

Parent's experience of attending the Royal Manchester Children's Hospital with their child who has autism.

Autism, a lifelong developmental disability, affects the way a child/young person communicates and relates to people around them. Within the Royal Manchester Children's Hospital there was an increased awareness of the specific needs of this particular group of children and young people; who often become stressed, agitated or distressed by changes to their routine or when faced with unfamiliar surroundings such as a visit to hospital.

This led to a hospital wide service improvement group being formed which aimed to address these issues. To do this staff:

- Listened to families' views of our services.
- Adapted the patient journey to meet individual needs.
- Held training sessions awareness for staff.
- Improved communication.

This is a parent's view of the improved service.

The only thing more frightening than having an ill child is having a child who isn't able to tell you what is wrong with them. This was my son three years ago when he was four years of age and he started to suffer from tonsillitis. But unlike most children, Marley has autism and communication problems. We only knew Marley was poorly when he took himself to bed and lay down burning a temperature of 40°C. Often he would refuse to take Calpol leaving me with little choice than to seek medical advice. This resulted in eight hospital admissions in a two year period. Each time was terrifying for me as Marley's main carer as I knew he was unwell but he couldn't communicate what was wrong. The only signs we could see were that he was lethargic and had a temperature.

Repeated episodes of tonsillitis had a knock on affect on Marley's school attendance, my job and made caring for him a lot more stressful. We often found our local hospital very stressful as they had little specialist knowledge of children with autism and little communication. The environment was stressful for him and difficult for him to understand as he was out of his normal routine. It made caring for him even more exhausting!

When a health professional mentioned that he needed to have his tonsils removed we were initially pleased but worried about how we were going to get him through an operation. I was extremely nervous about how Marley would

react to having the operation and whether the nurses and doctors would know anything at all about autism.

Marley's nurse consultant mentioned a specialised project at the Royal Manchester Children's Hospital where they were implementing a process to help children with autism who attended the hospital. I thought it was at least worth a go.

We initially saw an Ear, Nose and Throat (ENT) consultant who explained the procedure and we were given a form to fill in about Marley's likes and dislikes and mannerisms. I was really impressed with the nature of the questionnaire and the depth of the questions they asked. It made me feel a little more at ease.

The day of the operation dawned and although I had prepared with military precision to inform Marley as much as possible about the operation, I still felt sick in my stomach. There were lots of ifs and buts that were going through my mind about how I would handle different situations which arose, but mainly how the staff would interpret my son's behaviour.

I knew Marley still did not understand what was going to happen, even though we had talked things through lots of times. We had pictures of the ward and staff which had been sent to me by the hospital play services which helped me explain to Marley what different staff did.

When we checked into the hospital I knew we only had a limited window of time during which Marley would be compliant before he would want to go home or experience stress because he could not eat or drink anything.

We spoke to the doctors and the anaesthetists when they came to see Marley on the ward before he went to theatre and I was relieved that they had experience and knowledge of autism and understood why Marley was likely to be distressed by the unusual surroundings and the operation as these were outside his normal routines.

Unlike most other children, Marley did not have to wear a theatre gown as this was not seen as an essential part of the operation. It helped me and Marley as he was able to watch his favourite Ben Ten DVD on his portable DVD player whilst being anaesthetised. These concessions to Marley's autism meant that he did not go into the operating theatre upset and more confused than he already was. Although Marley was five years old at the time of the operation, consideration was given as in reality had a mental age of a two to three year old child. This was refreshing and a blessing for me as I did not have to keep explaining this.

That night Marley slept off the effects of the anaesthetic on a quiet ward which meant that we both got some sleep. In the morning Marley was discharged early at 7.00 am which meant he was able to get back into familiar surroundings at home so that he was back into his normal routine as soon as

possible. I was able to go and collect his antibiotics later that day from the hospital whilst he was resting.

Even though the staff said they did nothing, not having to explain over and over again to the doctors and nurses that my son had autism and what this meant for him, played an important part in ensuring his hospital experience was successful. In Marley's mind he did not have any negative experiences due to his autism which for him means that accessing medical services in the future will not be as daunting and frightening for him.

Most people will not think that accessing medical services for disabled children is stressful, but for a child with complex needs, autism, learning difficulties and speech problems the whole experience for both the child and their carers can be daunting and frightening when doctors and nurses do not have the knowledge and understanding of autism.

Signed Mrs S Servio 29/3/2011

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