feel. I know I would be devastated if a child came up to me and said that.

Now I'm fourteen years old and was admitted to a home for ill children after my uncle passed away and my aunt realized it was too difficult to maintain a home as well as take care of me. My aunt works at the home, she's my personal nurse. I don't really know

what I would do without her. The home isn't so bad, even if it was bad, I would just have to get used to it because it isn't like I have anywhere else to go.

Since joining the home, I was put on extra medication as I wouldn't have doctors monitoring me twenty-four seven. I'm not sure if it's the medication, or if it's just adjusting to a new environment, but lately I've been having weird dreams. I'm in a dark room, with just one distant light. Walking to it feels like walking to my death. At this point in life, I wouldn't really mind that.

Huntington's Disease has made me unable to move or speak. I can barely swallow. I eat through a tube. It's embarrassing. Knowing everyone in the home only sees you as this damaged human, instead of the healthy human you could have been. Sometimes I wish my ability to think went first. At least then I wouldn't have to acknowledge what's happening to me. "Come on, Zero. It's time for bed." my aunt spoke softly and stroked my forehead. Then, she tucked me in and went to the bathroom.

I was back in that dark room, with that small light in the distance. I'd read about lucid dreaming the day before. I don't think that was what was happening. There were bits of the dream I could control and bits I couldn't. I could also hear my aunt turn the bathroom light off. Was I dreaming? Can you usually hear things from the real world in a dream? Is it the new pills' effect? Or is it this disease getting to my head even more? I started to walk towards the distant light, until I could feel something shaking me. I slowly opened my eyes. My aunt was trying to get me to wake up.

"Zero. Zero! You forgot your night meds, here." She passed me a syringe. She knew I hated it when she did it. I just knew it would make her more upset. I injected myself with my dose of night medication. It only stung a little. My aunt took the syringe off me afterwards and tucked me back in. "I love you" I told her.

The light was even further. Maybe I should have told my aunt about my dreams. Was this what dying was like? If so, maybe I should walk toward the light. It would end my suffering as well as my aunts. She wouldn't have to deal with a sick kid anymore. I sat there staring at the light for a little while. I felt someone holding my hand in the real world. I wanted it to end. I walked toward the distant light.