

Parental Feedback on Cystostomy Button - Printable version

Our little girl was diagnosed with Urinary reflux grade 3 when she was only 6 months old. Ever since she has had recurrent UTI's and has been in and out of hospital with repeat infections. She has dilation to her right Ureter and some scarring on her Kidney as a result of the infections. Our daughter who is now 5 years old eventually became multi resistant to oral antibiotics and therefore was hospitalised for IV antibiotics each time she had an infection. With age her infections got some what better but the infection was always present because it was quite evident from the smell of her Urine.

Not so long ago it became evident that she also had an enlarged bladder and was not emptying her bladder completely when urinating. The remaining urine inside her bladder was clearly a major contributor to her recurrent UTI's. In addition to a UTI our daughter also had problems with continence and had recurrent problems with leaking which was because she was unable to empty her bladder. After debating on which antibiotics to use with our paediatric consultant because of her multi resistance, we were advised to look at surgical intervention as remedy.

We spoke to Mr Subramanian who suggested we think about having a 'Cystostomy Button' placed into her bladder, which would allow us to empty her bladder of any remaining urine. We decided to go ahead with the procedure and earlier this year our daughter had a cystostomy button placed into her bladder. The operation it self was quite straight forward lasting some 45 minutes or so. It is daunting to even think your daughter is being operated on even when it's a small procedure but it was so worth it. We had so much support from the whole medical team including the nurses and the outreach team. Mr Subramanian is clearly very experienced in his field and explained the procedure very well.

Our daughter now has a button in her bladder which doesn't stop her from any of her daily activities. She was back up and walking the day after her operation and the button gets covered with her clothes. She continues to go to the toilet on her own and we empty the remaining urine from the button after she has urinated; now eliminating the risk of infection. We empty her manually using the button 3 times a day. It is really easy and our daughter doesn't complain of any pain or discomfort. It keeps her dry during the day and the night so she no longer feels embarrassed.

Having the button placed was the best thing we could have done for our daughter and I would like to sincerely thank Mr Subramanian and his team for their hard work.