



Living with a stoma

A stoma is simply the forming of a hole in the body that can connect part of your body to the outside. It is used in bladder cancer treatment when the bladder has been removed and there is a need to find a different way to allow your wee to leave your body.

The whole idea of having a *stoma* is a very strange concept when you first hear about it. But rest assured, the creation of stomas goes back a long way in history – there is even a reference to surgery for forming one in the Old Testament.

Forming a stoma is a tried and tested operation, and it's a technique that is used in many operations in addition to those for bladder cancer.

How does it work?

The use of a stoma for bladder cancer patients is the most common way to get your wee out of your body after bladder removal.

In simple terms, the operation is to cut out a small section of your bowel, connect it at one end to your ureters (the tubes that drain your wee from your kidneys down to your bladder) and then the other end of the piece of bowel is poked through a hole in your abdomen so that your wee can flow out.



Here's a picture of a stoma. It might look weird if you've not seen one before, but in no time at all you'll be friends!

Your medical team might call this an **ileal conduit**. You will then wear a 'stoma bag', which is stuck to your skin, to collect the wee as it flows out. You then simply empty the stoma bag when it is full using a little tap at the end of the bag to pour it straight into the toilet. Getting used to having a stoma and learning to live with it will take a bit of time. But, like anything new, it will get easier with practice.

Quite a few other names are used for the stoma bags including stoma pouches, urostomy bags and urostomy pouches.

Preparation for having a stoma

The best preparation should start before your surgery. The important person to get in touch with is your stoma nurse, who will be your support before and after your operation. If you are not told about your stoma nurse, do ask to have a meeting with one before your operation. Be proactive, as this contact will really help later. Your stoma nurse will be able to tell you a lot about having a stoma.

We recommend asking for a few sample stoma bags prior to your operation that you can fill with water and stick on yourself in the place they will go after the operation, so that you can get used to the sensation and how you can do normal things while wearing it.

This is very valuable practice and is much better than having your first experience immediately after surgery, when you are feeling weak and vulnerable. Get to know how it feels, see what you have to be careful at doing to prevent causing a leak. Wear a bag to work one day to see how it feels doing your job. Have a shower with it on. Go for a run or go swimming. Give yourself time to 'roadtest' life with a stoma.

Most surgeons will ask you where you want your stoma. This might sound strange but there is a choice here ... left or right, higher or lower. Do you normally wear a belt or other garments that need to be taken into consideration for your stoma placement? Consider all your normal activities before you decide.



When you get into hospital for your operation, you will see the stoma nurse again and they will show you how to look after your stoma, how to change the stoma bags, and how you get your supplies of bags and the other things you will need.

We think that it is also very useful to talk to someone who has already gone through the operation and is living a happy life with a stoma. You can chat to many people with this knowledge on our **Confidential Forum** who can give you advice and the all-important tips about coping with the realities of having a stoma and how to prevent leaks.

Try many different sizes and styles of stoma bags to find one that suits you best. Learning these essential little tips really will make life with a stoma better.

Most people get back to a very normal life quite quickly after surgery. If things seem to be difficult for you, keep in contact with your stoma nurse for support and keep chatting with people in our forum who will be able to give you some first-hand advice.

However, it is important to know that having an radical cystectomy is a major event. Normally it involves a minimum of 6 hours in surgery, and you will need plenty of time to recover after it.

In the best cases you could be home after a week, but don't worry if you are in for

10 days or more. Everyone's ability to get to the stage that they can be discharged is different. Complications can occur and, if they do, the hospital is the best place for you. But you *will* go home, and your new life will begin.



With care, almost everything you did before surgery, you can do afterwards with your new stoma.

Life with a stoma

Whilst life with a stoma can be no trouble at all, the early days will be a challenge as you deal with the day-to-day realities. For the first day or two after your operation, your stoma nurse will be there to help you in hospital, but you will soon be expected to do it all yourself. This will be daunting, but do try to do this as soon as you can. Get as much practice as you can changing your stoma bag whilst you are still in hospital so that you have mastered it as best you can before you go home. The more you practice, the easier it will become. If you can, get a friend or loved one to watch whilst you are changing your bag so they can help if needed.

At first your stoma will be swollen, and it may take a few weeks before it settles down to its final size. Remember, your stoma has been made out of a living piece of your bowel and that it can bleed if damaged, so be very careful when you clean around it. A little bit of blood is fairly common, but anything more than this you should talk to your stoma nurse

about. Your stoma will also produce mucus that will look like pale threads in your wee. This is totally normal.

When you get home after your hospital stay you will be on your own looking after your stoma, and you will need to know when to empty your bag and change it. Give yourself plenty of time to get used to this so that you can do it at your own pace and without interruption. Remember, there are many different types of stoma bags, so if you are having any problems do consider trying other styles by different manufacturers.

Your stoma will shrink after surgery as it settles down, so make sure that the opening in your bag for your stoma continues to be the right size. Wrong-sized openings are the biggest cause of leak problems, so it is important to get this right. Again, your stoma nurse will help you with this even after you are back at home.

Leaks are most people's main concern, and they do occur. A correctly fitted bag is the best solution for this problem, but if you find it difficult to get a good seal between you and your bag, there are many things like pastes, washers and extension flanges that can really help. Not letting your bag get too full before you empty it also helps. An over-full bag is a dangerous thing!

Most people find that they need to empty their stoma bag as frequently as they previously needed a wee. The more liquid you drink, the faster the bag will fill, so keep an eye on your bag and get into the habit of emptying it before it is too full.

At night you will produce a lot more wee than your stoma bag can hold, so you connect your bag up to what is called a night bag. These normally hold 2 litres of fluid, so are easily adequate for the whole night. They work by simply attaching the outlet of your stoma bag to a flexible tube with an adapter. This tube is connected to the large bag, and your wee will simply flow into it throughout the night.

A good tip for getting the best flow during the night is to connect your stoma bag to the



night bag while it is still at least half full. When connected, apply a little pressure to your stoma bag to encourage your wee to flow into the night bag (to balance the pressure). Once you get this flow going it usually continues naturally through the night without any trouble.

Leaks can occur at night though, especially in the early days, so be prepared. Your hospital will probably be able to give you a supply of incontinence sheets that will help, but as you get more confident you will find that leaks become less frequent. If you are at all concerned, fit a waterproof mattress protector under your normal bedding so you needn't worry about the occasional leak if it happens.

When do I change my bag?

In order to avoid infections it is important that you change your stoma bag on a regular basis. We would recommend that you never wear a bag for more than 2 days before you change it. This will help prevent infection, and a bag that is kept on too long is much more likely to leak. A leak from a bag whilst you are having dinner is not what you want, so do change your bag when you should, particularly if you are going out for the evening. We know it is tempting to 'just go another day' but believe us, you will probably regret it.

Most people change their bags in the morning, as this is when you are producing the least wee, making the process easier.

Another good tip is to crouch a few times before changing your bag as this will empty most of your wee into the bag first. Do remember to change your night bag on a regular basis too, to prevent the smell of stale wee in your bedroom. Ask your local council about disposal of your old stoma and night bags, as many will offer a collection service.

Taking care of your skin

This is important. If your wee gets in contact with your skin for too long it can cause irritation. It can produce a rash, a bit like nappy rash, and if it's not sorted out it can end up causing you real problems. If you do get problems with your skin under the adhesive flange of your stoma bag, get it sorted as soon as you can.

It is important that the adhesive seal is good and fits snugly around your stoma. If the hole is too large, some of your wee will be in contact with your skin for a long time and the skin will become sore. Your stoma nurse can provide information about sprays that can protect your skin.

Getting your stoma supplies

Before you leave hospital your stoma nurse will make sure that you take a supply of stoma bags, night bags and the other things you need with you. They should also help you set up a regular delivery service that will provide for all your stoma needs going forward. There are many of these specialist companies that have contracts with the NHS to provide this service and you are usually free to choose whichever one you want. It is normal to use the one recommended by your stoma nurse, but do change to another supplier if you don't feel you are getting the right service. Most of these companies also make the stoma bags themselves. However, you are allowed to order any make of stoma bag from any supplier, and they will have to supply the make you have ordered.

These supply companies can be very good about giving advice too, so don't be afraid to talk to them if you are having any problems. Sometimes they can give you just the right advice or recommendation that solves your particular problem.

The best tips of all...

- When you can, carry a spare stoma bag, wipes etc, with you, so you can do a bag change if needed.
- Keep a spare stoma bag, wipes, etc. at work if you can for the same reason.
- If you are out and about and don't want to carry a spare with you, remember to put a roll of micropore tape in your pocket or handbag. It's essential for a temporary repair of an unexpected leak. **Just be prepared, and most, (if not all,) of your worries will disappear.**

It won't be long before you get into your own routine and everything will just seem normal. If you do have problems, ask for help. There are people who can help with every situation.

Find out more about the practicalities and emotional issues of living with bladder cancer on our surviving bladder cancer page.



About Fight Bladder Cancer

Fight Bladder Cancer is the only patient and carer led charity for bladder cancer in the UK.

At Fight Bladder Cancer, we take great care to provide up-to-date, unbiased and accurate facts about bladder cancer. We have a very supportive medical advice panel made up of some of the best professionals working with bladder cancer, and hope that our information will add to the medical advice you have had and help you to make decisions.

To donate, go to our **Just Giving** page:

[justgiving.com/fightbladdercancer](https://www.justgiving.com/fightbladdercancer)

or text **FBCD00 £5 to 70070**

Registered charity **1157763**

Please note that our services are not intended to replace advice from your medical team.

Robert House
Station Road, Chinnor,
Oxon OX39 4DJ
01844 351621

YOU CAN FIND A WEALTH OF INFORMATION, SUPPORT
AND ADDITIONAL DOWNLOADS ON OUR WEBSITE:

fightbladdercancer.co.uk