To create a mitrofanoff stoma, the surgeon will take your appendix and connect one end to your bladder and the other end to the wall of your abdomen (tummy), either into the navel or lower down below the level of most underwear. This small opening (stoma) is used to pass a tube called a catheter, along the new channel into the bladder so it can be emptied. If you have already had your appendix removed, don’t worry. There are other ways of making a Mitrofanoff channel. One way is by using a tiny segment of small bowel.

Some people also have their bladder enlarged at the same time as having the Mitrofanoff. (See separate information sheet on Bladder Augmentation).

You may be admitted to hospital a few days before surgery. This is to make sure you are well enough to have the operation. Also, sometimes it is necessary to empty the bowel and make sure it is clean before the procedure is started. A clean, empty bowel is especially important if you are having your bladder enlarged. This helps to prevent infections after the surgery. The bowel is usually cleaned by temporarily changing your diet to clear fluid drinks only (for one or two days) and by taking medicine that empties the bowel.

Although you will not be able to eat and drink immediately after surgery, you should be up and around and eating and drinking as usual after about 2 - 3 days. Your stay in hospital will usually be about 3-5 days. After the operation and when you go home, a catheter will stay in the stoma for up to six weeks, to drain urine from the bladder. You will then be asked to come back to the hospital and will be taught how to catheterise the bladder through your stoma. Many people will already know the basic principle because they have been using a catheter to empty urine through the urethra (the tube through which urine leaves the body) for some time.

The nurse or doctor will help you do your first catheterisation. Sometimes a washout is done at the same time. This just clears your bladder of any ‘debris’ which can cause problems by blocking the catheter. You can reduce the amount of this ‘debris’ by drinking a glass of cranberry juice every day. If you are on blood thinning medicines you should not take cranberry. If you are unsure seek medical opinion. Urinary tract infections sometimes occur following this type of operation (especially if you are not careful about keeping to a clean catheterisation routine), but cranberry juice is known to reduce the risk of these occurring.

Catheterisation via mitrofanoff is not a sterile procedure, but is a clean one. This is how it should be performed. Make sure you have everything you need before you start.

- A clean or new catheter each time you catheterise.
- Somewhere to wash/clean your hands
- A toilet or container to collect the urine

Wash your hands and prepare your catheter. Gently introduce the catheter into your stoma, making sure you go far enough in to drain the urine. When the urine has stopped draining, advance the catheter about a centimeter further to ensure your bladder is completely empty. Then slowly remove the catheter, twisting it as you do so and throw it away. Some catheters can be rinsed and stored in a clean container, depending on the type of catheter that you have chosen to use. Wash your hands again.

As with any surgery, sometimes problems do occur. The stoma can occasionally become narrowed (stenosed). If it becomes difficult for you to catheterise your stoma, this could be the reason. If this happens it is important for you to contact your doctor or specialist nurse immediately. At this stage, if a problem is developing, it is fairly easy to correct. This usually means either leaving a catheter in for a few days or stretching the stoma, under a short general anaesthetic, (not as bad as you think!). Do not wait until you cannot pass the catheter at all, as this can often be too late and will need more major surgery to fix. Apart from problems with stenosis of the stoma, difficulties in completely emptying the bladder, and urine infections can occur.
You should also let your doctor or nurse know if you have any of the following:

- Blood in the urine.
- Smelly urine.
- A temperature causing you to shiver or sweat.
- Difficulty draining any urine.
- Urine leaking from your urethra or stoma, which hasn’t happened before.

Never leave catheterisation for longer than four hours during the day. Your bladder may overfill and there is a real risk that it could burst if you have also had surgery to your bladder neck.

It is recommended that you wear a “Medic-Alert” (Tel: 020 7833 3034) to alert medical professionals that you have had a Mitrofanoff.

If you have any problems or questions concerning your Mitrofanoff, you should ask your doctor, continence nurse or ASBAH Specialist Adviser.

Further information and resources

A ‘Need to Go’ card is available from ASBAH. The credit card size laminated card may help service users access toilet facilities when out and about. To find out more telephone the helpline or email helpline@asbah.org

Radar - The disability network offers a key scheme which allows people with disabilities access to locked public toilets. Visit www.radar.org.uk or telephone 0207 250 3222 to find out more.

Link magazine

The essential magazine for people with hydrocephalus and spina bifida.

Link is published quarterly (Winter, Spring, Summer and Autumn) and is packed with the latest news, events and issues for individuals, carers and people living with hydrocephalus and spina bifida. To subscribe contact ASBAH’s Helpline 0845 450 7755 email: helpline@asbah.org or visit our web site: www.asbah.org and click on the publications page.

Coloplast and ASBAH are working in partnership to campaign for an increased awareness of bladder and bowel health and to support ASBAH’s members and families in their efforts to live a full and satisfying life.

Help us

ASBAH relies on people’s generosity and support so we can help our clients who depend on us for help and advice - people with hydrocephalus, spina bifida, their families and carers. To donate to ASBAH please visit www.asbah.org or call 01733 421327.

This information has been produced by ASBAH’s medical advisers and approved by ASBAH’s Medical Advisory Committee of senior medical professionals.