

b&b

Bladder & Bowel  
Community

# Facing up to incontinence



[www.bladderandbowel.org](http://www.bladderandbowel.org)



# Foreword...

Phil Assassa

**Consultant Urogynaecologist**



A healthy bladder and bowel is important to all of us, it lets us get on with our lives. Most of us take going to the toilet for granted and it isn't until something goes wrong that we realise how much of an impact a problem can have on our everyday lives.

Reading the stories in this booklet will confirm there is no doubt about the huge impact bladder and bowel problems can have on quality of life. Every single area of life is affected from relationships and ability to work to travelling and socialising. Everyday becomes a battle filled with the worry of being able to find a toilet in time, about a leak that cannot be controlled and the all-consuming embarrassment of having an accident in public.

However, despite the anxiety, disruption and change caused to peoples' lives, there is still a huge reluctance to seek help with many people even concealing symptoms from partners, loved ones and friends. Unfortunately, in a liberated society, people still find it difficult to talk openly about their bladder or bowel problems.

The physical symptoms are one thing, coping with the embarrassment, anxiety or loss of confidence can often lead people to become isolated and even less likely to seek help.

So when something does go wrong, plucking up the courage to talk about your problems can be the one thing that stops you from getting help.

The people in this booklet are real and their experiences have many things in common. They have all come forward to tell their story for one reason only, to encourage others to seek help and get access to the treatments that could turn their lives around.

Please remember that you are not alone, there are an estimated 21 million people in the UK with some form of bladder and/or bowel problem and a phone call is all it could take to change your life for the better.

**Please contact the Bladder and Bowel Community (B&BC) today and speak to one of our specialist continence nurses or physiotherapists for more information on the wide range of different treatments and products available.**

# The **consultant's** view

## Philip Toozs-Hobson

**Clinical Director and Consultant Urogynaecologist  
Birmingham Women's Hospital**



Incontinence can be extremely embarrassing and very difficult for a patient to openly discuss with a healthcare professional. In addition many healthcare professionals feel uncomfortable discussing an area of healthcare for which they feel inadequately trained. I've seen many patients over the years who have needlessly suffered in silence, trying to cope without professional advice or a support network, and often managing with inappropriate products such as sanitary pads. Incontinence and other symptoms of bladder and bowel problems are medical conditions that can be treated, and in some cases cured. Most estimates suggest that up to 1:4 people have occasional symptoms, but incredibly around 2.5% have symptoms that are socially disabling. That figure represents around 50 people per GP in the UK!

You should not have to merely 'put up with' your symptoms or condition, as there are a range of different treatment options now available that have already brought a new lease of life to many patients.

It's a common myth that these problems are an inevitable part of ageing or childbirth. This simply isn't true and the patients featured in 'Facing up to Incontinence' are testament to that fact. Men and women, young and old can experience bladder and/or bowel problems.

If you are already being treated and feel like you have hit a brick wall with your management pathway, do go back to your GP or consultant and ask them to discuss other options with you as there may well be another viable option out there. Many of the patients over the coming pages tried a variety of treatments before finally finding something that worked for them.

It is normal practice to be first offered what are known as conservative treatments, for instance, pelvic floor muscle exercises or lifestyle changes. Medication may also be offered to you alongside conservative treatments, depending on your symptoms and medical history. Surgery is a final option and will not normally be offered to you until you have tried other treatments for a length of time without success.

Having said that everybody is different and it does not follow that because a treatment worked for one person it will work for you, or even be suitable. However for everyone the first step on the road to recovery is to see a GP or continence advisor for assessment. They will then be able to make a diagnosis based on your medical history and only then will you be able to start discussing and considering treatment options.

With the right information and direction, you can take proactive steps to manage your incontinence effectively and start living your life to the full again.



*“The treatment has improved the quality of my life dramatically”*

## Emma Henderson

**Age:** 22  
**Location:** Droitwich  
**Occupation:** Care assistant /student  
**Diagnosis:** Overactive Bladder (OAB)

**Treatment:** Botox injections  
**Consultant:** Mr Chen  
**Hospital:** Alexandra Hospital, Redditch

# I was desperate for a solution

"I first remember going to the doctors about my bladder problems when I was seven. My Mum was fed up of me going to the loo and then a few seconds later demanding to go again. We were told it was nothing to worry about and I would grow out of it, but I didn't.

I went to the loo around 20 times a day and got up three times at night. It disrupted everything in my life – my sleep, schoolwork and friendships.

At senior school we weren't allowed to go to the toilet during class and I was reduced to tears many times because I was literally bursting for the toilet. When the lesson ended I would run as fast as I could to the loo.

If I was out with my friends I would leave them every five minutes to go. On one occasion there was the inevitable queue for the ladies so I had to pretend I was going to be sick so I could be next otherwise I would have probably wet myself.

In 2008 I spent four months with Camp America working as a special needs counsellor. The first few weeks my bladder problem got worse.

I thought I had an infection and drank lots of cranberry juice which made matters worse. On my return I insisted my doctor refer me to a urologist. After scanning my bladder and having a urodynamics test I was finally told I had a very overactive bladder. I simply burst into tears with relief. It wasn't all in my mind after all and now there was a possibility I would get some help.

I was put on Solifenacin, which is a drug used to reduce the frequency of passing urine, but it made little difference which was a huge disappointment as I was back to square one. Then one day, I came across a leaflet which

claimed that Botox may help ease bladder problems. So desperate for a solution to my bladder issues, I went back to my urologist to discuss it and thankfully he agreed that we should give it go. Before having the treatment I had to see a specialist nurse who taught me to self-catheterise in case the procedure caused me to retain urine as this can sometimes happen.

In February 2010, under a general anaesthetic, I had my first treatment. It was amazing and has improved my quality of life dramatically. Instead of getting up three times a night I only had to get up once. Botox gives me five good months, then I start to notice a difference and by the seventh month I'm ready for another treatment.

Thanks to this treatment I've got the confidence to go to university and I'm due to study adult nursing at Bristol. At last I am able to sit and concentrate for an hour without interruption.

I think I should have been offered treatment much earlier because OAB has really interfered with my studies. Young people with this condition need to put their foot down when they see their GP and ask to be referred to a urologist, because there are simple and effective options out there. Doctors should remember it is not only older women who have urinary incontinence."

Botulinum toxin is currently unlicensed for non-neurogenic detrusor overactivity, and as such may not be widely available as it is an "off licence" application. However in many hospitals in the UK it will be used, but this should only be after all licensed or conventional treatments have been tried and as either part of an audited series or in a trial setting.



*“Two years ago a miracle happened. I had surgery to implant a device that lets me know when I need to go”*

## Jemima Stolz

**Age:** 73  
**Location:** Preston  
**Occupation:** Retired time shares rep  
**Diagnosis:** Poor bowel control

**Treatment:** Sacral nerve stimulation  
**Consultant:** Mr Kiff  
**Hospital:** Wythenshawe Hospital, Manchester

# Don't be embarrassed

"I was in a charity shop in Bolton 32 years ago when I first realised I had a bowel control problem. I asked if I could use their loo but they said no and the next thing I knew everything had come away from me right there in the shop. I went to see my GP who said it might have been something I'd eaten and gave me some tablets. The tablets made something of a difference but I would still suffer with accidents on occasion.

I was working as a sales rep during the day and pursuing my passion for singing by performing in clubs at night, so you can imagine, I was terrified of soiling myself, particularly as there were times when I didn't realise I was doing it.

Life went on however and I was overjoyed to be offered a singing job in Marbella and I hoped the tablets would keep my problem under control. But my bowel incontinence returned and after eight months I daren't go on stage in case I had an accident.

I had numerous examinations at a private clinic but no-one could tell me what was wrong. When I moved to Gran Canaria I saw a host of specialists, one even suggested it could be malaria or cancer.

In Gran Canaria I met my late husband Roland. He was working for the same time-share company as me. At first I refused to go out with him because of my incontinence. But he didn't take no for an answer and I had to explain. Roland was amazing; he wasn't embarrassed or disgusted as I thought he would be and was very understanding.

I never went anywhere without wearing large incontinence pads and carrying a big bag of spare trousers, panties and pads. If we did

go out I would sit as close as possible to the toilet and carry a card saying 'I can't wait.'

When Roland died in 2004 I came home and underwent repeated tests as I was literally at my wits end. Eventually I was referred to a specialist at Wythenshawe Hospital in Manchester and he was the first to tell me the cause of my problem – little muscle action in my bowel.

By now I was so frightened of messing myself I didn't go out. Even at home watching TV I sat on a commode because I was afraid I wouldn't get to the loo in time.

Two years ago a miracle happened. I had surgery to implant a device called InterStim that stimulates my sacral nerves and lets me know when I need to go. Now I can go anywhere and eat anything as I'm finally free to enjoy time away from my home without having to worry about where the nearest toilet is.

People with a problem like mine shouldn't be embarrassed to talk about it and should seek a specialist who can discuss the most up-to-date treatment available."

There are a number of different surgical procedures available to treat incontinence. However, surgery is usually a final option after other more conservative treatments have been tried; speak to your GP or health professional for more information.



*“Things had got so bad I was in danger of losing my job”*

## Tara Wilson

**Age:** 44  
**Location:** North London  
**Occupation:** Admin officer  
**Diagnosis:** Spina bifida and irritable bowel syndrome

**Treatment:** Antibiotics; catheterisation; daily anal irrigation  
**Consultants:** Mr Leye Ajayi and Professor Christine Norton  
**Hospitals:** Royal Free Hospital and St Marks, Harrow

# Without this technique I wouldn't be here

"From birth I've had no control over my bladder or bowel. I wear incontinence pads 24/7, self-catheterise four to six times a day and irrigate my colon every morning. Whether my lack of control is due to my spinabifida or the surgery I had as a baby to fuse the bones in my spine, I'm not sure.

While I can walk, swim and skate, I've no sensation in the back of my legs from my knees to my buttocks. At 18 I suffered third degree burns when I sat on a cigarette in a pub and didn't realise the smell of burning fat was me.

My worst childhood memory is of an assembly at junior school. I asked if I could leave to go to the loo but was told I had to wait until the end. By then I didn't want to move because I knew the whole school would discover I had wet myself. Pad absorbency in those days was zero.

By senior school I learnt to limit my fluid intake to half a can of cola to prevent accidents and would carry spare pants just in case. Because I didn't drink enough I was in and out of hospital with urinary tract infections.

At 25 my urologist suggested I had surgery to make my bladder bigger. They removed a piece of my colon, opened up my bladder and stitched it in. Because the piece of colon had nerves attached, for the first time in my life I had the sensation of a full bladder.

However, I continue to catheterise and I have to get rid of the residue of urine otherwise there's a chance of infection. Catheterisation doesn't make me sore as I can't feel anything in this area. Every year I have a cystoscopy to check for scar tissue and cancer because of this lack of sensation.

My bowel wasn't too much of a problem at school because most of the time I was constipated. But over the past six years it has become a major issue and I thought it would cause me to lose my job as every few days I was having massive bouts of diarrhoea with only two seconds notice.

The gastroenterologist told me I have a lazy bowel that gets irritated by certain things. It's always going to be a problem whether I eat healthily or have junk food. I became desperate and five years ago asked to be referred to a specialist at University College Hospital London to see if there was anything that could help me.

He told me about anal irrigation which clears the lower part of your rectum and moves things on. It has changed my life.

I irrigate for 25 minutes every morning before getting ready for work. As long as I eat sensibly, avoiding rich foods, I rarely get diarrhoea now.

Without this technique, I wouldn't be here. If I had lost my job, then I would have lost everything – my house, my car – and life wouldn't have been worth living. Now I go around the country talking to nurses about the procedure.

My advice to anyone with problems like mine is to speak to someone – the Samaritans, a GP's counselling service, friend or fellow patient. Don't bottle it up. If you do it will tear you apart."



*“I missed most of my primary school education because I was in and out of hospital with severe pain in my bladder area and dreadful burning sensations down below”*

## Lydia Robinson

**Age:** 18  
**Location:** Birmingham  
**Occupation:** Student  
**Diagnosis:** Fowler’s Syndrome

**Treatment:** Sacral nerve stimulation, painkillers & antibiotics

**Consultants:** Miss Elneil Philip  
Toozs-Hobson

**Hospitals:** The National Hospital for Neurology and neurosurgery, London  
Birmingham Women’s Hospital

# Don't give up hope

"Growing up, I didn't usually get the urge to empty my bladder and mum was constantly reminding me to go to the toilet. When I did go, I never fully emptied and would sometimes have accidents. I missed most of my primary school education as I was in and out of hospital with severe pain in my bladder and dreadful burning sensations down below. If I had an infection, I would stop urinating altogether. Fowler's Syndrome, or an underactive bladder, was never diagnosed or even mentioned until I was around 16 years of age.

The typical patient with Fowler's Syndrome is a 20–30 year old woman, not a child, and I felt that some doctors thought I was imagining my symptoms and just didn't know why I kept being so unwell. I knew from experience that I had all the symptoms of a urinary infection but as it didn't always show up on the dipstick test, doctors would not prescribe antibiotics, causing my symptoms to worsen which usually meant I'd end up in A & E doubled up in pain. I also suffered from kidney reflux on the right side which means the valve does not work properly and urine flows out of the bladder back up the ureter to the kidney. I had numerous operations to try and repair this but finally my kidney became so damaged that it was removed in 2006.

About a year before, I had to be taught to self-catheterise to drain the retained urine. I was catheterising four or five times a day and I got very sore down below and when I began the transition to adult urology services at 16 years old, my new urologist suggested a different kind of catheter – a suprapubic – that went straight into my bladder through my belly button, allowing the area to recover.

He also raised the possibility of an underactive bladder and referred me to see a specialist in London who finally diagnosed Fowler's Syndrome. At this stage I was suffering from chronic fatigue and in so much pain in my bladder that I could barely manage to walk into

the room to see her. The pain had got so bad that every three months I was having epidural pain blockers. The specialist recommended a device called a sacral nerve stimulator which would stimulate the nerves in my bladder and tell me when I needed to go to the loo. This operation had not been carried out on anybody under the age of 18 so the hospital were reluctant to let me have the operation.

My specialist didn't give up and finally, in May 2010, I made history by becoming the youngest person to have the device implanted. The sacral nerve stimulator has made a huge difference and in spite of missing a great deal of schooling, I've managed to get five good GCSEs and have since started a BTEC health and social care course at Kingshurst Academy.

My advice to any young person with bladder problems is not to give up; you know your own body. Don't let doctors tell you it is just an older woman's condition. The medical profession needs to be better informed about conditions like mine and to realise that young people can have chronic bladder problems too."

Sacral nerve stimulation patients are required to remain under continuous healthcare professional follow up at one of the highly specialised centres around the UK. Please call the Bladder & Bowel Community on 01926 357220 to find your nearest centre.

**Specialist centres are located throughout the UK**





*"There have been times when I have got very low, but I've got through thanks to the support of my family and also by talking to others with similar problems"*

## Adam Douglas

**Age:** 44  
**Location:** Leeds  
**Occupation:** Former Royal Dragoon Guard, now working for Leeds NHS Equipment Services  
**Diagnosis:** Double back fracture; pelvic nerve damage; left leg paralysis; bowel and bladder incontinence

**Treatment:** Implanted bilateral sacral nerve stimulator catheterisation; pads; Botox  
**Consultant:** Neil Harris  
**Hospital:** St James University Hospital, Leeds

# Everyone takes going to the loo for granted

“Everything down below was working well until I was 36. Then at the outbreak of the Iraq war I was called up. Within 19 days I was in an exchange of fire with the Iraqi army on the outskirts of Basra and thrown to the ground by an anti-tank warhead.

At first I didn't realise I'd been hit as the shock of impact covered the extent of my injuries. Later I learnt my radio pack and body armour had saved my life.

In a Kuwaiti field hospital some hours later, a doctor noticed my clothes were in shreds and that I had burns on my neck and arms. An X-ray revealed two spinal fractures and so I was immediately immobilised. Back in the UK, I spent the next nine months undergoing intensive surgery on my spine.

To begin with I retained urine and faeces and had to be catheterised. Because of all the surgery, I didn't notice I'd lost any sensation of knowing when I wanted to go to the toilet. This was due to significant injuries to my nerve tissue.

I used a sheath catheter and irrigation system to help control my bowel incontinence and Botox injections for my bladder incontinence. The Botox made me retain urine, which can happen in some cases, so I was taught to self-catheterise. After a couple of years my urologist became concerned about the amount of Botox I was having and suggested I try a new implanted device to stimulate my sacral nerves.

In order to prepare my body for the implant and surgery, I had to come off the Botox and let everything get back to its very worst state. Then for three weeks I used an external device to see if the implant would work for

me. For the very first time in years I could sense twitching at the bottom of my spinal cord.

I then had a bilateral device implanted. This let me know when I wanted to pass a motion or urinate. It's simply fantastic. Although I don't have total control, the majority of the time it allows me to find a toilet. I still wear a sheath catheter in case I cough or sneeze but usually I go to the loo in the normal manner like I used to.

I don't have to wear pads during the day any more although I still use them at night in case a sudden movement in bed causes me to leak.

Sometimes the implant settings need adjusting and the batteries have to be replaced every five years, but this doesn't involve major surgery.

Everyone takes going to the loo for granted. They don't realise incontinence changes your life around and it doesn't help that adult incontinence remains such a taboo subject. Even some GPs have frowned at me when I've turned up with nappy rash or an infection around my bottom and asked for a prescription.

There have been times when I have got very low, but I've got through thanks to the support of my family and also by talking to others with similar problems. Don't be on your own with something like this. Find someone you can talk to.”

\* Adam is the chairman and founder of The Forgotten Heroes, a charity set up to support the carers of the thousands of injured servicemen and women in the UK.



*"I can now chase my children around the garden without having an accident"*

## Natalie Pike

**Age:** 37  
**Location:** St Albans, Hertfordshire  
**Occupation:** Works for extended schools' programme  
**Diagnosis:** Stress and urge urinary incontinence

**Treatment:** Pelvic floor exercises; incontinence pads; Tension-Free Vaginal Tape surgery  
**Consultant:** Mr F A Sanusi  
**Hospital:** Spire Harpenden Hospital

# Overcome your embarrassment

“The day after my second baby was born I knew things weren’t right. I had no control whatsoever over my bladder. When I took my three-day-old son for tests I mentioned this to the midwife who agreed it wasn’t normal and referred me to a urology nurse.

It was too soon after the birth for me to have many of the tests and I was told to return when things had settled down. The nurse suggested there was a chance my incontinence would sort itself out, however, it didn’t. I had to wear massive incontinence pads day and night which made me sore and hot. If I got up when my baby was crying at night I had to go straight to the loo, not to my baby.

My bladder problems began in my late twenties. I enjoy sport and I found that occasionally when I was running I would leak. I also noticed that as soon as I put my key in the door I needed the loo immediately. At the time this wasn’t a huge problem.

But, after my first baby was born I noticed I was leaking more, especially when I was on the treadmill and exercise bike at the gym. I mentioned this to my GP who recommended pelvic floor exercises. These helped a little with my urge incontinence but not with my stress incontinence.

Twelve weeks after my second baby was born I went back to see the urology nurse. I had to sit on the loo so she could measure my urine flow and check whether I’d emptied my bladder. She also monitored me internally while I did my pelvic floor exercises and found I had a strong pelvic floor with a score of nine out of 10.

This was a surprise because on occasion, I couldn’t stand from a sitting position without losing bladder control and so nine months after giving birth, I had surgery. A tape was

inserted through my abdominal wall to help support my urethra and keep it in its correct position. When I came round my tummy felt sore inside but the next morning I was bouncing around.

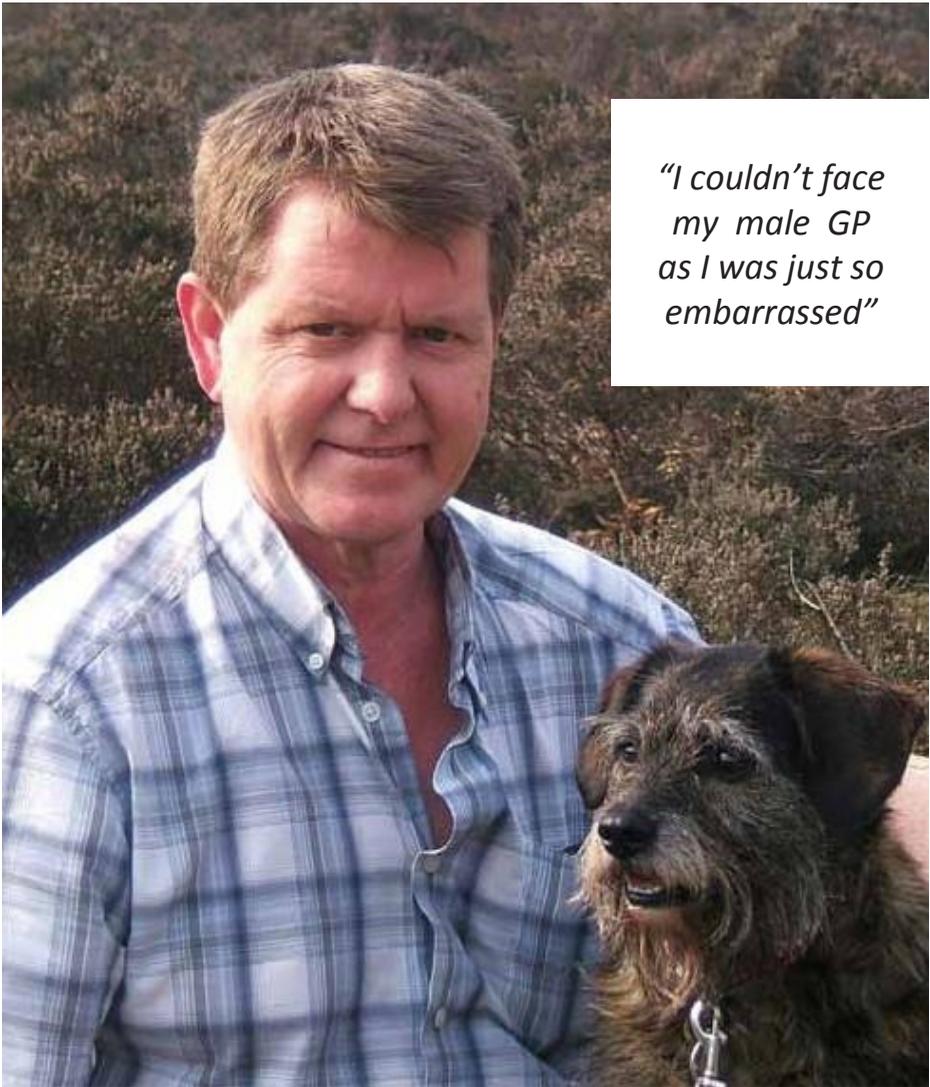
Tension free vaginal tape is an ideal treatment for stress incontinence. I can now chase my children around the garden without having an accident and go to the park again with friends and their children. Before I had my surgery I would have to cancel outings like this because of my incontinence.

I don’t have to wear pads any more, but I do carry spare knickers in my bag because I still have urge incontinence. That’s something I’m learning to live with and plan around to avoid accidents.

Since my procedure many friends have told me they leak but don’t do anything about it, because they are embarrassed or scared of investigations in that area.

For many women, the reluctance to visit a healthcare professional isn’t helped by the fact that so many urologists and gynaecologists are men. There is help out there if you can overcome your embarrassment.”

There are a number of different surgical procedures available including tension-free vaginal tape, trans obturator tape and colposuspension. Surgery is usually a final option after other more conservative treatments have been tried; speak to your GP or health professional for more information.



*“I couldn’t face my male GP as I was just so embarrassed”*

## **Tim** Harvey

**Age:** 51  
**Location:** Bracknell  
**Occupation:** Highways Agency Traffic Officer  
**Diagnosis:** Overactive Bladder (OAB)

**Treatment:** Treatment: Sheath catheter and leg bag; incontinence pads and towelling nappies

# Don't be embarrassed to talk to your healthcare professional

"Looking back I had problems at school. I was always the one with my hand up asking to be excused. But in my late twenties it got worse and I started wetting the bed. Initially it happened once a month which I simply put down to the stress of working all hours as a sales rep.

Then it started with greater frequency, every week and I was scared to go to sleep. To keep awake the next day I drank lots of coffee which meant even more problems at night.

For 10 years I was too embarrassed to talk to anyone about it. How can a man in his thirties say he's wetting the bed?

I then began having accidents in the day. On one occasion I was miles from home filling up the car and suddenly needed to go. I just couldn't hold it and a puddle appeared on the forecourt. From then on I had to wear incontinence pads and waterproof pants every day and toilet map so I knew where the next loo was.

It was at this stage that I saw a urologist and at 39 I underwent a procedure called hydrodistension to increase the size of my bladder. This helped during the day for five or six years, although I was still wetting the bed two or three times a week.

In my mid-forties, when I was working for the highways agency, my incontinence got very bad again. I always took two spare pairs of trousers to work with me and every 10 minutes would ask my colleague to pull up so I could go to the toilet.

I reached my lowest point when I had five accidents in one day. One was in front of the public. My pad leaked and a puddle appeared on the motorway. I realised I had to do something but still could not face my male GP as I was just so embarrassed talking about it.

Eventually I saw a female doctor who was very understanding and referred me to a urologist. I was put on different drugs but none worked.

In 2009 I had another hydrodistension but something went wrong. My body started retaining water and I had to go back into hospital and have an indwelling catheter put in through the urethra, which also meant I had an external collection bag. Over the next six months, I had 20 indwelling catheters put in and suffered from numerous infections which is a common side effect. Every time the catheter was changed, I had to have morphine administered as the procedure was so painful. In the end they had to use child-size ones. Frankly, I felt life wasn't worth living anymore and I was in so much pain that I had to take four months off work.

My urethra had become so scarred that I had to be given laser treatment to remove the scar tissue inside my bladder but this has left me with no control whatsoever. I now leak half a wine glass of urine every 15 minutes.

Incontinence has slowly taken away my dignity and self-respect. I am now classed as disabled but it is very important for me to continue working because it helps me retain some sense of dignity and self-respect. I now wear a sheath catheter that is rather like a condom. It self-adheres to my penis and has a tube that empties into a large bag attached to my leg. Now when we're doing a five-hour job in the middle of the motorway my colleagues are envious because I can go but they can't.

You must remember that you can't die from incontinence but it has an enormous impact on every single aspect of your life. If I'd done something about it in my early thirties I wouldn't be in this state – I can't get in and out of the bath without leaking. Life doesn't have to be like this. Don't be embarrassed like me, go and get treatment."



*“It’s brilliant. If anyone has a problem like mine, sacral nerve stimulation is well worth trying. All I have to show for it is a tiny scar on my right bumcheek”*

## **Susan** Keates-Robinson

**Age:** 41  
**Location:** Loughborough  
**Occupation:** Full-time Mum  
**Diagnosis:** Bowel incontinence

**Treatment:** Sphincter repair surgery;  
Sacral nerve stimulation  
**Consultant:** Andy Millar  
**Hospital:** Leicester Royal Infirmary

# Bowel incontinence

## wasn't going to beat me

"Everything was fine until my daughter India was born seven years ago. She was two weeks overdue and after eight hours in labour, I had a forceps delivery. Accidentally the medical staff went in too far and cut into my sphincter, which is the circular muscle around the rectum that holds in your faeces. I don't blame them, because they were doing the best they could to get my daughter out quickly and safely and I got a healthy 8lb 7oz baby.

The first symptom I noticed was flatulence. If I needed to pass wind, I couldn't hold it in, which is something you don't want to happen when you're 34. For the first few weeks I thought this could be something that occurs after giving birth, but then when I went back to my gym and started eating healthily to get back into shape, I noticed I was seeping and soiling my underwear. I was so embarrassed. You can talk about breaking a leg to your friend, family or GP but something like this is really difficult to talk about.

I went to see my GP who referred me to a consultant and eighteen months after India was born, I had surgery to repair my sphincter. I was told this wasn't always successful and sadly it didn't work for me. The procedure was very uncomfortable and I felt like I had gone through the operation for nothing. It left me housebound for four weeks with an infection and I still had my unpleasant symptoms.

I was back at work at a health clinic in Leicester and so even more concerned about my embarrassing wind. At home, if I joined my daughter on her trampoline and jumped up and down I felt as though my insides were coming out.

But you can get used to anything. I learnt eating fruit and vegetables made me looser. If we were going out and I didn't know where

the loos would be, I didn't eat these. I also realised that if I passed a motion after I ate, I'd be okay for some time. I therefore tried, if possible, to go to the loo within an hour of every meal. This also meant there was nothing left in my bowel so if I passed wind, I didn't smell.

The inside of my bowel was still working and so I could always sense when I wanted to pass a motion but the problem was getting to the toilet in time. If I didn't, there'd be seepage. Outings were planned in meticulous detail so I knew the location of the loos and I chose restaurants where I could sit near the Ladies.

I had lived with this for five years when my consultant told me about a new treatment called sacral nerve stimulation that might help. For three weeks I had a test device inserted and kept a diary about its effects. After the first day I noticed a difference and so I had the real thing implanted.

It's brilliant. I don't have flatulence anymore and I can hold my faeces in again. If anyone has a problem like mine, sacral nerve stimulation is well worth trying. It only took an hour for the device to be implanted and all I have to show for it is a tiny scar on my right bum cheek.

I can also now eat whatever I want and jump and run around with my daughter without any worries. A problem like mine can get you down, but I'm a positive person and was determined this wasn't going to beat me."

Your healthcare professional will be able to tell you about the range of treatments available to treat post natal incontinence symptoms.



*“I regard using the device and doing my pelvic floor workout in the same way as I do my morning press ups”*

## Nicky Allen

**Age:** 55  
**Location:** West Sussex  
**Occupation:** Mail order fashion company director  
**Diagnosis:** Urinary incontinence; womb prolapse

**Treatment:** Hysterectomy; vaginal wall repair; pelvic toner

# My pelvic floor was in a bad way

"I first noticed my bladder problem when I joined a gym in my late thirties. Whenever I jumped up and down in the aerobics class I would start to leak and have to rush out to the loo. I also found myself crossing my legs when I sneezed.

Although I eventually stopped going to the gym, my incontinence continued and gradually got worse. I was now leaking every time I laughed, coughed or sneezed. I was also wetting my knickers just after I'd been to the loo and thought I'd finished peeing. Things got so bad I had to wear sanitary towels and carry spare ones in my handbag.

I also had this very strange sensation with my undercarriage and went to see my GP who referred me to a gynaecologist. The gynaecologist explained I had a womb prolapse and this was pushing against my bladder making the incontinence worse. I was also told in no uncertain terms that my pelvic floor was in a bad way and needed sorting out.

First I underwent a hysterectomy and then six weeks later I saw a gynaecological physiotherapist who taught me how to go about strengthening my pelvic floor. She got me to squeeze my pelvic floor muscles and then measured the effect on a scale of one to five. My score was zero. To get things working properly again I was told I needed to reach at least three on that scale and was given exercises I could do at home.

But it's not that easy locating your pelvic muscles and working them. Even though you're hanging on to your tummy and clenching your bottom, you're not always

sure you've found them and are doing the exercises correctly.

Luckily I spotted an ad for a pelvic floor muscle developer in a national newspaper and sent off for it. Within six weeks of using it my physiotherapist found that my squeeze factor had gone up to three. I was thrilled.

At first I used the device little and often, gradually building up my muscle strength. I started on the lowest resistance setting, and then as my muscle tone improved, I moved up to the next one. Having something to work against makes the exercises so much easier to do.

I regard using the device and doing my pelvic floor workout in the same way as I do my morning press ups and do 20 exercises at a time. The workout with the toner has really helped my incontinence problem and I no longer need to wear sanitary towels.

I know now that I should have done pelvic floor exercises years ago after my two children were born. I'd heard about them, but didn't bother doing them. If I had, I might not have had my womb prolapse and the incontinence problem.

Women in their fifties like me who have urinary problems because of the condition of their pelvic floor must realise they won't get better without help. They need to think how bad the problem will be by the time they're in their seventies. Pelvic toning could help them too."

Always seek medical advice and undergo a full assessment from a specialist health professional before using a product to assist with pelvic floor muscle development.



*“I can’t believe I’ve finally found a treatment that helps. It’s given me a new lease of life”*

## Nora O’Neill

**Age:** 74  
**Location:** London  
**Occupation:** Retired care worker  
**Diagnosis:** Overactive bladder (OAB)

**Treatment:** Surgery to tighten bladder; Sacral nerve stimulation  
**Consultant:** Mr Jeremy Okrim  
**Hospital:** University College London Hospitals

# Everyone takes going to the loo for granted

“I’ve had bladder problems all my life. As a child if there wasn’t a loo around and I had the urge to go, I would have an accident. In my teens and twenties I started wearing sanitary towels the whole time and continued doing so until I was in my seventies.

My lack of bladder control got worse after I had my three children. I did try pelvic floor exercises but sadly, they didn’t help. In my thirties I was told I had an overactive bladder and needed surgery to tighten it up. The first operation made no difference. Two years later they tried again, this time the procedure helped for about six months. Eighteen months later it was done a third time and I again got relief for just a few months.

I was then prescribed drugs but they didn’t work either. Eventually I was told there wasn’t anything else they could try and I was devastated. As the years progressed my bladder got weaker and weaker and I was getting up 10 times a night to go to the loo. Not surprisingly I was desperately tired during the day and I had to take early retirement due to ill health.

If I did go out at all it was to the shops or to visit family locally. I always wore two or three pads at a time and took a big bag of spares along with me everywhere I went. I was continually worried that I smelt and forever asking my family if I did.

Two years ago Botox injections were suggested but because they have to be repeated every six months and there was a chance they might over-paralyse my bladder and I would need a catheter, I wasn’t keen.

Soon afterwards I was told about a new treatment called sacral nerve stimulation. I was 72 but decided to go for it. I was surprised how short a time the procedure took – about half-an-hour – but, because of

my age I was kept in overnight.

I use a remote control to set the device at the appropriate level to allow me sufficient time to get to the toilet. You do sense the vibrations inside you at first but soon get used to it.

The instructions booklet was hard to understand and I had to go back to the hospital for advice on how to change the batteries in my remote and learn how to adjust it.

I can’t believe I’ve finally found a treatment that helps. It’s given me a new lease of life. I was getting up so many times during the night that my husband had to move into the spare bedroom. Now that I only get up once a night, we’re back sleeping together.

In December 2009, two months after having the device implanted, I was able to fly to Sydney on my own to see my younger sister who’s very ill. I couldn’t have contemplated such a long flight before my surgery.

And it means I’m in pocket. I was spending a fortune on huge numbers of sanitary towels every week. I had to get the expensive sort because the cheaper ones weren’t absorbent enough.

My only regret is that this treatment wasn’t around years ago. If anyone has my kind of incontinence and is offered this, they should go for it. You also have to remember incontinence isn’t a disease, just a big inconvenience and you have to pitch your life around it.”

## Bladder & Bowel Community Just Can't Wait card

A big problem with an overactive bladder is finding a toilet in time. B&BC has a 'Just Can't Wait' toilet card for you to use when you're out and about, shopping or socialising. It may help you gain access to toilets.

It doesn't guarantee you access to toilets but it states that you have a medical condition which requires the urgent use of a toilet, and most places you visit will try and help you.



The Just Can't Wait card is now absolutely free. To apply for a toilet card please visit our website at [www.bladderandbowel.org](http://www.bladderandbowel.org)

# Bladder and bowel treatments

Once you have received formal diagnosis and know what is causing your symptoms, your doctor or continence advisor will discuss with you the range of treatments available, how they could help and if they are suitable for your needs before agreeing a treatment plan together. Below you will find further details on the treatments discussed within this booklet. For more information please contact B&BF or speak to your health professional.

**Botulinum toxin (Botox)** – you need to have had detrusor overactivity diagnosed and have previously tried conservative treatments (bladder retraining and anticholinergic medication), and be prepared to learn to self catheterise in case you develop problems emptying your bladder. This treatment is currently unlicensed for non-neurogenic detrusor overactivity and may not be available as it is 'off licence'. Your GP will need to refer you to an urologist or urogynaecologist to be considered for this treatment.

**Catheterisation** – a catheter is a thin tube which is used to drain urine from the bladder. There are three main types of catheters; intermittent catheters, indwelling catheters and suprapubic catheters which are used as a management aid by people who cannot empty their bladder properly

**Pelvic floor muscle exercises** – when done correctly these exercises can build up and strengthen the muscles in the pelvic floor and help control both bladder and bowel function in men and women, to help you hold on longer and prevent leakage. A number of products are available to aid exercises and you should discuss options with a health professional before trying any over the counter treatments.

**Anal Irrigation** – this is a procedure for emptying the lower bowel and is used to prevent faecal incontinence, chronic constipation or as a method of bowel management. It works by introducing lukewarm water into the bowel. It should only be used on the advice of a GP or health professional

**Sacral nerve stimulation** – Sacral nerve stimulation is used to treat symptoms of overactive bladder, urinary retention, faecal incontinence and chronic constipation in patients who have failed or could not tolerate more conservative treatments, such as medications or biofeedback. A small device is surgically implanted to stimulate the sacral nerves with gentle electrical impulses which can help you resume normal bladder and bowel function. It is not suitable for everyone so please discuss this with your GP who can refer you to a consultant if appropriate.

**Surgery for stress urinary incontinence** – there are a number of different surgical procedures available including tension-free vaginal tape, trans obturator tape and colposuspension. All are performed under local, regional or general anaesthetic and in some cases day surgery may be an option. Surgery is usually a final option after other more conservative treatments have been tried; speak to your GP or health professional for more information.

**Management products** – some people cannot be completely cured and others may need some extra help while awaiting treatment. There are a range of products and devices available to help you manage bladder and bowel control symptoms. Many can be purchased discreetly and in confidence either online or via a mail order service. Please contact B&BF for more information on product choice and availability.



## Bladder & Bowel Community - Listening, guiding and supporting you

We provide information that allows you to make educated and informed choices, which will enable you to enjoy a greater quality of life.

We campaign for better services, treatments and products on your behalf, provide user-friendly booklets and fact sheets; offer online support forums and a magazine twice a year. It is not just a problem for the elderly and is not an inevitable part of ageing. There is help available.

### We aim to:

- **Help break down isolation**
- **Promote emotional well being**
- **Encourage self help**

### Get in touch:

- Find the contact details of your nearest NHS Continence Advisory Servicer visit our website at [www.bladderandbowel.org](http://www.bladderandbowel.org).
- Email us at [help@bladderandbowel.org](mailto:help@bladderandbowel.org) write to us at The Bladder and Bowel Community, 7 The Court, Holywell Business Park, Northfield Road, Southam, CV47 0FS.
- Visit the website for information on how to manage your bladder or bowel control problems. You can also register on our Forum, which offers support, encouragement and understanding from people with similar problems. [www.bladderandbowel.org/forum](http://www.bladderandbowel.org/forum)

**Please contact us today to find out more about the work of Bladder & Bowel Community and how we can help you. For all general enquiries, please call 01926 357220.**

# A New Beginning



The Bladder and Bowel Community is very close to my heart. Being an ostomate and living my life battling bowel disease and a chronic illness I know the importance of the Bladder and Bowel Community all too well. My aim has always been to break the taboo of living life with a Bowel or Bladder dysfunction/diversion or condition, raise awareness, and help people to understand that we are not defined by our condition. We won't let it stop us from achieving our goals and aspirations in life.

The B&BC has been an integral part of the Bladder and Bowel Community and for years it has been instrumental in helping and supporting thousands of people across the country, including myself. With a staggering 14 million people a year in the UK suffering with Bladder and Bowel conditions at any one time, our support network is crucial.

Unfortunately, early in 2016, the B&BC was at risk of disappearing. Given my own personal experience

of receiving advice and support from the foundation, I realised that I could not let this ship sink. Therefore, I went about sourcing investment and the Bowel and Bladder Community is very much alive. It's a new Beginning.

**Blake Beckford**



Join the

# Community Support Network

Sign up to our forum for support, advice and to join the conversation.

[www.bladderandbowel.org/forum](http://www.bladderandbowel.org/forum)



Bladder & Bowel  
Community

Published November 2016.

The Bladder and Bowel Community provides information and support for people with bladder and bowel issues. We publish a wide range of user friendly booklets and factsheets.

For more information please call us on 01926 357220, email [help@bladderandbowel.org](mailto:help@bladderandbowel.org) or write to us at The Bladder and Bowel Community, 7 The Court, Holywell Business Park, Northfield Road, Southam, CV47 0FS.

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