UROSTOMY
ASSOCIATION

Your neobladder questions answered

For people with a urinary diversion

Not everyone requiring treatment for a damaged or diseased bladder receives a urostomy. For some people, a neobladder is more suitable. If you've been told this is an option for you, you're bound to have lots of questions.

Here are answers to some commonly asked questions:

What is a neobladder?

A neobladder is a general term applied to a specific type of bladder reconstruction.

Your surgeon will aim to construct the neobladder by using a piece of your bowel. This piece of bowel is reshaped to create a functional reservoir for your urine. The neobladder is then connected to your:

- ureters (the tubes that drain urine from your kidneys) at the top
- urethra (the tube that takes urine out of your body) at the bottom

Because the surgery for a neobladder takes longer and is slightly more complicated than that for a urostomy, it is likely to involve a longer stay in hospital afterward.

How will I know if I am suitable for a neobladder?

There are three primary considerations:

1. Is everything else working as it should? - The main consideration is whether you will have a functioning urethra and urethral sphincter after your cystectomy. A neobladder would not normally be an option if your urethra has disease (e.g. stricture, sphincter-weakness or cancer).
2. Your quality of life after surgery - If you do have a functioning urethra, the next consideration is physical fitness. Having such a complex surgery can take its toll on your body. A urostomy might be more suitable for you to ensure you have the best quality of life after your surgery.
3. The extent of your condition - Due to the extent and or exact location of your condition, a neobladder may be not suitable; this is something that your surgical team explain to you.

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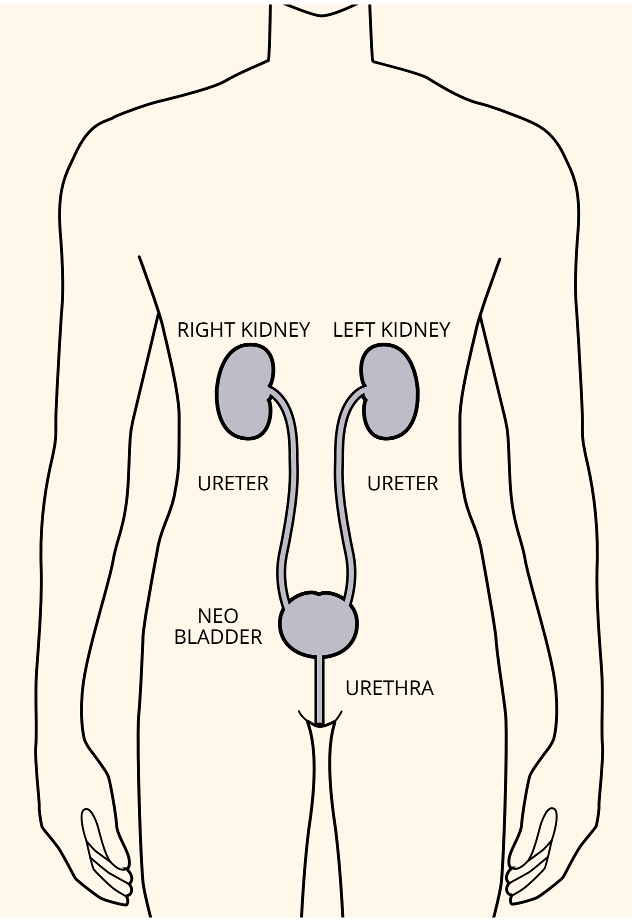

Other factors that a surgeon will take into consideration:

- Age (usually under 75 years of age)
- General health and fitness
- Motivation (how motivated someone will be to spend time training their neobladder)
- Expectations:
    - Is the individual prepared to tolerate a degree of urinary incontinence, particularly at night (affecting approximately 3 in 10 people)
    - Is the individual prepared to self-catheterise should they develop excessive or abnormal continence (affecting approximately 1 in 10 people).

What does neobladder surgery involve?

When surgeons perform a cystectomy with the intention of forming a neobladder, they will usually attempt to keep as many of the nerves intact around the area of bladder. This has the added benefit of preserving sexual function in some people, particularly women.

Once the cystectomy is complete, the surgeon will fashion your neobladder using a section of your bowel. You may experience a short period of altered bowel habit afterward, but this is normally temporary.

After a cystectomy and neobladder formation, you'll wake up with several tubes attached to your body. These are perfectly normal and are there to help reduce the risk of complications.

These include:

- a urethral catheter
- a tube on your lower tummy that goes directly into the neobladder. This is called a suprapubic catheter.
- ureteric stents - thin tubes that drain urine from your ureters
- a wound drain

You'll stay in hospital for up to three weeks after surgery. Initially some of these tubes will need to be flushed by nursing staff – probably three or four times a day.

Before the catheters are removed, you'll need an Xray (cystogram) to ensure that the internal sutures have healed. This is usually carried out between 10 days and two weeks following surgery. Once this healing is confirmed, your urethral catheter will be removed, followed by the suprapubic catheter. These are usually removed at the same time; however some patients will be discharged with one or both of the catheters still in place, and have them removed during an outpatient appointment.

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What is it like living with a neobladder?

It takes a while to get used to a new bladder and learning how to look after it. Like anything new, it will get easier with time and practice. Your nurse will be there to support you before and after your operation.

The bowel tissue used to make your neobladder will continue to produce mucus, which might appear as pale threads in your wee. Although this is not a problem for most people, about one in 20 patients find that excessive mucus is causing urine retention or infections. In this case, they might need regular "flushing" of their neobladder.

Again, your nurse will teach and support you in learning how to do this. It is natural to feel anxious about going out in public and to worry about finding a toilet in time. It helps to plan ahead, because being prepared can help you feel more confident.

How will I wee with a neobladder?

The initial few weeks are critical while you train your new bladder both to hold urine and empty it when required. Most neobladders hold a very small volume to begin with, but they gradually expand to hold more urine as time goes on.

There are several ways to train your new neobladder. These are:

1. delaying emptying your bladder by contracting and strengthening your pelvic floor to increase your neobladder capacity.
2. sitting to pass urine (both men and women)
3. learning to relax your pelvic floor at the same time as gently straining down to empty your neobladder.

With time and practice, most people learn to empty their new bladder in the same way as before their operation, by weeing into the toilet. Men and women will have to sit to empty their bladder, and you'll usually have to strain or apply gentle pressure with your hands over your lower tummy to start with.

At first, you will have to empty your bladder every hour or so. The feeling of needing to wee will be different from before your surgery and you will learn to identify the new sensations which tell you that your bladder is full.

Over time, your new bladder will stretch and be able to hold more urine. But you may still have to empty it every four hours. You may also need to use a catheter a few times during this period. This helps to ensure your new bladder is completely empty. If you need to do this, your nurse will show you how.

However, if you have difficulty passing urine in this new way over time, you might need to use a catheter to empty your new bladder on an ongoing basis. Again, your nurse will support you with this.

Will I experience leakage of wee?

Early on, you might experience some leakage, particularly at night. Rest assured; this usually gets better after a few months. Your nurse can suggest things to help and may refer you to a continence adviser.

Your nurse will teach you how to do pelvic floor exercises. It is important to keep doing these as they can help you have more control over leakage.

What will I need when I return home after surgery?

Most people don't need to be prescribed any particular equipment, although you will probably want to get some protective sheets.

You will be given the phone numbers of who to contact for advice once you're back at home. The teams are there to support you, so do ask for their help with any questions or difficulties you may have.

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About the Urostomy Association

This leaflet is just one in a series. You can see the full list on our website in the resources section. There you can also find our blogs, videos and webinars.

We know that sometimes you just want to talk things over, so we have specially trained buddies who have had their own urinary diversions and are happy to help. There is also a private Facebook group where you can ask questions and share your experiences with other people living with a urinary diversion.

We're also here to raise awareness of all matters around urinary diversions, and we run campaigns and appeals, liaising with like-minded organisations, policy makers and health professionals. Our aim is to build a supportive community around your needs.

Please remember that this leaflet is for information only, and you should contact your own stoma nurse about questions relating to your own care.

Lastly, we can only continue to support members of our community live their best lives, before and after surgery, thanks to charitable support.

Kind donations enable us to run our helpline and keep members up to date through our regular magazine, e-newsletters, group meetings, social media and fact sheets. Thanks to donors, we can inform and support stoma care professionals, increase awareness across healthcare and the general public, and influence urostomy policy and practice.

All of this, and much more, is possible because people choose to donate, fundraise and say thank you to our charity. If you would like to make a donation or support us in other ways, please visit our website at **urostomyassociation.org.uk.**

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