

Parental Feedback - Mitrofanoff Procedure - Printable version

Dear Parents/Guardians,

I am writing this as an open letter, which I am giving to Mr. Subramaniam to pass on to any parent that he feels might find it helpful to have some information about the Mitrofanoff procedure from the parents perspective.

My son is 12 and he had his Mitrofanoff operation in February, this year. As I write this, he is five months post op. Every child is different and no two children will have the same problem, and my son's problem was quite rare in a child of his age and because of that by the time he was referred to the team at St.James' Hospital he had overflow incontinence which meant that he had to wear incontinence pants day and night. As with most boys of his age sport is a passion, he is a keen rugby player and plays football, tennis, and cricket to name a few. As your child may already be experiencing it was difficult for him in the school changing rooms, going on camp, sleeping over at a friends, trying to find a discreet way of changing without other children finding out. As a teacher of nearly 30 years experience I know how mean children can be! It has been a constant source of worry for us that he might be bullied or teased if other children found out.

The suggestion from the hospital was that Adam had a Mitrofanoff procedure. Nobody we knew had ever heard of it, including friends and family who are Medics! My son was generally well in every other way and as a parent one thinks long and hard about subjecting your child to unnecessary invasive surgery. My husband and I spent a long time thinking about it and I must say Mr. Subramaniam was very patient with us and gave us what we needed, time and information so that we could make an informed decision. My son was involved in all the discussion and ultimately he decided that it was the right thing to do and he decided he wanted to go ahead.

We had fantastic support both from Mr. Subramaniam and Craig, the Outreach Urology Support Nurse specialist from Ward 15. My son had the opportunity to talk to Craig before the operation and find out exactly what was going to happen during and after the operation and bring home a selection of catheters and literature to read about the Mitrofanoff procedure. I cannot praise Craig enough, he spent two hours with my son, answering all his questions and he has been fantastic support during my son's stay in hospital and has been ever since.

The team at St.James' was wonderful, without exception. The day before the operation we met the Paediatric Anesthetist, who was lovely and made us feel very reassured. The operation went well and as my son had elected to have an epidural, he was amazingly pain free; I wish I could say the same for me! As a parent of course you go through agony worrying about your child, but the fact that he was so comfortable made it so much easier. The "pain team" came round every day and carefully monitored my son, in conjunction with the Anesthetist, he never complained of any pain.

After a record breaking, four nights stay my son left hospital looking and feeling very well and confident that he could cope. Craig made sure we had everything we needed and he rang us every day to check that we were coping! We soon got used to the routine. At first my son had a catheter in place to allow his bladder time to heal; after a few weeks we gradually reintroduced urine into his bladder, we did all this at home with support from Craig and Mr. Subramaniam.

The whole process was gradual, timed specifically for the needs of my son and we were supported every step of the way. We were concerned about how easy it would be for my son to do the self catheterization; he managed it first time without any problem, this gave him confidence and he has had no problems since. The first day he catheterized he was dry all day and he hasn't looked back since. His main aim was to be able to wear designer underpants! It was worth the ridiculous £15 I paid for a pair just to see his face! To be dry and confident for the first time in nearly five years was fantastic. He has now come off night drainage and is dry at night as well- the world is his oyster, he can sleepover, get changed and do everything a child of his age should be doing!

He is now catheterizing every three to four hours. He is a boy and we do have to nag him to remember; amazingly at school he manages to remember, at home he gets involved in playing football or on the

computer and everything goes out of his head! We bought him a watch that can be set to vibrate at different intervals to discreetly remind him that he needs to catheterize; that was very useful until he lost it! The Mitrofanoff, sadly, was unable to cure the problem of losing things!

All in all, we think it has been worth it. It has improved the quality of our son's life, which was the aim of the operation. He is really well, back at school and involved in everything. As with all surgeon's, Mr. Subramaniam waxes lyrical about the fantastic scar! To be fair we do tease him a lot and he accepts it with much humour and good grace, he has done a fantastic job and because of his skill the scar has already faded, the Mitrofanoff site is neat and barely noticeable and it is below the line of his boxer shorts, so is not visible when he is getting changed.

I am confident that our experience has not been unusual; we have nothing but praise for the whole team, these people are dedicated professionals who really care about the children in their care, and the whole family. The quality of care is above and beyond people just doing their jobs. We miss our daily phone calls with Craig, but he still checks in every week to make sure we are doing well and we can always ring the ward if we are concerned.

I hope that this has been helpful in alleviating some of your concerns. Mr. Subramaniam has my telephone number and I would be happy to talk to you about any worries you may have that I have not addressed. My main advice to you is to be guided by the professionals, in my experience they act in your child's best interests and often see the bigger, long-term picture which sometimes as parents we are too closely involved emotionally to fully appreciate- it is difficult to be objective when it involves your child.

Good luck, your child couldn't be in safer hands.

Very best wishes

Liz