

Carer's Perspective on the Review Process

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Meet Oliver aka Pudsey Bear or cyborg. (We find humour a vital necessity in our house!) This is after his most recent surgery for his bone-anchored hearing aids. He wears two. Oliver is now 22 years old, he has Asperger's Syndrome and for the last 8 years has attended hospital, at times monthly, since he lost his hearing to a cholesteatoma (well, two eventually) and developed chronic ear disease.



It probably shouldn't have happened – not because of any omission on anyone's part, but because until he collapsed at the age of 14 and was taken into hospital, I did not know that he had no vocabulary for pain, and quite possibly no concept of it either. He had never once complained. On the next morning, I arrived on the children's ward to be met with a cheery, "He's doing fine – hasn't even needed pain meds." I was thrilled that he could have improved so much

overnight and I approached him with a big smile. It fell instantly when I saw his face. It was so obvious that he was far from fine. A few questions later I got out of him that he hadn't been to the toilet all day. Why? "Because my feet make a thump, thump into my head." He was in so much pain he hadn't even been for a wee. The nurse was apologetic, "I asked him how he was and he said he was fine." Of course he did, he has AS: it's a learned polite response to what is usually no more than a common courtesy. It turned out that the disease had eaten back through the mastoid and was heading towards his brain. They told me two weeks longer and I might have lost him. No pain?

From that moment Oliver's physical well-being became a whole other responsibility. I already had to prompt him to eat and drink, but now I had to find ways to teach him pain, giving him every possible clue to recognise things that feel bad, and every possible word to use to do so. While working this out, I had to become finely attuned to other signs – the far-away look, the grumps, the shadow under his eyes – that indicate that he is not 100%. The whole picture doesn't just come in words, and reminds me of Mrs Wakefield talking

of the state of Tom's scalp as his 'silent testimony'. The day my son finally said a) I'm thirsty and b) my ear is gummy was a happy day indeed.

The next job I had to do was to communicate this to the hospital staff. So I wrote a list: ways to ask questions to elicit clear responses, words to use and words not to use. This hand-written note stayed on the front of his file for years. I suppose it was our personal forerunner of the hospital 'passport'. And I continued to act as translator between Oliver and his consultant until they fully understood one another.

Now, all of this was necessary for an intelligent, eloquent boy to get the right level of care and communication. When I think of how much harder it must be for people with complex needs, severe communication difficulties, sick and frightened in a hospital –well, I could just cry. So the opportunity to take part in this review process felt more like a civic duty- to speak for the rest of the mums and dads and other carers and our children, especially for those who can't speak for themselves. I'm no saint. I don't come with a halo. But I do come with a brain, an education, a brass neck and a big mouth. And if I'm struggling to be heard –what about everyone else? Best put it to good use, then!

So, to the experience of the Review process itself. What could I contribute? Well, in the first meeting at my first hospital surrounded by CEOs and Executives and Operations Managers, I was worried that the answer was 'not a lot'. There was a lot of medical jargon and acronyms that most people in the room were so used to they didn't think to explain. And on one level, that's fair enough. It's their (your) career and education. Of course you know things I don't – that's why I go to medics for medical advice. But on another level, that was already a demonstration of what role I needed to play: a reminder that the people at the centre of these reviews probably don't understand you either and that one of the key issues was/is communication.

The next thing I learned was, not being in the profession, I didn't have to worry about my own reputation or practice, so I was free to ask whatever questions I wanted. I was able to cut through the strategic, political or economic debates and get to the heart of questioning what was actually happening on the wards. I wasn't prepared to accept references to policies or pages in a handbook. I was able to keep it real and push for examples of practises at work. E.G. When we were talking to one anaesthetist about reasonable adjustments, he had some excellent examples ready to share. But to make sure he was really

thinking outside the box, I offered my son as another case to see if he could suggest suitable adjustments that would serve him. (I'm pleased to say he did!)

Obviously when it came to discussing the carers' role in a hospital visit, I had much experience to draw on – mine and that of other carers I have known over the years. It was good to feel that this learning could be put to important use. And again, it put me in a position where I could justifiably ask awkward questions. I would like to emphasise at this point that I didn't do the reviews to have a go at medical staff, or to air personal grievances (because I don't have many). What I mean by awkward questions is, having no axe to grind; I could be completely transparent and not get bogged down in practice comparisons. I was able to remind staff of the carers' expertise and how hard we work to support the hospitals to best care for our children and adults.

I felt that most staff spoke freely on the ward visits, when we weren't sat around tables in meeting rooms. Personally, I would have liked more of that.

My personal gain from taking part was learning the term 'reasonable adjustments'. The positive point about jargon is knowing when it's beneficial to use it! I feel empowered through my learning on the reviews, both from better understanding of hospitals generally, and knowing more of my entitlements in order to support my son. I was particularly happy to encounter hospitals that talked of their 'partnership' with carers, and would very much like to see more of this. One of the clearest lessons was from a children's ward we happened to visit, though it wasn't strictly on our brief. The doctor there talked about how they treat each child as an individual, because they are young and at different stages of their development, and they all react differently. Also, varying ages means varying grasps of language so all staff take great pains to communicate effectively with the patients and to use a variety of ways of eliciting information about how the child is feeling. All of this is considered 'normal practice'. It seems to me that much of this is lost when it comes to treating adults. The dynamic changes. But, in the case of our people with LD, maybe it shouldn't.

As a parent/carer I want to remind you that you came into this profession because you wanted to make people well, to help them and because you care about them. So do we. And we want to help you to do it. We hope that the findings from the reviews can help make that central again. Because at the end of the day, that 22yr old, 5'8" man is still my baby and I need to know he is safe in your hands.