

Patient information factsheet

Neobladder aftercare advice

We have given you this factsheet because you have had a neobladder (an operation to create a new bladder). It explains what to expect as you recover from your operation. We hope it helps to answer some of the questions you may have and enables you and your family to take an active part in your recovery. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What to expect after leaving hospital

When the medical team caring for you feel you are medically fit, you will be able to go home. We advise arranging for a family member or friend to pick you up from hospital if possible. You will not be able to drive yourself home.

Discharge summary

When you leave hospital, we will give you a copy of your discharge summary. Please keep this in a safe place as it contains details about your hospital stay and who to contact if you have any questions or concerns. We will also send a copy of this discharge summary to your general practitioner (GP).

Recovery time

Most people recover from this operation in three months.

Eating and drinking

It is important that you continue to eat a healthy, balanced diet when you get home. The Eatwell Guide breaks down how much we should eat from each food group (for example, carbohydrates and protein) to achieve a healthy, balanced diet. For more information about how to eat well, please visit: www.nhs.uk/live-well/eat-well/food-guidelines-and-food-labels/the-eatwell-guide

You may find that some foods upset your stomach and cause loose bowel motions, including foods high in fibre, such as porridge, Weetabix or brown bread. If this is the case, avoid these foods for the first few weeks after your operation.

If your appetite is reduced while you recover from your operation, you may find it helpful to:

- eat things that are high in calories
- eat little and often (some people find snacking regularly helps in the first few weeks)
- gradually increase your portion size (a whole meal should be approximately the size of the palm of your hand for the first few weeks)
- soups and casseroles are good options to begin with
- prioritise eating carbohydrates (our main source of energy) and protein (essential for wound healing) over vegetables

Patient information factsheet

- eat cold, plain, dry foods (if you are feeling sick)
- buy some nourishing, high protein, high calorie drinks (also known as build-up drinks) such as Complan (these can be found in supermarkets and pharmacies) and have three to four of these drinks a day to supplement your food

If you are losing weight without trying to or are struggling to eat enough, you may benefit from a consultation with a dietitian. Ask your GP or consultant to refer you.

Bowels

Your bowel habits may change after your operation, and you may experience constipation or have loose stools. To help with this, we advise:

- eating regular meals three or more times a day
- drinking lots of fluids
- taking regular walks during the first two weeks after your operation

If you have diarrhoea, it is important that you drink lots of fluids to replace the fluids you have lost.

Exercise

From the day after your operation, it is important that you exercise every day while you recover. You should aim to exercise multiple times a day and gradually increase how much you do until you are back to your normal level of activity. We recommend starting with short walks and then gradually increasing the distance and/or how often you walk each day.

When you get home, you may feel extremely tired and may often need to take a nap during the day. This is normal and should improve within the next four to 12 weeks.

If you are planning to restart routine exercise, such as jogging or swimming, you should wait until about six weeks after your operation and start gradually (you may need to modify your exercise if your wounds are uncomfortable).

Do not do any heavy lifting (anything heavier than a kettle of water) until 12 weeks after your operation. Once your wounds are no longer painful, you can usually do most activities. If you are unsure, contact us for advice using the details at the end of this factsheet.

Exercising regularly also reduces your risk of developing blood clots in your legs.

Medication

After your operation, it is important that you are comfortable enough to cough, take deep breaths, walk and do exercises. We will prescribe you pain relief medication when you leave hospital to ensure your pain is controlled to allow you to do these things comfortably at home. It is important that you take the prescribed pain relief medication regularly for the first few days. Not moving because of pain will slow down your recovery and may lead to complications.

After the first few days, only take the pain relief medication when needed (when you experience pain). Remember to always read the instructions before taking any medications. Some medications must be taken with food.

Some pain relief medications can cause constipation. We will prescribe you a mild laxative (a type of medicine that can help soften stool and treat constipation) to take while you take the pain relief medication. You should continue to take this laxative until you are able to easily pass soft stools.

You will need to give yourself a daily enoxaparin (a blood-thinning medication) injection for 28 days after your operation to prevent blood clots. We will teach you how to safely do this at home before you leave hospital.

Wounds

We will close most wounds with dissolvable stitches (stitches that do not need to be removed) and/or skin glue. If you need any further wound care after going home (for example, you need to have your stitches removed or you need your dressing changed), we will arrange for you to visit a practice nurse at your GP surgery or for a district nurse to visit you at home.

It is normal for your wounds to be slightly red and uncomfortable for the first one or two weeks. Scar tissue may develop as your wounds heal, making your wounds feel lumpy. This will usually improve with time.

Washing and showering

It is very important to keep your wounds dry until they have fully healed (this usually takes around one week but it may sometimes take longer). While your wounds heal, you can have showers, but these should be kept short, and you must not get your wounds completely soaked. Do not have baths.

For the first week or two after your operation, you should pat your wounds dry with a clean towel as soon as you are out of the shower. Do not rub your wounds, as this may cause them to open.

Caring for your catheters and stents

We will send you home with a urethral catheter and most likely a suprapubic catheter (SPC) and ureteric stents (thin, flexible, plastic tubes inserted into your lower tummy to help drain urine from your bladder while your internal stitches mend) in place.

It is important that you keep an accurate log of how much urine comes out from each of the catheters and stents until we remove them. We have included a 'urine output log' at the end of this factsheet for you to use.

You will need to alternate flushing your catheters with 50ml of water or saline (salt water) three times a day. We will explain how to care for these (including how and when to flush your catheters) before you leave hospital and answer any questions you may have. For more information about how to care for your catheters, please read our:

- 'Caring for your urethral urinary catheter' factsheet: www.uhs.nhs.uk/Media/UHS-website-2019/Patientinformation/Digestionandurinaryhealth/Caring-for-your-urinary-catheter-1619-PIL.pdf
- 'Caring for your suprapubic urinary catheter' factsheet: www.uhs.nhs.uk/Media/UHS-website-2019/Patientinformation/Digestionandurinaryhealth/Caring-for-your-suprapubic-catheter-1619-PIL.pdf

If your catheters become blocked (there is no output for two or more hours or you experience lower tummy pain) while you are at home, contact us using the details at the end of this factsheet.

We will arrange an appointment for you to come to the urology centre so we can remove the stents and the SPC. After we remove the SPC, we will usually perform a cystogram (an x-ray test to examine your bladder) to make sure your new bladder has healed. We will explain the test to you in more detail on the day and answer any questions you may have.

After your cystogram, if your new bladder has healed, we will attach a flip-flow urinary catheter valve to the end of your urethral catheter. A flip-flow urinary catheter valve is like having a tap fitted to a catheter instead of a drainage bag. We will explain how the valve works and then explain how to train your bladder using it.

Once you have begun bladder training, we will arrange another appointment for you to come back to the urology centre so we can remove your urethral catheter.

Bladder training

After your operation, your new bladder will initially only be able to hold a small amount of urine at a time, so you will not experience the sensation of a 'full' bladder as you did before. The amount of urine your new bladder will be able to hold will gradually increase with time. After three to six months, your new bladder should be able to hold about a pint of urine. The first year after having this operation is often the hardest as you adjust to life with your new bladder, but this will improve as you train your bladder.

Bladder training after this operation involves learning how to use your new bladder (including emptying it on a regular basis) and strengthening your pelvic floor muscles (a group of muscles which stretch from your tailbone to your pubic bone, forming a sling underneath your back and front passage). The training involves slowly increasing the amount of urine your bladder can hold without you unintentionally passing urine.

To begin your bladder training, we will ask you to open and close the flip-flow valve every hour to drain your new bladder. At night, you will need to attach a night bag to the open flip-flow catheter, so your new bladder can empty while you sleep.

After two days, we will ask you to open and close the flip-flow valve every two hours. After another two days, we will ask you to increase the time to three hours (this may be too long to start with and you may experience some leaking). Some people find that lying down helps to achieve the three-hour target. As you increase the time between emptying your new bladder, you may notice that your catheter leaks around the edges. This is normal and should improve after we remove the catheter. **You must not go over four hours without emptying your bladder.**

Please keep a record of the how much urine comes out each time you empty your new bladder while bladder training. We have included a 'bladder training log' at the end of this factsheet for you to use.

Urinating after the catheter is removed

After you have completed your bladder training, we will remove your catheter. It is important that you continue to empty your new bladder every three to four hours (including overnight). You should use an alarm clock to make sure you wake up regularly at night to do this. Many people will experience leakage at night over the first couple of months as they get used to waking up regularly. Leakage can also happen when you cough, laugh or strain. We recommend wearing incontinence pads for the first few weeks or months after your operation.

The nerve supply to your new bladder will have been interrupted by the operation, so you will not get the same sensation as you did with a normal bladder when you need to pee. You will need to learn a new way to:

- **recognise when you need to pee** - The feeling people get when they need to empty their bladder after this operation varies. Some people experience a feeling of fullness, while others report that they feel like they need to pass wind or pressure. Your body will normally find a way of telling you when it is time to pee.
- **empty your bladder** - You will need to relax your pelvic floor muscles and tense your tummy wall muscle to push down and empty your bladder. Sometimes you may also need to push down on your lower tummy with your hand to help empty the last bit of urine.

We advise doing pelvic floor exercises to help strengthen your muscles, as this may help with emptying your bladder. However, it is important that you don't overdo these exercises. For more information about pelvic floor exercises, see the 'useful links' section at the end of this factsheet.

Some people may also find that their neobladder is hyper-continent (it is not able to empty fully) or they are unable to pass urine due to a build-up of mucus. If this is the case, you may need to perform clean intermittent self-catheterisation (CISC). CISC involves inserting a small, flexible plastic tube (catheter) into your bladder to allow the urine to flow out. The tube is then removed and discarded. We will show you how to do this if necessary.

Driving

You must not drive until you are confident that you can drive safely. You should be able to do an emergency stop and turn the steering wheel quickly without experiencing any pain. For many people, this is usually around four weeks after their operation, when they are able to do most of their normal daily activities. However, for some people, this can take six weeks.

If you are not sure when you can start driving again, contact your insurance company for further guidance.

Work

Most people are well enough to return to work six to 12 weeks after their operation. However, if your work involves heavy, manual labour, you should not return to work until at least 12 weeks after your operation (unless you can be placed on lighter duties).

We will give you a medical certificate for work when you leave hospital, which will usually cover you for four weeks after your operation. If you need an extended medical certificate, you can speak to your GP.

Patient information factsheet

When to seek medical help

Serious complications after this type of operation do not occur very often, but it is important that you know what to look out for while you recover.

Contact us **immediately** if you experience any of the following symptoms **within the first three weeks** after your operation:

- a high temperature (38°C or above)
- a fever (cold sweats and shivering)
- increased abdominal pain (not improved by over-the-counter pain relief medication)
- calf pain and/or swelling
- chest pain
- breathlessness
- bloating
- vomiting (being sick)
- symptoms of a wound infection (a hot, red, swollen or painful wound or fluid leaking from the wound)
- feeling generally unwell

Follow-up care

We will send you a letter in the post for a follow-up outpatient appointment. This appointment will usually be four to six weeks after you leave hospital. At this appointment, your consultant will explain your pathology result and what happens next.

Your feedback

Your feedback helps us to celebrate what's working well and identify where we need to improve. We would be grateful if you would take a moment to review the service you received while in our care. To complete our short online survey, visit: <https://gthr.co.uk/c0c9> or scan the QR code below. Please select 'E8 ward' as the service you visited.



Contact us

If you have any further questions or concerns in the **first three weeks** after your procedure, contact us.

Urology advanced clinical practitioners
Telephone: **07920 274648** (24-hour line)

E8 ward (urology and HPB)
Telephone: **023 8120 6510** (24-hour line)

After three weeks, contact your urology clinical nurse specialist or GP for advice.

Outside of working hours, contact NHS **111** for advice.

