Monsters at the Window: Cure Brings Terror for a Child

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I was diagnosed as deaf when I was 5 years old. The family legend holds that I was born deaf but had taught myself to lip read. More probably I had conductive deafness from the recurrent ear infections that were part of childhood in 1950s Scotland. I remember the illnesses, nightly almond oil ear drops, and the pink, foul-tasting medicine that was dosed for every infection! I also recall trouble over not paying attention or not coming when called. Conversely, I developed the reputation of being studious and focused, especially on reading.

Once the condition was discovered, the adults became awkward and serious. I was very aware of the double standard of effusive reassurances that things were fine in the face of mounting evidence that I had done something terribly wrong. My father and our family doctor were jovial; my mother and others were overwhelmingly sad. Everyone talked about the big event that would make my life wonderful. I was not sure how or why things would change. Life seemed pretty good already. This big event appeared inevitable, and the adults were unanimously convinced that I would be gloriously and joyfully improved by it. I was repeatedly told how lucky I was to have the opportunity to be “cured.”

I shamelessly loved the assessment process. Hospitals were wonderful places, full of people who treated me as someone very special. My favorite was the elderly audiology technician. He made a great fuss of finding pillows so I could reach the testing equipment and of adjusting the cumbersome earphones to fit my tiny head. He told me I was a secret agent radio operator who had to push the button when I heard the signal. For a child with a fertile imagination in post-war Britain, this was heaven! He sat expressionless behind the glass at his machine, and I squirmed at my table waiting for “signals.” Only my mother’s face revealed that all was not well. She stood behind the technician. Her expression and involuntary movements conveyed that I was missing signals. I started to push the button whenever she reacted. As the situation deteriorated, I pushed the button randomly with mounting anxiety to please. The technician quietly asked “Are you sure?” Then I was ashamed. The journey home was solemn. The discussion with my father that night inevitably ended in tears. I had failed terribly and was hurting everyone. I had no idea what was going on.

The surgery seemed like a great adventure as well as the opportunity to take away whatever was upsetting everyone. I was supposed to be apprehensive or play the brave victim but I couldn’t wait for the surgery—my suitcase was packed for weeks beforehand.

The details of admission are fuzzy, but I recall the anesthetist telling me to count to 10 as he put the mask over my face. My dreams were vivid and frightening, full of monsters that grabbed my throat and made me bleed and choke. I woke suddenly in the pre-dawn. About 20 children slept in cots and beds down each side of the ward. The long windows were outlined in pale grey light. A nurse wrote in a pool of light at a table in the center of the ward. Everyone in this peaceful scene seemed oblivious to the horrendous noises from the other side of the windows! I was a very sensible child who knew monsters did not exist, but the blood-curdling cacophony was positive evidence that monsters would break through the windows at any moment and devour the helpless sleeping children. My throat was too dry and sore to call a warning. A wave of terror overpowered me. I must have screamed because the nurse came quickly. To my horror, her voice was guttural and coarse. She made sounds I could not recognize—they were ugly and hurt my ears. She was a monster disguised as a nurse! I fainted in terror.

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When I awoke, the ward was bustling with everyday activity. The nurses acted kindly, but they all made noises like monsters so I kept very quiet. The other children did not seem alarmed. The noise was ugly, painful, and overwhelming. I tried to shut it out with pillows. This new world was not as promised. I needed my parents to take me home. They looked happy and relieved, but their voices were also loud, coarse, and guttural. I “knew” how they spoke—I had lived with them all my life. The “speech” I “knew” was sweet and gentle. I had to learn to live in the ugly speech world and keep my world of “sweet speech” secret. Even with my parents, I had to watch lips to understand. They were thrilled that I could hear, that I was “normal.” I did not want to disappoint them by sharing how uncomfortable, frightening, and exhausting I found the hearing world. I went along with the general consensus that all was wonderful and that I was grateful for my “cure.”

Of course I have adjusted to the noisy world. I still can’t bear loud sounds and continue to lip read. I am told I speak too softly. I have learned to enjoy (most) music and the dawn chorus of birdsong no longer sounds like monsters screeching at the window. Above all, I have learned to discuss with patients that the benefits of treatment may not be as anticipated and may only be realized after a transition period. In particular, patients considering cochlear implants can relate to the sometimes cruel surprise that transitioning to a hearing world can be difficult whereas everyone in the environment is convinced the experience must be wonderful. I have become attuned to the comment from any patient, “I know I should be grateful but . . .”. It is always a great opportunity to relieve distress. The outcomes of every treatment depend on the patient’s perspective, and we should not assume all is wonderful even if the medical/technical results are perfect.

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