

## Discussions about Mitrofanoff



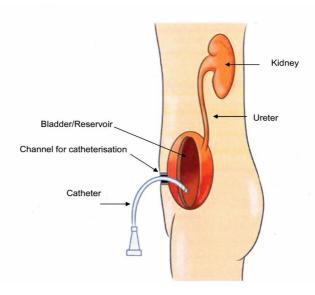
This booklet provides general supporting information, alongside clinical information, which will be provided by your Doctor or Specialist Nurse.

#### What is a Mitrofanoff?

A Mitrofanoff, or Continent Urinary Diversion, is a surgical procedure and alternative method of collecting and storing urine in the bladder.

Urine can be collected from the existing bladder, or there may be a need to make the bladder bigger, with a piece of bowel. Alternatively, a new bladder or reservoir can be made from bowel.

A channel is created between the skin surface on the abdomen and the reservoir/bladder. This can then be emptied by passing a small tube (catheter) through the channel, which is usually made from the appendix.



#### How will this operation help me?

This procedure is considered when there are problems filling or emptying the bladder or the bladder has been removed.

#### What happens if I have had my appendix out?

If you have had your appendix out, then the surgeon can use another piece of bowel or a part of the tube that connects your kidney to your bladder (ureter).

#### Are there any risks?

All procedures/treatments carry some degree of risk and your consultant will discuss these in detail with you. Risks should be balanced alongside the quality of life without treatment. Your surgeon will discuss any potential problems with you before the operation, so don't be afraid to ask any questions.

#### How long will I be in hospital?

You will be in hospital up to 10 days. On discharge, you will be instructed on how to wash the bladder out, to prevent any blockages.

You will then go back to hospital about 6 weeks later and be taught how to catheterise and care for your new continent diversion.

#### When can I resume normal activities?

You will be advised to have a period of rest to recover from your operation when you are discharged home. Time will vary, depending on what you do for a living and how you feel. You will not be expected to return to work/college for up to 2- 3months. Speak to your doctor, specialist nurse or occupational health department.

## Telling others

It is understandable that you may be worried at how other people will accept you or how your social role may have changed following the procedure. Relatives and friends may enquire about your operation. You can tell them as much as you want them to know. You can be brief, explaining that you have had abdominal surgery or that you have had an operation to remove or bypass your bladder.

If you have children, keep explanations honest and simple.

It is a good idea to have a medical alert bracelet in case of emergencies.

### Do I need to eat / drink anything special or extra?

You don't need to eat a special diet, but are advised to have a healthy well balanced diet including a variety of fruit and vegetables. If you experience any problems with your bowels, speak to your nurse or doctor

You should drink normally; fluid intake needs to be approximately 1.5-2 litres, spread over the day and include plenty of water. Reducing fizzy drinks and drinks containing caffeine may help to reduce any irritation.

#### Can I drink alcohol?

Alcohol can be taken in moderation; although like everyone else, you may need to get up in the night, therefore it is strongly advised not to drink excessively, as you may not wake up to empty your bladder.

#### Will it affect my sex life?

Intimacy and sexual relations are an important part of personal life. Allow time for complete recovery of your general health following the procedure. After this period, intimate relationships can be resumed when you feel ready. Try not to be embarrassed, talk to your doctor or nurse if you have any worries or queries as they will be able to offer specialist advice and help.

## Where will I get my catheters from?

Catheters are available on prescription. Your specialist nurse or doctor will advise you on the catheters that are available to you and equipment required. You will also be advised on how to obtain your prescriptions.

#### How often will I have to catheterise?

Your will be advised by your health care professional on catheterising, which initially could be every 2-4 hours during the day and before going to bed, you may have to empty at night time. Your nurse will advise you further on this.

#### What about urine infections?

- · Cloudy urine
- · Strong smelling urine
- · Feeling unwell
- · High temperature
- · Abdominal and or kidney pain

Any of the above may indicate you have an infection. It is important to contact your doctor, as you may need a course of antibiotics.

You may also benefit by increasing fluid intake. The introduction of cranberry juice or capsules may help reduce bladder infections, mucus build up and irritation. Cranberry should be avoided in any form if taking Warfarin.

#### What about travelling abroad?

You will be able to travel. Always ensure you have adequate supplies of catheters/equipment with you. Also it may be useful to have some spare catheters in your hand luggage in case your baggage is lost. It is advisable to catheterise prior to starting out on a long journey.

## Will I have to wear special clothing?

You can wear your normal clothing; some people apply a small dressing over the stoma site to prevent it rubbing against their clothing. Dressings are available on prescription.

#### What about sports activities?

Once fully recovered from your operation, your normal sporting activities can resume. However, you may need to avoid some contact sports if there is any risk of abdominal injury. If swimming, it is advised to wear a waterproof adhesive dressing over the site. Speak to your nurse or doctor for further advice.

## What should I do if I have a problem?

Problems such an infection, spasm, leaking, bleeding or discharge should not be ignored. You will be given contact details from your health professional of how and where to contact them for general advice and support.

If you are unable to insert your catheter, this will require urgent hospital attention.

You will be advised how to contact your doctor/nurse, if you need to seek urgent advice or help.

It is advised that you obtain a medic-alert bracelet or pendant.

#### Follow up

You will initially be seen in clinic three months after your hospital discharge. Then you will be seen between six monthly and yearly for ongoing monitoring. Your doctor/nurse will advise of any screening tests that will need to be done.

#### Further sources of information

#### **Mitrofanoff Support**

Mitrofanoff Support

Website:www.mitrofanoffsupport.org.uk Email: info@mitrofanoffsupport.org.uk

Telephone: 01202 886444

#### **Urostomy Association**

The Urostomy Association (UA) is a national charity to help people with a urinary diversion

Website www.urotomyassociation.org.uk

T: 01889 563191

E: secretary@urostomyassociation.org.uk

#### **Diversions**

Diversions is a support network, based in the North West of England, for families with a child or young person living with a bladder or bowel diversion/dysfunction

Website: diversions.org.uk Email: diversions@live.co.uk Tel: 07816513889 (Melissa) Tel: 07814613669 (Rachael)

#### **Medic Alert Foundation**

www.medicalert.org.uk/

Email: info@medicalalert.org.uk

Tel 0207833 3044

## **SOS Talisman LTD**

Tel 0208554 5579

Website: sostalisman.co.uk



#### **Further information**

Bladder and Bowel UK

Disabled Living Tel: 0161 607 8219

Email: bladderandboweluk@disabledliving.co.uk

Website: www.bladderandboweluk.co.uk

Bladder and Bowel UK, working as part of the charity Disabled Living, provides impartial advice and information regarding bladder & bowel problems, products and services.

Other booklets in this series: Discussions about constipation Discussions about having a supra pubic catheter

No part of this document may be photocopied or circulated without the authors permission.

Karen Irwin: Continence Nurse Advisor

Illustrations: Les Eaves

# **Neleflex**

Teleflex provided an educational grant to support the production and distribution of this booklet. Teleflex had no editorial input into the content of this booklet other than a review for medical accuracy.

Copyright © PromoCon. 2014 Review 2017 Disabled Living. Registered Charity No: 224742