



Complex Child E-Magazine

www.ComplexChild.com

Mitrofanoff: Living with a Cathing Stoma by Michelle Detwiler

Those of you who have children with neurogenic bladder know the issues and pain of helping your child empty her bladder by catheterization. Our daughter Emily was born with L4-L5 paralysis of the lumbar spine, and in the beginning she showed signs of kidney reflux. However, she seemed to empty her bladder normally, so we didn't have to think about urinary catheterization as an infant. But after numerous bladder infections over the years, it was becoming clear that she needed some help emptying her bladder.

Learning to catheterize a little girl whose hips are severely affected by Arthrogryposis, a joint and ligament disorder, is very difficult. Emily's legs were straight and stiff and didn't bend like most people's hips and legs bend. Five times a day she required a clean intermittent catheterization. And even though Emily has paralysis, she could feel the catheter every time it was inserted. She did seem to get used to it, but if another caregiver had to cath her, it was more difficult to get the catheter inserted and did cause her pain. When I spoke with Emily's urologist about our concerns with cathing Emily, he suggested that we think about a bladder augmentation procedure to make cathing easier.

What is a Mitrofanoff?

This surgical procedure, called Mitrofanoff or appendicovesicostomy, is the creation of a permanent stoma or opening on the abdomen to catheterize through. The Mitrofanoff is usually created with the appendix, which is removed from its original position with the vessels still intact. A stoma or cathing valve is created by molding the appendix into a channel and sewing it to the bladder and then sewing the other end of it to a small opening on the abdomen. The opening is usually made at the belly button. In our daughter's case, however, the vessels couldn't stretch to the belly button, so her stoma is on the right side of her abdomen.

Mitrofanoff Surgery

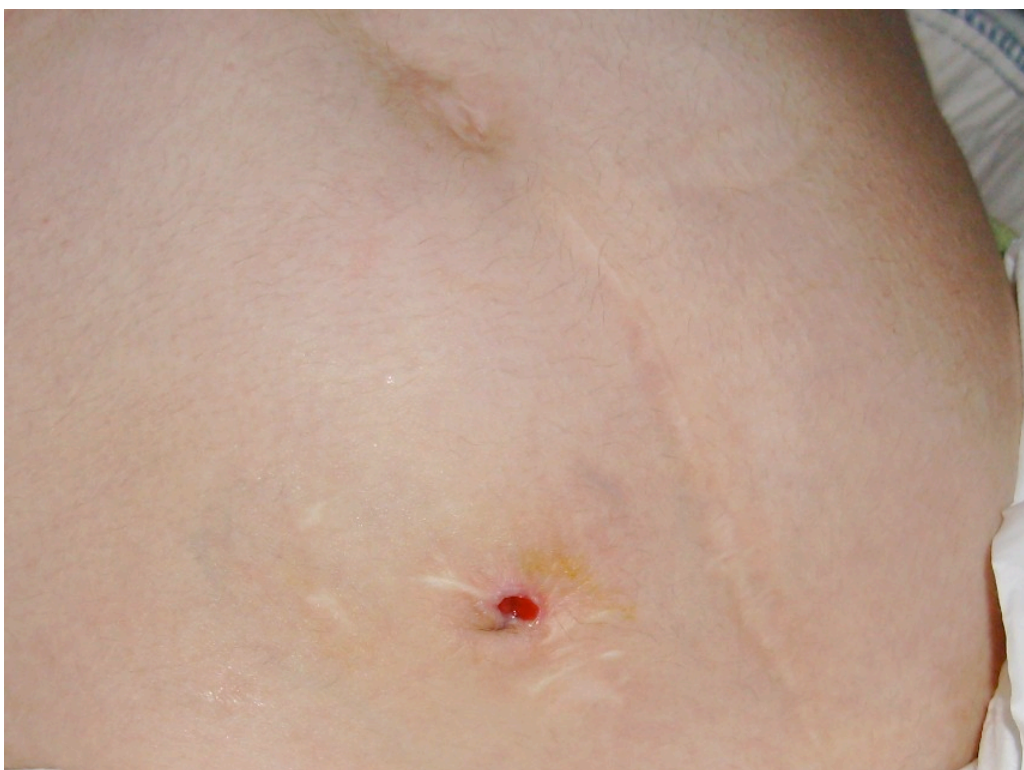
The Mitrofanoff surgery is a major surgery that took about three hours from start to finish. When the surgery was completed, Emily had a catheter sewn into her new stoma to make the tract and keep it open. She also came out of surgery with a catheter inserted

into her urethra. She used this lower catheter for a few weeks until the new stoma was healed.

Recovery

When thinking about recovery for this procedure, we were told that it usually takes about three to six weeks. Emily was in the hospital for about five days. During the recovery phase, the surgery site was very painful, and Emily needed to go back to the hospital for a week due to a bladder and kidney infection. It took about a month for the Mitrofanoff to completely heal up.

In this photo of our daughter, the stoma opening is just below the red area. The stoma always looks like this, and the red mucosal area is not unusual.



Cathing through a Stoma

Once the stoma was healed, the surgeon removed the stitches and the catheter that had been held in place. How easy and wonderful it was to use the Mitrofanoff for the clean cath! Our doctor talked with us about the importance of cathing regularly through the Mitrofanoff. There are a number of ways to cath and we utilize a clean cath procedure:

1. Wipe the stoma with a Betadine swab.
2. Put lubricant on catheter and insert into the stoma.
3. Remove catheter and wipe the stoma site clean.

Catheterization can be performed in the bed or in a wheelchair. No more moving or positioning to catheterize, just lift the shirt and insert catheter!

Pros and Cons

We have been catheterizing Emily through her Mitrofanoff for nearly five years now and in this time she has only had two or three urinary tract infections. There are a number of pros and cons for this Mitrofanoff procedure.

Pros:

1. Cleanliness, no more infections due to perineal bacteria.
2. Ease of cathing, no positioning issues.
3. No desire to skip cathing time because of inappropriate toileting facilities.
4. Can be used for nighttime indwelling catheter.
5. No need to cover with any dressings and can be left open to the air.
6. No issues with swimming or bathing.
7. A child who is developmentally on track can easily learn to catheterize herself at an appropriate age.

Cons:

1. Surgery and recovery is difficult and painful for the patient.
2. The stoma site can leak (but usually only when a catheter has been left in place for a long time and then removed).
3. It can be difficult to insert a catheter when the bladder is very full.
4. Catheterization absolutely has to be done regularly so the stoma does not close up.

While the Mitrofanoff surgery is not for everyone, we have certainly benefited from the procedure. Our daughter seems to be happier when we catheterize through the stoma. It doesn't hurt and we can cath her while she is sleeping. If we had to think about doing this procedure all over again, we would have done it sooner!

If you cath your child regularly and are interested in this procedure for your child, you should contact your urologist who can give you more information.



Michelle Detwiler is a freelance writer, wife and the mother of four kids, two of whom have complex medical needs. She lives with her family in a rural area in Washington State. Michelle has written for Premie Magazine, Exceptional Parent Magazine, and last fall completed her first book, Foster Parenting the Medically Fragile Child. For more information about the Detwiler family or her book you can find her blog at <http://thetenderscribe.blogspot.com>