The last week in August is National Deaf Awareness week. Deafness is probably one of the most neglected disabilities, society’s attitudes to the deaf handicapping those who suffer this affliction. My father-in-law has become very deaf over the 21 years I have known him. It has changed him from a sociable person who used to participate actively in conversation at parties, to someone who has become increasingly isolated, not only at large, noisy events, but in day-to-day conversation in the household. My own father is becoming increasingly deaf, but as he never listens to what people are saying it probably doesn’t worry him all that much! But, having said that, it is unlikely not to concern him — he just has a different way of dealing with it. How do we, and yes, let’s make it personal, deal with anyone who is deaf? I remember trying to explain to a profoundly deaf person who was taking money for the car park managed by the Society for the Deaf in Claremont, Cape Town that I needed change and would pay later when I came back. I realised that the man could not hear anything I said, but I spoke more and more loudly, gesticulating wildly. Eventually we both burst out laughing. He still smiled at me when I came back later and paid for my parking — no doubt used to the idiotic posturings of those challenged in other ways.

I suspect that few people have much contact with people who are profoundly deaf. A really excellent essay in The Lancet eloquently describes the experiences of Amanda Kvalsvig, a doctor, who has been deaf for about 15 years. What is particularly important about this essay is the way in which she extends people’s perceptions about deafness to disabilities in general. She says she has heard all the deafness jokes and made a few herself. She also describes ‘... those reassuring little phrases’, such as ‘well, at least you’re not blind’. She says that there may well be a sensible response to this, but so far it has eluded her. The most important lesson her own disability has taught her is that she really has no idea what life is like for her patients — something that we could all do with learning. Whenever she meets a disabled person, she has to keep reminding herself that she must not try to guess what their difficulties and concerns will be. As she says, ‘ask the elephant’. Unfortunately, Kvalsvig points out, this is not always possible in medicine. But, she says, many of us don’t know when to stop speculating and just ask. Does this all sound familiar?

I have a friend, Andrew, who is a psychiatrist and has become deaf. Unfortunately he is in New Zealand, so I have not gained as much insight from his approach to his disability as I may have done. But I know that he now works part time. Kvalsvig also says that she knew that her days as a clinician were numbered and assumed that there would be a well-defined moment when she decided to stop. Apparently the reality was rather different, as I suspect it is for Andrew as well. She describes simple exhaustion as the main reason for stopping clinical work. Hearing aids and lip reading do not help as much as those of us who can hear well assume, although hearing aids are useful for certain types of deafness. In others, all they do is magnify a disorganised mess of noise. Lip reading is extremely tiring, as only a small fraction of the vowels and consonants can be seen by watching someone’s mouth. The rest is done by following the cadence of speech and facial expressions — Kvalsvig describes it like solving crossword puzzles very fast. The ‘currency of disability’, to Kvalsvig, is effort and frustration.

However, she also points out that deafness is not always the same phenomenon. She is not very deaf when reading a book, but she feels ’...pretty deaf’ when she holds her violin. The lesson to take home from the experience of someone who is able to describe her life as a deaf person so effectively, is that there is no abstract experience of deafness, or any other disability. Every disabled person has their own unique experience of their own disability — listen to them.

(I would love everyone to read ‘Ask the elephant’ by Amanda Kvalsvig. You can find it by searching the text on www.thelancet.com if you are a registered user. Or please e-mail me and I will send you a copy electronically.)


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