fight bladder CANCER

Patient Information Booklet

# Living with a stoma

## & getting used to your new normal

A GUIDE
FOR CARERS
BY CARERS,
PROFESSIONALS
& PATIENTS

Financial support provided by **Merck**, the **Merck-Pfizer Alliance**, **MSD**, and **Roche**.
*All editorial control has been retained by Fight Bladder Cancer.*

fight bladder CANCER

# YOU'RE NOT ALONE

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to help you in your FIGHT

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## Bladder Buddies

***Join our private online Facebook forum:***
**facebook.com/groups/BladderCancerUK**

DIGITAL COPY FOR PATIENTS & CARERS

# ABOUT THIS DIGITAL BOOKLET

**The Fight Bladder Cancer Patient Information Booklets are a range of free information materials covering the entire bladder cancer pathway and are tailored to each individual circumstance.** They offer a wealth of information and real patient experience and stories.

**ENDORSED BY**

The British Association of Urological Surgeons

British Association of Urological Nurses

British Uro-Oncology Group

## Other free support materials

In addition to our patient information booklets we offer a range of free materials to those affected by bladder cancer, including ***Fight* Magazine**, the only magazine of its type in the world, full of inspirational patient stories, medical research and clinical trial information. It is available in both print and digital editions.

We also have a **monthly newsletter** for patients that you can opt in to at: **fightbladdercancer.co.uk/contact-preferences**

We hope you find this booklet, and the others in the series, useful. Please get in touch with us at **info@fightbladdercancer.co.uk** for more information about how we can support you.

*We're here to help!*

MSD, Roche and the Merck-Pfizer Alliance have provided financial support to Fight Bladder Cancer to cover the costs associated with the production and dissemination of this information booklet. All editorial control has been retained by Fight Bladder Cancer.

MSD Roche Pfizer MERCK

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This series of booklets has been prepared by a team of patients and medical professionals working together to give the best guidance for patients.

The booklets have been produced in conjunction with the **British Association of Urological Nurses** (**BAUN**), the professional organisation for specialist urology nurses in the UK, and are endorsed by the **British Uro-Oncology Group** (**BUG**) and the **British Association of Urological Surgeons** (**BAUS**).

## WITH THANKS TO ALL THE CONTRIBUTORS

### THE FIGHT BLADDER CANCER FORUM MEMBERS

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**Anita Brown** | **Ros Bruce** | **Mary Lovett** | **Dorothy Markham** | **Malcolm McNinch**
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### THE FIGHT BLADDER CANCER TEAM

**Melanie Costin** | **John Hester** | **Valerie Hester** | **Emma Low** | **Anne MacDowell**
**Sophie Maggs** | **Deborah Major** | **Paul Major** | **Dr Lydia Makaroff** | **Sue Williams**
and our late founder **Andrew Winterbottom**

### MEDICAL PROFESSIONALS

**With particular thanks to:**

**Hilary Baker**, MSc, NMP, RN, Macmillan Lead CNS for Uro-oncology, University College London Hospitals; FBC Trustee

**Professor Alison Birtle**, FRCP FRCR MD, Consultant Clinical Oncologist, Rosemere Cancer Centre, Lancashire Teaching Hospitals; Honorary Senior Lecturer, University of Manchester, Secretary British Uro-Oncology Group; FBC Trustee

**Professor Jim Catto**, MB ChB PhD FRCS (Urol), NIHR Research Professor, Professor of Urology, University of Sheffield; Editor in Chief European Urology

**Dr Bill Phillips**, MBChB MSc FRCGP, GP, FBC Medical Adviser

**Jane Brocksom**, Lead Nurse for Urology, St James's Hospital, The Leeds Teaching Hospitals NHS Trust; BAUN President 2018–2020

**Lucy Bowden**, BSc, Urology CNS, Stockport

**Heather James**, RGN, BSc, Uro-Oncology CNS, Glan Clwyd

**Morna Jones**, BSc, Lead Urology CNS, East Kent

**Laura Noble**, BSc, Uro-Oncology CNS, Newcastle

EDITORIAL: **Wendy Hobson** DESIGN & PRODUCTION: **designcouch.co.uk**

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# Contents

Our **patient tips** come from **real bladder cancer patients** across the world!

**Don't feel you need to read this booklet all in one go. It is designed in bite-sized chunks so you can take it in at your own pace.**

**Fight Bladder Cancer** is a patient-led charity in the UK that exists to:

- **support anyone affected by bladder cancer**
- **raise awareness** of the disease in order to improve early diagnosis
- **campaign for and support research** into this disease
- **affect policy** at the highest level to bring about change

**Fight Bladder Cancer** has a worldwide reputation and is supported by top international healthcare professionals.

# Hello

Anyone who is having their bladder removed as a treatment for bladder cancer will need another way to wee after the operation. The two main choices in the UK are a stoma – a hole in the abdomen – or a neobladder – a replacement bladder created out of tissue from the bowel. Your consultant will explain the options to you and your individual choices, as not everyone is suitable for both procedures.

Backed by experienced professionals, this series of booklets has been written by people like you, who have been through their own bladder cancer journey and can share their first-hand experiences. They understand the emotional storm that you may feel is whirling around you and will help you to calm that storm and feel more in control.

## You need the right knowledge

While your medical team will explain things to you, most people need time to reflect on all the new information they have to take on board, and often look for more guidance from other sources. That can be very valuable, but do remember:

- a bladder cancer diagnosis can mean many things and is as individual as you are
- always check that the source of the information is a reliable one, such as a nationally respected research institute or organisation like Fight Bladder Cancer or Cancer Research UK
- discuss what you have found with your clinical nurse specialist (CNS) or medical team so you are sure it is relevant to your specific situation.

**Remember that every person is different** – physically and mentally – so what is right for one person may not be right for another. Investigate, ask questions, talk to people and listen to their viewpoints, then make the best decisions for you.

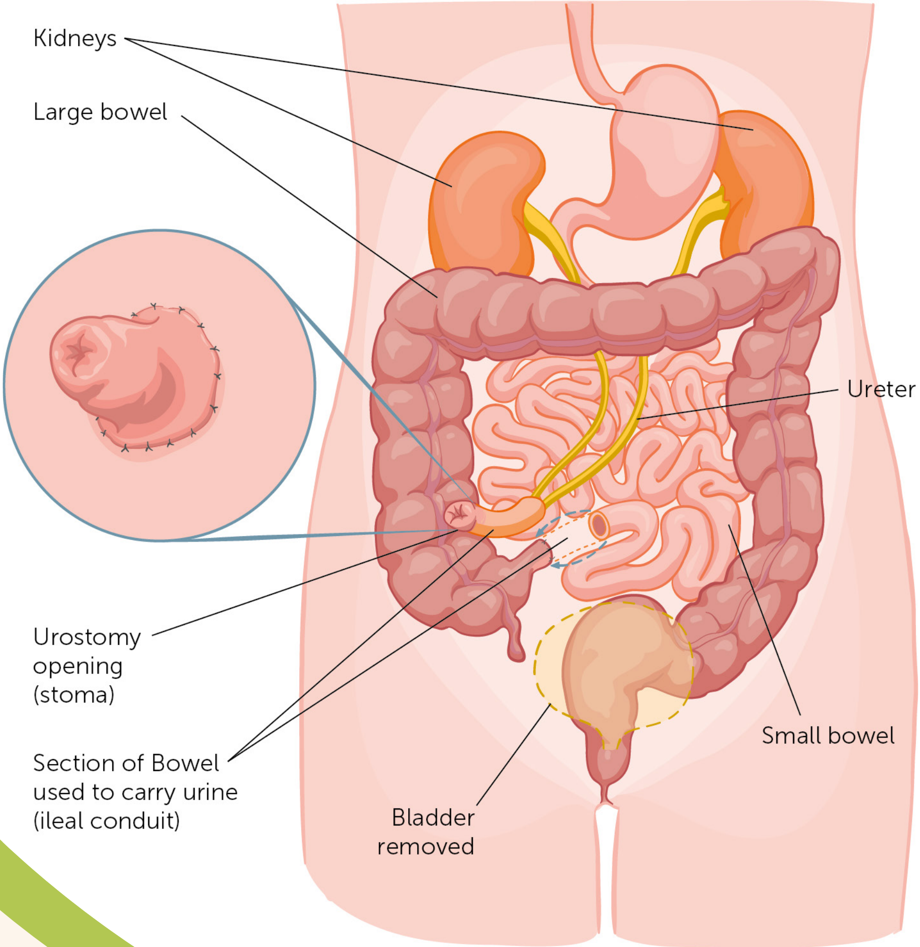
**PATIENT TIP:**

'Make sure you find out as much as possible. There is plenty of helpful info online, but be careful that you don't read things that aren't relevant to your situation. Stick with reputable cancer sites.'

# What is a stoma?

**A stoma is simply the creation of a hole in the body that allows you to connect part of the inside of your body with the outside.** It is used in many operations, but in the case of bladder cancer treatment, it is used to allow you a different way for wee to leave your body when your bladder has been removed.

In simple terms, the operation involves cutting out a small section of your bowel and connecting one end to your ureters (the tubes that drain your wee from your kidneys down to your bladder). The other end of the piece of bowel is poked through a hole in your abdomen so that your wee can flow out. Your medical team might also call it an ileal conduit.



The stoma is usually put just to the right of your tummy button. It can sometimes be repositioned slightly if you have scar tissue, a hernia or other contra-indications, but it is always located within the area of an abdominal muscle called the rectus.

You will then wear a stoma bag, which is stuck to your skin, to collect the wee as it flows out. When the bag is full, you pull out a little stopper at the end of the bag and empty it straight into the toilet.

It may seem an odd concept at first to have a hole in your abdomen but, in fact, the creation of stomas goes way back in history. It is a tried-and-tested operation.

**There are quite a few other names for stoma bags – stoma pouches, urostomy bags and urostomy pouches – they are all the same thing.**

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. Most patients find it doesn't hold them back from doing all the things they normally enjoy.

Ron

**PATIENT TIP:**

'Knowing I needed my bladder removed was hard. Having a choice between a bag or a neobladder made things even harder! I read the various pros and cons but decided to ask people who had been in the same situation how they got on, the good and the bad – it helped me so much.'

# Making your choice

The operation to construct the stoma is usually performed at the same time as the bladder removal, known as a radical cystectomy (RC), the details of which you can find in another booklet in this series, *Muscle-invasive bladder cancer*.

In order to decide whether a stoma is right for you, or whether you would prefer a neobladder, you can also read our companion booklet *Living with a neobladder*.

Your medical team, including your doctor and clinical nurse specialist (CNS), will explain to you what procedures are involved, what outcome you can expect, and how the stoma operation compares with the operation to create a neobladder.

**Talk to your doctors and CNS so you can balance the risk factors with the potential benefits and make the best choice for you and your lifestyle.**

You can also join the Fight Bladder Cancer private online forum, where patients and professionals can help to answer your queries.

## Things to think about when making your choice

**STOMA**

- 80% of patients choose a stoma
- suitable for almost all patients
- need to learn how to use, clean and empty the bag
- shorter operation and recovery time
- potential to affect body image
- potential leakage issues

**NEOBLADDER**

- suitable for patients with full kidney and liver function, good bladder control and a healthy urethra
- need to learn techniques to recognise when you need a wee
- longer operation and recovery time
- may need to self-catheterise
- no need for collection pouch
- potential for incontinence, especially at night, for some time

# Before the operation

**Once you have made your decision to have a stoma when your bladder is removed, you can start to find out about what it will be like to live with this new way of weeing.**

You are bound to be apprehensive – everyone is – and that's only natural, so the first person to get in touch with is your stoma nurse, a specially trained nurse who will be your main support both before and after your operation.

If no one introduces you to your stoma nurse, take the initiative and ask for a meeting before your operation. Be proactive, as this contact will really help later.

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 the FBC private online forum or we can put you in touch with a Bladder Buddy. They can give you advice and the all-important tips about coping with the realities of having a stoma – like what to do to prevent leaks. This kind of advice can be very helpful, especially in the first few months after your operation.

**Your stoma nurse knows exactly what the procedure involves and should be a mine of information about management.**

**PATIENT TIP:**

'Being on the FBC forum was a great help and after my operation it also gave me the confidence to start giving advice to other people.'

Sue

## Early practice

It's also worth asking for a few sample stoma bags before your operation. You can fill one with water and stick it on yourself in the position that the actual stoma bag will be after the operation. You'll then be able to get used to the sensation and see that it should not get in the way of your day-to-day activities.

This is very valuable practice and is much better than having your first experiences of a stoma bag immediately after surgery when you may be feeling weak and vulnerable.

Get to know how it feels to wear a stoma bag and how it moves with you. Work out what might cause a leak and what you have to be careful doing to prevent that happening. Wear one 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 'road-test' life with a stoma.

Try as many different sizes and styles of stoma bag as you can until you find the one that suits you best. **Learning these basic essentials will give you a lot of confidence that will help you to adjust much more quickly to life with a stoma.**

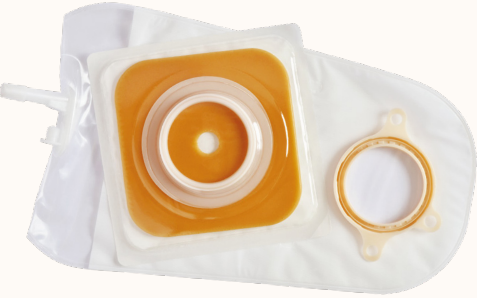
## After the operation

**For the first few days after your operation, the nurse will look after your stoma for you. They will make sure that the bag is emptied and changed as often as necessary.**

As soon as you feel ready, your stoma care nurse will show you how to empty, clean and replace your stoma bags.

You will need to empty your stoma bag several times a day, about as often as you would normally wee, and change it about every two days. You may have some problems to begin with, especially at night when the stoma may leak, but the nurse in the hospital, or a district nurse when you get home, will help while you get more familiar with your stoma and how it works.

Rebecca



## Give yourself time

While most people quite quickly get into a routine with their stoma, it is important to remember that you have just gone through a major surgical operation. You will normally have been in surgery for at least six hours, probably longer, and you will need plenty of time to allow your body to recover. In the best cases you could be home after a week, but don't worry if you are in hospital for ten days or more. Everyone's ability to get to the stage where they can be discharged back home is different. If you need those extra days of professional care, then the hospital is the best place for you. You will be home when you are ready to begin your new life.

**Remember that you have just gone through complex surgery and you will need plenty of time to allow your body to recover.**

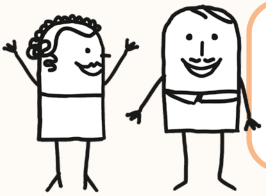
Before you leave hospital, the nurse will make sure you have a supply of stoma bags and all the other equipment you need. Don't forget that you can call the stoma nurse for advice even after you are back at home.

## Don't be afraid to ask

**The fact is most people get back to a normal life quite quickly after surgery, but everyone is individual so don't be discouraged if you find things difficult.** You won't be the only one, that's for sure. 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.

**PATIENT TIP:**

'Three months after my op I returned to work, and I'm determined to live my life as normally as possible, even with a stoma – a bag for life.'



Above all, don't be embarrassed. We have all been through it and know just how tough it can be.

# Getting used to your stoma

**The fact is that, with care, almost everything you did before your stoma surgery, you can do afterwards with your stoma.**

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 piece of your bowel and that it is a living piece of your body and can bleed if damaged, so be very careful when you clean around it. A little bit of blood is fairly common, but anything more should be reported to your stoma nurse.

The stoma will also produce mucus (a thick white substance), which appears as pale ‘threads’ in your wee. This is totally normal and the amount of mucus will decrease over time.

**PATIENT TIP:**

‘At first you make mistakes – like not attaching things properly or leaving the taps on your night bag open – but you soon manage things properly. Do get a mattress cover for those early days, though. It’s not always possible when travelling so I take a big rain poncho to put under the sheet … just in case.’

All stomas are different sizes and shapes – this is totally normal. Your stoma is unique to you!

When you have the operation, your surgeons uses stents – small tubes – to help give the access needed to perform the operation. When you come out of hospital, some of these stents will come out via the stoma. They come away gradually for up to 14 days. Your stoma nurse will advise how to deal with them. Once they come away from the stoma, it becomes easier to position your bag. If you’re still having problems, try a different manufacturer or style of stoma bag.

# Emptying and changing the bag

If you can, get a partner or friend to watch while you are changing your bag so that they can help if needed.

**PATIENT TIP:**

'The only change I make is that I wear a leg bag when I'm working.'

**PATIENT TIP:**

'Make sure you gather all your supplies together before changing your bag.'

**PATIENT TIP:**

'Stoma pouches with a bendy/fold-up tap can occasionally be hard to open and close. If this is the case, rub a small amount of Vaseline around the bung to solve the problem.'

**Your stoma nurse will give you full instructions on emptying and changing the bag. Get as much practice as you can changing your stoma bag while you are still in hospital so that you have mastered it before you go home.** The more you practise, the easier it will become. Give yourself plenty of time to get used to the procedure so that you can do it at your own pace and without interruption.

The nurses will advise you and you will soon get used to making sure you empty it at the right time. 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.

## Changing the bag

**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 two days before you change it. This not only helps to prevent infection, but also a bag that is kept on too long is much more likely to leak.

Obviously you don't want a leak at any time if you can help it, but a leak while you are having dinner or when you are going out for the evening is not ideal. We know how tempting it is 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 first, as this will empty most of your wee into the bag first.

**PATIENT TIP:**

'After fitting a new bag, if you're using a two-piece system, give the pouch a yank to ensure it is clipped onto the flange securely.'

**PATIENT TIP:**

'I use wet wipes from my supplier to clean around the stoma and then dry wipes. You must make sure the skin is completely dry before applying the bag.'

**PATIENT TIP:**

'I always change my bag in the mornings, as that is when the stoma is less active.'

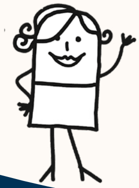
**PATIENT TIP:**

'If I take my bag off in the shower I let the water gently clean the area around the stoma and always do it first thing. I get my wipes and gear ready so it's pretty easy.'

# Night routines

**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 (3⅓ pints) 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 to get 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 (it's to do with balancing pressure). Once you get this flow going it usually keeps flowing naturally through the night without any trouble.



Ask your local council about disposal of your old stoma and night bags as many will offer a collection service.

**Do remember to change your night bag on a regular basis, too, to prevent the smell of stale wee in your bedroom.**

## Your stoma at night

**Our private online forum members came up with their best tips on managing your stoma at night.**

'To avoid twisting of night drainage bags during the night, use an anti-twist strip, fastening the tube of the bag to your leg.'

'To avoid an airlock in the night drainage system, connect the night drainage bag to a stoma pouch that already has some wee in it. Squeeze the wee through into the night drainage bag and the stoma pouch should then remain empty overnight.'

'Flat-pack night drainage stands can be either free-standing or slid between the mattress and the base of the bed, and are ideal for travel.'

'Reusable night drainage bags must be washed thoroughly after each use. Vinegar or disinfectant can be inserted using a syringe or small funnel, and then agitated and flushed through with warm water. However, it is acceptable to use just plain water. A night drainage bag should only be used for a maximum of five nights before replacing it.'

'Again, experiment with night bags, plug yourself in and enjoy the unbroken sleep.'

'The simplest method of night drainage is to use disposable bags, which are emptied and thrown away after each use.'

'At night I attach my bag to a night bag, which holds much more. I stand it in a washing up bowl just in case.'

'Some people find a leg bag more convenient than a night drainage bag for additional capacity.'

'I cut a hole in one side of my pyjama bottoms on the hip and use an extension tube on my night bag so I'm not restricted at all. I have long uninterrupted sleep now – bliss!'

'Place the night drainage stand in a plastic bowl or inside a large plastic bag (ensuring there are no holes in the bottom) for extra security.'

# Potential concerns

Most people have a few problems at first but there will always be someone you can call on for help – your stoma nurse, Bladder Buddy or someone on the FBC private online forum. Remember that there are many different types of stoma bag, so if you are having any problems try other styles by different manufacturers. **Let's look at some common problems …**

## The wrong 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.

**Your stoma will shrink after surgery as it settles down, so make sure that the opening in your bag continues to be the right size for your stoma.**

## Leaks

**Leaks are the main concern of most people and they do occur occasionally, but if they are frequent, then something is not right.** A correctly fitted bag is the best solution for this 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 overfull bag is a dangerous thing!

Leaks can also occur at night, especially in the early days, so be prepared for it happening. Your hospital will probably be able to give you a supply of incontinence sheets but as you get more confident you will find that leaks become very infrequent. 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.

If you do have a leak and notice wee smells from carpets, beds or furniture after a leak, wash thoroughly with a solution of bicarbonate of soda in warm water.

**PATIENT TIP:**

'I was told that the actual stoma is the "least of your worries" and this is so true. With time, please believe that you will love your stoma. It is saving your life. You can and you will be OK with your stoma.'

## Urinary tract infections

**Bacteria are commonly present in a stoma, but are usually flushed away if you drink plenty** (approximately 2–3 litres (3½–5¼ pints) per day). Tell your doctor if you have cloudy, unpleasant-smelling urine, discomfort or pain around the stoma or kidney area and a raised temperature, as you may have a urinary tract infection (UTI) and antibiotics may be appropriate.

!

**Contact your doctor if you have cloudy, unpleasant-smelling urine, especially if it is accompanied by discomfort or pain around the stoma or kidney area and a raised temperature**

## Hernias

**A hernia is a weakness in the abdominal wall often at a site where the abdomen has been opened surgically.** This can occur either around the stoma or at the incision site, and a small bulge develops. A hernia support belt may be worn to help prevent a hernia from developing or to support an existing hernia.

Discuss any concerns you may have with your specialist nurse. Surgical correction is only advised if the hernia is causing great discomfort or obstruction. The hernia is repaired and the abdominal wall strengthened using a fine mesh.

## Bleeding from the stoma or urethra

**The stoma has many tiny blood vessels, so it is not unusual to see specks of blood when cleaning it.**

This is normal. Bleeding may also occur if the stoma pouch is rubbing against the stoma and this should be fixed to prevent ulceration of the stoma. If the bleeding is excessive, seek medical help as soon as possible, as a large blood vessel may have been damaged. If any bleeding comes from inside the stoma, this should be investigated urgently. Sometimes urine infections and kidney stones can cause slight bleeding.

If your urethra was left in place after surgery, it is important to report any bleeding or discharge that may occur as soon as possible.

## Kidney stones

**One cause of kidney stones is recurring UTIs, but a high fluid intake can help prevent them.**

If you do pass a stone, save it and give it to your GP, who can arrange to have it analysed. Further tests may then be required.

# 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.

There are sprays that can add protection for your skin and information about these can be provided by your stoma nurse. Also ask about products available if you have sore places around your stoma.

Rebecca

Johnstone

'I sometimes wear braces, as belts can catch my stoma if they are in the wrong place.'

**PATIENT TIP:**

'When using paste, or similar products, wet your finger to avoid it sticking to your finger when you are trying to apply it to your skin.'

**PATIENT TIP:**

'Some of us men shave around our stoma, which can be fiddly. If you put the cap of the stoma removal spray over it as you are shaving, it's a perfect fit and prevents any nicks.'

'Wear loose, clothing to start with until you find things that fit comfortably.'

Colin

Margaret

# Comfortable clothing

Although many people are able to go back to wearing the clothes they did before the operation, the position of your stoma may make certain items a bit more tricky.

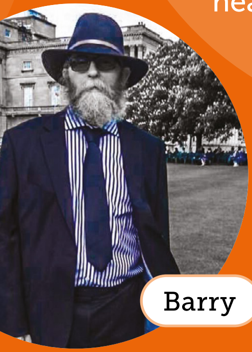
Clothing which may cause problems includes underwear, skirts or trousers with a tight waistband or belt which presses directly onto the stoma. Other patients are often the best source of information about comfortable, practical and stylish clothes and where to find them. We are happy to introduce you to other patients who will be able to help and advise about the practicalities of day-to-day life.

**Our private online forum members came up with their best tips for clothing that works with your stoma.**

'I found it more comfortable to wear jeans that didn't go tightly across my abdomen and also no belts. Anything pressing in too hard when I sat down would make me need the toilet. Once I was healed up, all was fine.'

**Lorraine**

'For the first few weeks after surgery I found tie waist or elasticated trousers easier than jeans. Once things had settled down I've been able to wear all the clothes I was wearing before.'



**Barry**

'I've switched to high-waisted or full brief knickers, as they give more support, as well as covering the pouch.'

'I wear my normal clothes with my shirt out rather than tucked in most of the time. Do whatever is most comfortable for you.'

**Liz**

'I got boxer shorts on prescription which had a pocket to hold the pouch securely until I felt more confident attaching my bag.'

# 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 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 with 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.

They will also be able to supply a range of mattress protectors, deodorising products and other items to help you manage your stoma.

**PATIENT TIP:**

'When attaching your bag, take a few minutes to press the bag firmly with your hand, or warm it under your arm, as the heat will encourage it to stick.'

If you are staying somewhere overnight, for extra piece of mind take a cheap mattress protector with you to pop under the sheet, so you don't have to worry if you do have a leak.

**PATIENT TIP:**

'If you don't like the smell when you empty your urine bag, order some of the deodorising spray from your chosen stoma supplies company.'

# Travelling

It can be a bit unnerving when you start to travel, whether that's a short trip to visit family and friends, or to take a longer holiday somewhere, but if you take a few sensible precautions, you should soon get into a routine. Here are some patient tips from our forum.

'When driving, always keep a night drainage bag in the glove compartment of your car to empty your pouch in case you are held up in traffic, but don't forget the connector between the two!'

'If you are flying, get a travel certificate from your nurse and ask the airport for a hidden disability lanyard – it helps with security. They will be more discreet and understanding when patting you down and it will also enable you to take extra supplies in your clear plastic travel bag.'

'You don't need anything particular for swimming. You can always get a special belt which covers the bag and then wear swim shirts over the top if you are worried about appearance.'

'On holiday I wear a high-waisted retro bikini. Nobody is aware of my bag and I swim and sunbathe without a problem.'

!

**A great idea for when you are out and about, is to keep some spare bags and equipment with you so you are never caught out!**

**PATIENT TIP:**

'If you are out and about and you 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 for an unexpected leak.'

## Remember …

**with a little practice and patience you should be able to get into a routine with your stoma and do all the things you have always enjoyed.**

# Clinical trials

Research is vital to increase our knowledge base, to help with prevention of disease and to develop new and better forms of diagnosis, treatment and after-care. A clinical trial can be offered at any stage in the bladder cancer journey and usually compares new with standard treatments. Each one will have its own eligibility criteria and you should discuss your suitability with your medical team. You can apply for trials outside your area if you are prepared to travel.

You will find a list of current UK trials in *Fight* magazine or at **fightbladdercancer.co.uk/research**

## New treatments for bladder cancer

A great deal of research is underway to develop knowledge in the fight against bladder cancer; new studies are being established, and new treatments are being offered. There are quite a few exciting scientific discussions and new clinical trials of immunotherapy and targeted therapy drugs, many of which are particularly targeted at advanced bladder cancer.

Visit **fightbladdercancer.co.uk/newdevelopments** to keep abreast of the new treatments.

# How Fight Bladder Cancer can support YOU

**Fight Bladder Cancer** is a UK-based charity that was founded and is led by bladder cancer patients and their families, so we know exactly what you are going through. Depending on whether you are a carer or a patient and where you are on the cancer journey, you are likely to experience a range of emotions from panic and fear to confusion and anger – this is completely normal. The most important thing that you should know is **you are not alone**. We're here to support you and guide you to the people and resources you need.

Our four main principles are: **offer support**, **raise awareness**, **campaign for research** and **affect policy.** So as well as being involved internationally in the development of knowledge about bladder cancer and its treatment, we have a strong support network that includes:

- a **dedicated website** at **fightbladdercancer.co.uk** with a wealth of information about bladder cancer, its treatment and how people cope
- **our private online Facebook forum** at **facebook.com/groups/BladderCancerUK**
- **our *Fight* magazine** – sign up for your free digital or print copies at **fightbladdercancer.co.uk/contact-preferences**
- download back issues of *Fight* from **fightbladdercancer.co.uk/downloads**
- **Support groups** in many locations throughout the UK and online
- a **Bladder Buddy service** which will team you up with a carer or patient who has gone through similar experiences
- a **regular e-newsletter**
- a **public Facebook page** at **facebook.com/BladderCancerUK**
- a **Twitter feed** **@BladderCancerUK** and **Instagram** **@BladderCancerUK**
- a **LinkedIn company page** **linkedin.com/company/fight-bladder-cancer**

# What do patients say?

*We chatted with cancer patient **Susan Mullerworth** about living with a stoma.*

## How did you adjust to life with a stoma?

Initially, I wondered how I would cope. I had so many questions. I thought I may feel unclean, I believed I would never be able to wear flattering clothes. I wondered what other people would think of me. Now I know this was absolutely normal. I have also learned that I can wear whatever I am comfortable wearing, and I can go out and about with the confidence that no one need ever know.

> **I have also learned that I can wear whatever I am comfortable wearing, and I can go out and about with the confidence that no one need ever know.**

While I was recovering from surgery, I contacted as many suppliers as I could find and I sampled all the bags and products available. I listened to advice, especially about my 'shape' following surgery. I was mindful of the reducing size of the actual stoma after surgery and ordered bags to be cut accordingly. A bit like a belly button – you may end up with an 'inni' or 'outti', so your stoma could be best suited to a particular shape of bag. I found a charity that sends any spares to developing countries.

## Do you have any practical tips?

Drink as much as you can, preferably water. If your wee changes colour, call your doctor as you may have an infection, and this should be treated soonest. Most stoma wearers keep a supply of antibiotics just in case.

Day-to-day life for me now involves just a few extra minutes added to my daily routine, namely a change of stoma bag at a suitable time.

I have small cosmetic bags containing spare bags that are in handbags, glove compartments and all over the place so I am never without one when I need it.

As my energy increased, I returned to work. I gave presentations without hiding behind a lectern, I regularly swim and go to the sauna. I travel, and even go down helter-skelters! Above all, I enjoy my life immensely.

**Whatever you did before your diagnosis, please remember you have every possibility of doing it again.**

Careful management is the key to dispelling worries. Yes, most people get the occasional leak but you will learn to manage this. Remember, too, that It could just be a faulty bag, so speak to your supplier if the leaks persist.

Get a RADAR key to give you access to disabled toilets throughout the UK, especially in railway stations, for example, or even in restaurants or libraries. You can buy them online from Age UK or many other sources. You can also get a 'Jump the Queue' Me+ card just in case you have an acute problem.

As and when you are ready, join us in naming your stoma, or telling us what you can do. We can embrace our life and thank our surgeons and supporters.

## How was Fight Bladder Cancer able to help you?

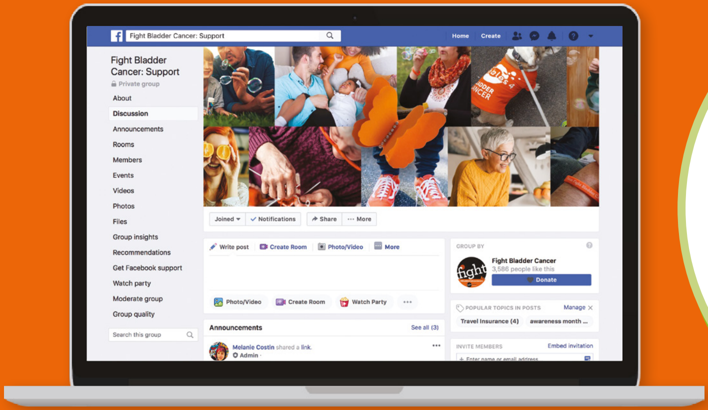
Before having my radical cystectomy, I managed to gather as much information as I could – which wasn't easy when I felt lousy and was in shock trying to come to terms with the diagnosis.

FBC made me realise I was not alone. They provided information that helped me make decisions on my treatment choices, and introduced me to a Bladder Buddy who knew exactly what I was going through.

After my surgery, I was so glad to be alive, but I literally had to take one day at a time, and all that time, FBC and my Wee Buddies were there to listen and support me until I got my strength back. ”

## Fight Bladder Cancer Support – our private forum

**On our private online members-only forum, patients, carers, families and professionals can discuss any worries or issues 24/7, find out about treatment options, or raise any other questions. Everyone is welcome.**



**PATIENT TIP:**

'The great thing about the private forum is being able to post questions, no matter how silly or trivial they may seem, and get immediate answers from others in the same position.'

**Join our private online forum at:**
**facebook.com/groups/BladderCancerUK**

# Can you help us in the fight against bladder cancer?

Supporting bladder cancer patients and their families is our primary objective. We are facing a growing demand for our services and urgently need more funds, so we rely on the generosity of friends like Susan to support our work.

**Listen to what Susan said about FBC:**

*'Now I'm a Bladder Buddy and I can tell you: wee are here for you. I support Fight Bladder Cancer absolutely, unconditionally, passionately because they are there for not just me but every one of us affected by bladder cancer. Let's please not forget the husbands, wives, partners, carers, family members and loved ones; they need help and support too.'*

## Your donations matter

A donation from you would ensure that we can be here when it matters most, to help improve the lives of people affected by bladder cancer.

Ways that your donations can help:

- providing support and information to everyone who calls and emails
- setting up and running patient support groups (Fight Clubs) around the UK
- connecting patients through our Bladder Buddy scheme
- spreading awareness of bladder cancer and campaigning to improve early diagnosis

We rely on voluntary donations and with your support can make a difference to the lives of thousands of people every year. Whatever you choose to do – whether you want to make a one-off donation or set up a monthly gift, do some fundraising, volunteer or raise awareness – we **thank you** – from the bottom of our hearts.

## Fundraising with transparency & credibility

- **we are open, honest and transparent**
- **we will always comply with the law** as it applies to charities and fundraising – we will be respectful of your rights and your privacy
- **we will be fair and reasonable** – treating all supporters and the public fairly – showing sensitivity and being adaptable
- **we will be accountable and responsible** – managing our resources wisely

We are committed to ensuring that we meet the requirements of the Fundraising Regulator and follow the Code of Fundraising Practice to ensure we meet the highest standards, so you can donate and fundraise for us with confidence and trust. You can read our fundraising promise at **fightbladdercancer.co.uk**

### This is how you can make a donation to Fight Bladder Cancer ...

**Online:** The easiest way to donate is via the donation button on our website **fightbladdercancer.co.uk/make-a-donation** where we offer a secure platform to make donations.

**By post:** If you prefer, you can send a cheque (payable to Fight Bladder Cancer) to our office at **Fight Bladder Cancer, High Street, Chinnor.**

**Call the office:** If you'd rather speak to someone in the team about donating, fundraising or volunteering – then call us on **01844 351621**. We would really love to chat with you.

Registered with FUNDRAISING REGULATOR

# Finally …

The aim of these patient information booklets is to provide comprehensive but straightforward information to support you in your fight against bladder cancer.

We understand what you are going through and we know you will have other questions.

**We are here to help.**

## REMEMBER, YOU CAN CONTACT US AT ANY TIME FOR SUPPORT

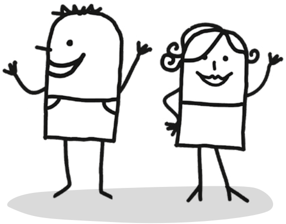
**or to engage with us in fighting bladder cancer**

via our website at
**fightbladdercancer.co.uk**

via our online forum at
**facebook.com/groups/BladderCancerUK**

by email at **info@fightbladdercancer.co.uk**

by phone on **01844 351621**



## Patient-held records

**In 2016, NICE approved the use of patient-held records (PHRs) – researched and developed by FBC and BAUN – for bladder cancer patients.** Already used successfully in obstetrics and diabetes care, they are designed to inform and involve patients in their care and facilitate communication between the different groups of people caring for them. They also provide a useful source of data on cancer care.

They can be used in digital or printed format and filled in by the patient with their CNS at each consultation. Both patient and hospital keep a copy. The PHR contains all the information relevant to the patient and their diagnosis and treatment. The documents are currently available for any CNS to personalise and download from **baun.co.uk/publications/bladder-cancer-patient-held-record**

### National Cancer Registry and Analysis Service (NCRAS)

Information on cancer incidence, diagnosis and treatment is recorded by the UK government in order to assess and improve the quality of service, treatment and research. It is derived from medical records from GPs and hospital departments, including independent hospital and screening services. The NCRAS has the legal authority to collect this data without requesting consent. The data can only be released for specific medical purposes.

If you wish to view your own data, or to opt out of registration, you can write to the Director NCRAS, Public Health England, Wellington House, London SE1 8UG. More information can be found at **ncin.org.uk**

**We have one last patient tip to share with you here. If you would like more tips on managing your stoma don't forget to join the FBC private forum where you can chat freely with other patients.**

**PATIENT TIP:**

''If your belly isn't flat (because let's face it – whose is?), pull up the skin to flatten it with your left hand and attach the bag from the bottom of the stoma to get a really good seal.'

# My patient tips

Jot down anything you have found particularly useful and send us your ideas by email, post or on the forum.

# My useful information

Hospital number ____________________

NHS number ____________________

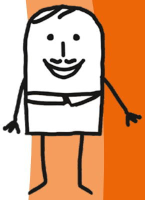
GP ____________________

Consultant ____________________

CNS ____________________

Other MDT members ____________________

____________________________________



If you come across terms you don't understand, you will find a comprehensive glossary in our *FIGHT* magazines or online at

**fightbladdercancer.co.uk/get-help/glossary**

Many photos in this booklet are of patients who have successfully undergone radical cystectomy.

*Everyone associated with the preparation and production of these booklets has made every effort to ensure that the information was correct at the time of going to press. However, the booklets are not intended as a substitute for professional medical advice. Anyone affected by bladder cancer, or any other medical problem, must seek the care and guidance of a suitably qualified doctor or medical team. Neither the publisher, nor contributors, nor anyone associated with them will take responsibility for any actions, medical or otherwise, taken as a result of information in this book, or for any errors or omissions.*

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This booklet is part of a series that covers all aspects of bladder cancer. The booklets are available free in print or digital format. You can order them via your clinical nurse specialist or download direct from Fight Bladder Cancer at **fightbladdercancer.co.uk/downloads**

## THE SERIES INCLUDES:

- Tests & investigations
- What is a TURBT?
- Low-risk & intermediate-risk, non-muscle-invasive bladder cancer
- High-risk, non-muscle-invasive bladder cancer
- Muscle-invasive bladder cancer
- Living with a stoma
- Living with a neobladder
- Advanced bladder cancer
- Surviving bladder cancer
- Diet & nutrition
- Carers' A to Z guide
- New developments in treatment for bladder cancer

**ENDORSED BY**

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British Association of Urological Nurses

British Uro-Oncology Group

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**Fight Bladder Cancer**
High Street
Chinnor | Oxfordshire

**+44 (0)1844 351621**

**info@fightbladdercancer.co.uk**
**fightbladdercancer.co.uk**

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