



bladder
CANCER

Patient Information Booklet

Living with a neobladder

& getting used to your new normal



A GUIDE FOR PATIENTS BY PATIENTS & PROFESSIONALS



YOU'RE NOT ALONE

Call us
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**WE ARE
HERE**
to help you in
your FIGHT

Matching you with a patient
with a similar diagnosis – get
one-on-one support from our

**Bladder
Buddies**

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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.

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!

ENDORSED BY

The British Association
of Urological Surgeons

British Association of
Urological Nurses

British Uro-Oncology
Group



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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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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

Dr 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; FBC Trustee

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: Design Couch

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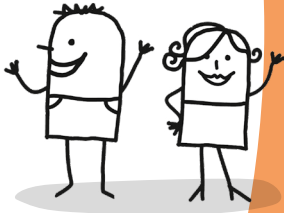
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Our **patient tips** come from **real bladder cancer patients** across the world!



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 medical 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 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:

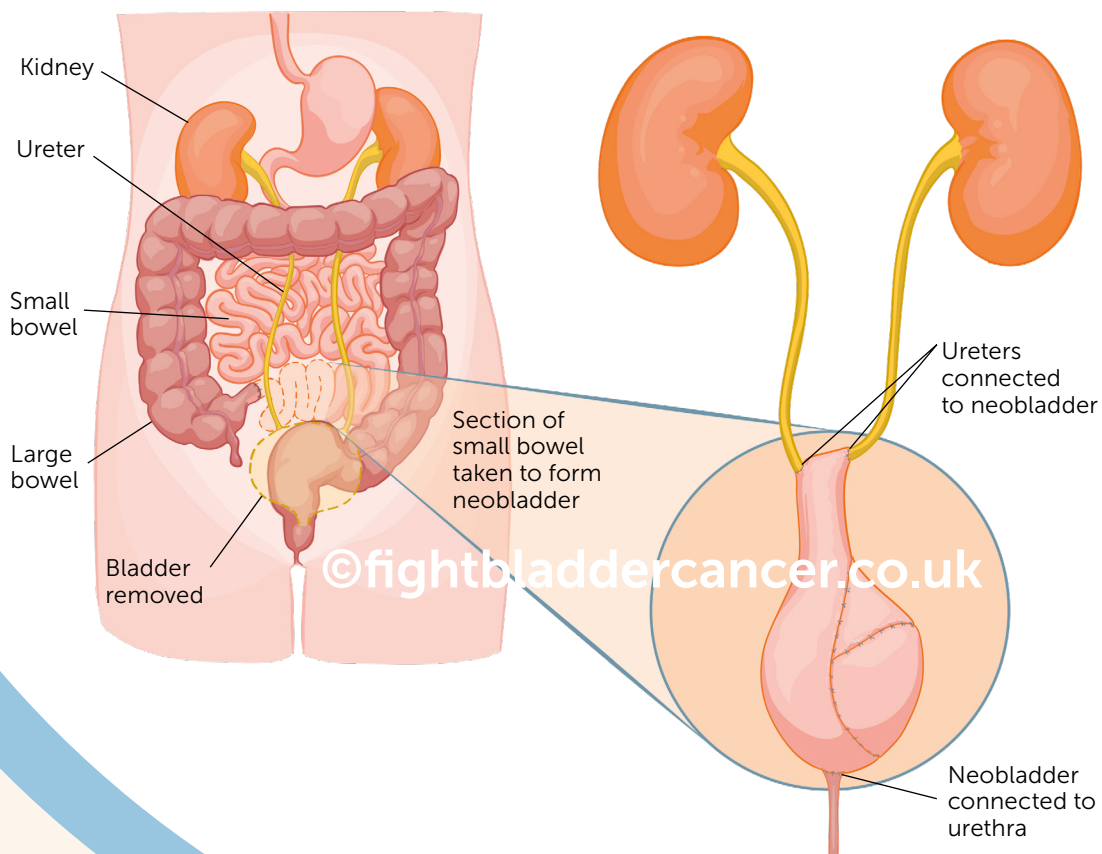
‘Make sure you find out as much as possible. There is plenty of helpful info online, but be careful that you don’t read things that aren’t relevant to your situation. Stick with reputable cancer sites.’

What is a neobladder?

A neobladder is one of the two main alternative ways to allow you to wee after you have had your bladder removed, although the procedure is not available in all hospitals. The other is to have a stoma – a hole in the abdomen to which a bag is attached to collect the wee.

About 80% of patients choose a stoma.

Forming a neobladder is carried out at the same time as you have your bladder removed (a radical cystectomy or RC). To create a neobladder, a piece of your bowel is cut out, and the remaining bowel sewn back together again. The section of bowel that has been removed is opened lengthways and then stitched together to make a new 'bladder'. This is then joined to your ureters (the pipes that bring your wee from your kidneys to your bladder). This new bladder, the neobladder, is then connected to your urethra, so that your wee is expelled through the normal route.

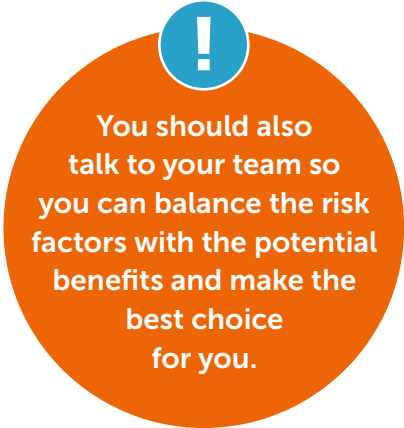


Making your choice

You will find full details of the radical cystectomy operation in another booklet in this series, *Muscle-invasive bladder cancer*. Ask your clinical nurse specialist (CNS) or contact Fight Bladder Cancer.

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

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 neobladder operation compares with the operation to create a stoma. You can also join the Fight Bladder Cancer private online forum, where patients and professionals can help to answer your queries.



You should also talk to your team so you can balance the risk factors with the potential benefits and make the best choice for you.

Things to think about when making your choice

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
- possible incontinence issues, especially at night, for some time

STOMA

- suitable for most 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

Another option, which is not common in the UK, is a Mitrofanoff. Surgeons create an artificial reservoir inside the body, in which the urine is stored, with a stoma in the abdominal wall into which the patient can insert a catheter to drain the reservoir when necessary.



Don't forget – your final decision must be right for you – and your lifestyle!

It is important that you have good bladder control and do not suffer from incontinence before having neobladder surgery as control will not be improved by surgery.

If your cancer has spread to the urethra, then you will not be able to have a neobladder as the urethra will have to be taken out to ensure all the cancer is removed. Some hospitals do not offer neobladders to patients over 70 as their pelvic floors are not as strong as younger patients.

Before a final decision is made, there will need to be blood tests and scans to make sure that a neobladder is the best option.

PATIENT TIP:

'To have a bag or a neobladder was a personal decision. It all depends on you and what you feel would be best for you. Do as much research as you can.'

Neobladder surgery

Your consultant should provide you with all the information you need to know about the specific details of your operation. If you are not clear on something, do ask. Make sure you know about all the permanent changes to your body as well as the temporary ones. Talk to your consultant about sex and make sure you know where to go to find information and any specialist advice and aftercare you need. Ask how many neobladder procedures they do each year and who will deal with any problems if they occur after the op.

A bladder reconstruction is a major operation and it is likely that you will need to stay in hospital for two to three weeks, during which your urology team will watch you closely to monitor your improvement and make sure that no complications occur. You will be given lots of fluids through a drip until you are able to drink enough normally, and you will also be given appropriate pain relief.

The medical team will help to guide you through this process. Don't be embarrassed to ask questions and keep asking until you have the information and help you need.

Getting used to having a neobladder and learning to live with it will take a bit of time but it will get easier with practice.

What are the potential risks of having a neobladder?

All treatments and procedures have risks, and your medical team will talk to you about them. The most common complications are:

- urinary tract infections
- mucus build-up (which may cause kidney stones to form)
- blood may become too acid (hyperchloraemic acidosis)
- incontinence by day and/or night
- inability to empty the new bladder completely and the need for self-catheterisation
- change in bowel habits
- erectile dysfunction (in male patients)
- sexual dysfunction (in female patients)

After the operation

Once you have had the operation, give yourself time to learn to control your neobladder and try not to be too impatient. If you take things step by step, you'll soon find you are gradually getting back to a normal, unrestricted life.



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

PATIENT TIP:

'Walking as soon as you can helps the digestive tract empty and the neobladder to function better.'

PATIENT TIP:

'Try not to do any heavy lifting for about six months.'

Fight Bladder Cancer has a Bladder Buddy service. They will put you in touch with someone who has had a similar procedure so you can talk one-to-one.



Paula

PATIENT TIP:

'Drink plenty of water. There will be less irritation if the urine is weaker, which makes me more able to tolerate holding more in the neobladder.'

Dylan

Do look after yourself. Try to keep to a healthy diet and drink plenty of liquids. These extra liquids are very important in the early days to prevent constipation. You have just had a length of your bowel cut out and what is left needs some tender care!

Avoid food or drinks that are likely to cause problems, such as highly spiced foods and carbonated drinks.

Pelvic floor exercises

The surgeon will leave behind the section of the urethra where the sphincter muscles are located. These are the muscles which work to help keep you dry. The surgeon will also attempt to preserve as many of the nerves in this area as possible. Even so, the neobladder will not work in the same way as a normal bladder.

The nurses will give you pelvic floor exercises and it is important that

you do them every day to gradually strengthen those muscles so you gain full control of your neobladder.

Balance rest and exercise

Get plenty of sleep and take plenty of rest, but don't sit about! Gradually introduce regular gentle exercise into your day as soon as you can. Walking, for example, will help speed up your return to a normal routine.

On the other hand, don't overdo it; lifting heavy items, for example, is not a good idea.

PATIENT TIP:

'Do not underestimate the importance of the pelvic floor exercises. Make it a routine as they really help with the control.'

Learning to use your neobladder

The first few months after the operation are all about getting used to this new way of having a wee. Remember you are learning a brand new skill and very few people get it right first time. Don't feel a failure if it takes longer than average to get it all sorted and be prepared for some incontinence in the beginning. Some people are lucky and it just 'clicks' and they are sorted within a couple of months. Many take longer, sometimes a lot longer, but you will get there.

Your medical team will give you any specific instructions you need to live with a neobladder. If you don't understand something, ask them to explain it again.

Do have a chat with people in the Fight Bladder Cancer private online forum who have neobladders – they will happily give you their best advice.

Mucus

One thing the nurse will explain to you is that your new bladder will produce a thick white mucus. This will always be in your wee from now on, but is normal and is nothing to worry about.

If you have a catheter

Straight after the operation you will have a catheter in the new bladder and a drain in your abdomen. These will normally be removed after a couple of days, but you will also have two fine tubes which will be draining the kidneys that will normally have to stay in for seven to ten days. Whilst you have the catheter in place, it is important that this isn't blocked by mucus so you will be shown how to flush your neobladder to remove any excess.

If you get any serious problems, like not being able to empty your bladder at all, even with a catheter, go straight to the hospital where you had your operation. If you are having difficulties in any way, contact your CNS.

PATIENT TIP:

'Take your time getting used to your new bladder. Don't panic if it seems to be taking a while to get the hang of it all.'

Capacity

Immediately after surgery, the capacity of your neobladder will be limited and it is important that it is emptied at regular intervals so it does not get too full; you will learn this with practice. You will probably need to set an alarm to wake yourself up at night in order to go to the loo in good time.

Try to avoid holding on in the hope that this will stretch the bladder. It is better that this happens slowly.

Regaining bladder control

Since all of the bladder and part of the urethra are removed during surgery, it is quite common to have some leaks or incontinence in the early days. There are simple precautions you can take in the beginning to avoid any embarrassment, such as protective underwear and plastic sheets for the bed.

Learning to use your neobladder and recognising when it is full will help you get the hang of it.

PATIENT TIP:

'It took several months for my neobladder to stretch to its ideal size. I emptied every two hours for the first month, then three hours, then eventually four. It was tiring for a few months but so worth it – I'm so happy with my decision.'



Gareth

PATIENT TIP:

'Drink plenty of water. Don't hold back on fluid intake to reduce the number of loo visits.'

PATIENT TIP:

'Don't try to hang on to pee too long. Better to go more often and increase the volume slowly than to hold more. It takes time for the neo to stretch; doing too much too soon can overstretch it.'

PATIENT TIP:

'Take each day as it comes – some people take longer to achieve continence than others. It takes patience but things do get easier, slowly but surely.'



Denise

How do you empty your neobladder?

The nerve supply to your new bladder will have been interrupted, so you will not get the same sensation as you did with a normal bladder when you need to wee. You will need to learn a new way to recognise when you need to go to the loo, as well as learn a new technique to empty your new bladder.

The feeling you get when you need to empty your new bladder will be different and varies between people. Some people experience a feeling of fullness, while others report that they feel like they need to pass wind! Don't worry, your body will find a way of telling you when it's time to wee.

You may find that particular triggers make you want to wee, such as standing up or sneezing. Watch out for them so you can be prepared.

PATIENT TIP:

'Days will improve sooner than nights and neos can continue improving for a couple of years post op. It took me four weeks to get capacity, but several months for good continence. Just have patience – it's a marathon, not a sprint.'

PATIENT TIP:

'When you are getting used to things, be careful standing up and sitting down, as these are the actions that can provoke leaks.'

PATIENT TIP:

'I would encourage men to sit down to pee whenever possible as it is the only way to completely empty the bladder and reduce the possibility of infections.'

A different technique

You will also have to learn a new way to have a wee. You will need to relax your pelvis and strain your abdominal muscles to squeeze your wee out. Most men find that they need to sit down to do this rather than trying to do it standing up.

It is important not to strain too much, however, so take your time and don't try to force it out at all costs.



If in doubt, ask for help as many times as you need to. Don't be afraid to ask the same question more than once.

PATIENT TIP:

'I have found that stretching a couple of times before you wee is a good idea. Stand up and stretch both arms above your head, then bend from side to side before you sit down to wee.'



Self-catheterising

While you are still in hospital, you will be shown how to use a thin catheter in case you need to rely on one to empty your bladder completely. Wee left in your bladder can make you more prone to infections and could cause problems for your kidneys.

Some people may need to self-catheterise more regularly in order to ensure that the neobladder is emptied completely. Your CNS will go through the procedure with you if necessary.

Your neobladder at night

Most people find they get used to keeping their neobladder under control more easily during the day than at night. Don't worry – take a few sensible precautions and you will find the solutions that best suit you. Patients on our private forum have shared their practical tips.

'As an insurance policy, I would recommend wearing an incontinence pad for a night's sleep to avoid the occasional accident. This also means you don't have to set a night alarm that disturbs not only your sleep pattern but also your partner's.'

'There will be a few leaks in the early stages, so get a waterproof mattress cover and incontinence pants for when you come out of hospital, just in case.'

'I suggest not drinking after 9pm. It gives you the opportunity to have a reasonably empty neo when you settle down for bed.'

'I know people have to get up in the night, but for them their body wakes them. With the neobladder it doesn't. You'll need to set your alarm so that you can get up regularly to empty it.'

'When getting used to my neobladder at night, I bought puppy training pads to go over my bed sheets. They are light and discrete and cheap.'

'When you are training a neo, men can get a condom catheter to use with a night bag if they need to get a bit more rest. Now my neo has stretched I only need to get up a couple of times in the night.'

Getting support and advice

Most people encounter a problem or two when they have had a major operation and are coping with this new way of doing things. The time it takes to adjust will vary, but be assured that other people will have encountered the same problems.

There is no need for you to suffer in silence. Contact the team at your local hospital for any problems with your neobladder; they have tremendous experience in helping you deal with any difficulties or worries you may encounter.

You can also get many tips and advice from other people with neobladders by joining the Fight Bladder Cancer private online forum, which you can access from fightbladdercancer.co.uk

Remember ...

life is as good as you make it. With the right help and a little determination, you should be able to return to the activities you enjoyed before your operation.

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



What do patients say?

We asked Jo Peacock about her decision to have a neobladder.



What was your initial reaction to your diagnosis?

To say I was devastated by my cancer diagnosis would be a gross understatement. I was a healthy 48-year-old non-smoker. How could this be happening?

We discussed both the stoma and neobladder options, but my consultant advised that I was suitable for a neobladder and that it was worth serious consideration. I opted for the neobladder, and although the recovery was likely to be a bit longer, for me it felt like the right option.

A year on, I am fit, well and adjusting to my new normal life. I still catheterise daily, and I don't have that normal feeling when I need a wee, which took a while to get used to.

It isn't easy: the chemotherapy was extremely tough, and then the operation left me weak and very dependent on the people around me, but I took it slowly, did as I was told and gradually I started to get back to some normality, gaining strength day by day.

I'm now back at work and leading a normal life, but continue to go for regular check-ups.

How was Fight Bladder Cancer able to help?

I found Fight Bladder Cancer quite early on. I was keen to get as much information as possible and link with other people who could offer support and advice from their own experiences. I joined the private forum and was so glad I did. The support was invaluable throughout my treatment; so many kind words of support, I never felt alone.



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 where you are in your cancer journey, you – and those closest to 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 free **FIGHT magazine**, which has articles on all aspects of bladder cancer and is available in print or digital editions
- **Fight Club support groups** in many locations throughout the UK
- a **Bladder Buddy service** which will team you up with a patient or carer who has gone through similar experiences
- a **regular e-newsletter**
- a **public Facebook page** at facebook.com/BladderCancerUK
- a **Twitter feed** [@BladderCancerUK](https://twitter.com/BladderCancerUK)

PATIENT TIP:

'I jump on to the support forum when I'm low. Chances are that someone else is feeling or has felt the same and so I never feel stupid or alone.'



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](https://www.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 Jo to support our work.

Listen to what Jo said about FBC:

'I continue to use the forum and feel part of a massive family. Everyone has their own story to tell, with good days and bad days, but we are all in it together, and it's so important to know someone else has been through something similar. I also offer advice and support to others who are just starting their journey.'



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, 51 High Street, Chinnor, Oxon OX39 4DJ.**

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

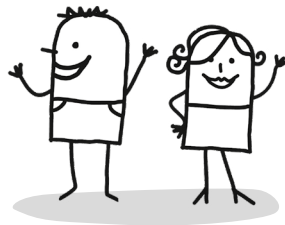
fightbladdercancer.co.uk

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

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.

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 _____

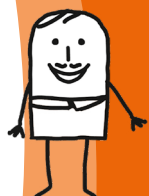
NHS number _____

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/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.

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 direct from Fight Bladder Cancer at **fightbladdercancer.co.uk**

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

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British Association of
Urological Nurses

British Uro-Oncology Group

Fight Bladder Cancer

51 High Street | Chinnor
Oxfordshire | OX39 4DJ

+44 (0)1844 351621

info@fightbladdercancer.co.uk

fightbladdercancer.co.uk

 facebook.com/BladderCancerUK

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