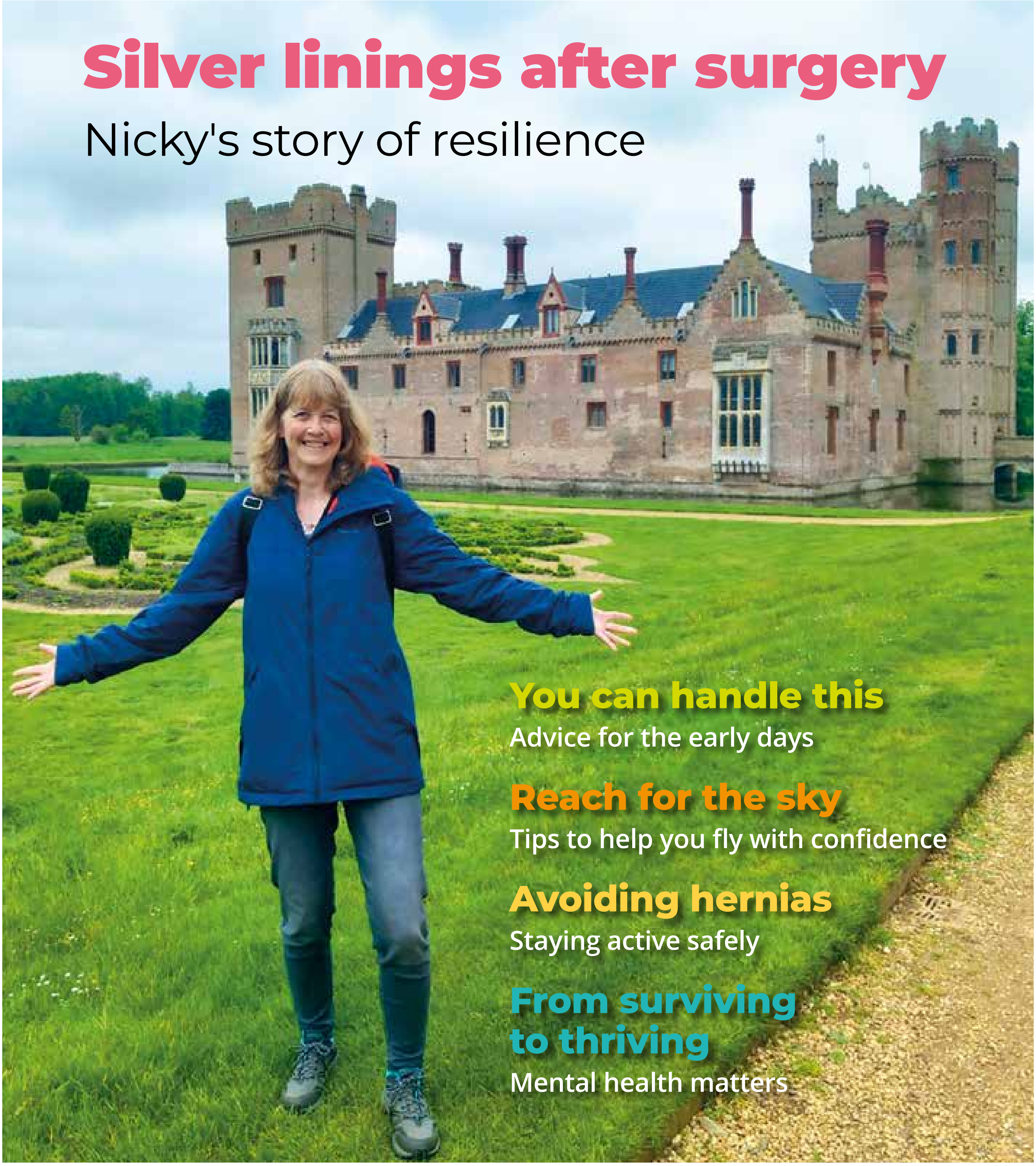
UROSTOMY
ASSOCIATION
Incorporating all types of urinary diversion

journal

Spring 2026 Issue 136



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Nicky's story of resilience

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Advice for the early days

Reach for the sky

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Staying active safely

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Welcome to our Spring Journal

As we move into Spring, the season of renewal, it feels timely bringing you personal stories shared by urostomates Nicky, Billy and Tony. Having regained fitness after surgery, they're embracing life to its fullest again, taking on fresh challenges and discovering new interests. As they're proving, life with a bag doesn't need to limit you - far from it!

We welcome your feedback as well as your contributions for the Journal. Please get in touch via *editor@urostomyassociation.org.uk* or at *Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge CB3 0AX.*

Articles, emails and letters for consideration for the summer edition should arrive no later than **15 June**.

Thank you.

Thank you to all three for sharing their journeys to give reassurance to anyone who needs it because, let's face it, life with a stoma isn't always smooth. Particularly if you're in the early stages of recovery after your operation, it can feel overwhelming at times.

If this is where you are, please be patient with yourself. Getting used to your urostomy, physically and emotionally, is a big adjustment. Our 'You can handle this' article on page 14 is for you, full of tips and encouragement.

Are your thoughts turning to booking a holiday? If you're keen for a break but nervous of flying with your urostomy, we've got you covered. Turn to page 24 for advice to help you prepare well and fly with confidence.

It was heartwarming to hear about the royal recognition UA volunteer Donna Watson received for her service to others - read all about it on page 46. A big thank you to Donna and all our volunteers. Without you, we would not be able to reach as many anxious urostomates with the advice and support they need to enjoy life again. You really do make a difference.

See you in the summer!

Paola

Paola Simoneschi
Journal Editor

On the cover

Urostomate Nicky is finding that life has silver linings after surgery. Read her story on page 8.

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Printer:
One Digital, Brighton

Journal advertising

Published three times a year (spring, summer and winter), the Journal is essential reading for urostomates. We welcome advertising – please get in touch via *editor@urostomyassociation.org.uk*.

Photo credits

Thank you to UA supporters who have provided photos for this edition. All other photos are courtesy of Canva and the Centre for Ageing Better.

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Please contact your own stoma nurse or GP about any questions relating to your care.

Managing your data

Our privacy notice, updated June 2025, can be found at *urostomyassociation.org.uk/privacy-policy*. Please get in touch if you would like to update your communications preferences.

Listen to the Journal **FREE** of charge

A recorded version of this magazine is available free of charge for people who are partially sighted or blind. Please email *info@urostomyassociation.org.uk* or call **01223 910854** to find out more.

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UROSTOMY ASSOCIATION
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About the UA and **our support for you**

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About us

Life with a urinary diversion can feel daunting, so it's vital that people have somewhere reliable to turn for the reassurance and support they need, from diagnosis to living life to the full again. The Urostomy Association is the national charity for them and for their families and carers, too.

We never want anyone who may be feeling anxious to miss out on our support. That's why we provide our services **free of charge**, regardless of their financial circumstances, so they can access what they need, when they need it, helping them stay well so they can enjoy life.

We offer information and support through our helpline, website, regular magazine and e-newsletters, group meetings, webinars and fact sheets.

We also campaign on behalf of everyone living with a urinary diversion, making sure their voices are heard wherever they need to be.

One-to-one support

There is nothing quite like speaking to someone who understands what you may be going through because they have been there too. We can link you up with one of our trained volunteers in your area who knows from their own experience what it is like going through surgery for a urinary diversion and adapting to life afterwards.

Our volunteers provide support over the telephone and - wherever possible - face to face. We aim to link you to someone who has the same type of urinary diversion as you.

Join our friendly community

Joining the UA is really straightforward - and we'd love to welcome you! Simply complete the form on our website: *urostomyassociation.org.uk/join-now* - or call the office - and we'll keep you up to date with all the latest!

Show your support

As a charity, we can only do what we do thanks to the generosity of our supporters. Making a donation of whatever you can afford helps us continue our vital work for everyone who needs us.

You can donate online at *urostomyassociation.org.uk/donate,* fill in the donation form at the back of the Journal or call our office on **01223 910854.**

> *"It is encouraging to see these challenges acknowledged within a national strategy."*

A welcome **step**

The majority of people requiring a urinary diversion have a bladder cancer diagnosis. It is therefore with great anticipation that we welcomed the Department of Health and Social Care's (DHSC) new National Cancer Plan for England, launched in February.

Bladder cancer is classified as one of the rare and less common cancers – with breast, prostate, lung and bowel being the four most common. For the first time, the Government has made a clear commitment to focus specifically on rare and less common cancers within a national strategy, with a dedicated chapter in the plan. This is a significant and welcome milestone, reflecting growing recognition of the distinct challenges faced by people affected by these cancers.

Addressing inequalities

The plan addresses many of the longstanding inequalities experienced by people with rare and less common cancers, including poorer survival rates, delayed diagnosis, lower awareness of symptoms, limited data, and fewer treatment options.

The plan includes 13 commitments directly related to rare and less common cancers, and in practice, almost all of the 70+ wider recommendations are intended to be inclusive of these cancers as well.

We would like to thank Cancer52 for representing our charity, alongside many others, in its engagement with the DHSC on this important development. We are particularly grateful for Cancer52's commitment to work with DHSC to monitor progress against the plan, including the development of quality standards and cancer manuals, faster decision-making on treatments and medical technologies, improved access to genomic testing, and the delivery of personalised care plans.

The real test

Brian Fretwell, the Urostomy Association's Chairman, said: "The publication of the plan is an important moment, particularly its explicit focus on rare and less common cancers. These cancers, including bladder cancer, have too often been overlooked, leaving patients with poorer outcomes, delayed diagnosis and limited treatment options and, for many, the life-changing reality of living with a urostomy.

"It is encouraging to see these challenges acknowledged within a national strategy. The real test will be how these commitments are put into action, and we are keen to work with Cancer52 and other partners to ensure the plan delivers meaningful improvements for bladder cancer patients and their families."

The National Cancer Plan England is available at *www.gov.uk/government/publications/national-cancer-plan-for-england*.

SILVER LININGS after surgery

By **Nicky Rogers**

My husband Neil and I moved to Wymondham, Norfolk, a fortnight before the nation went into lockdown in March 2020, just two months ahead of my 60th birthday. Two years later, we found ourselves at Norfolk and Norwich University Hospital after I fractured my foot. We joked about how convenient the hospital was for us, being only a 12-minute drive away. A year after that, it became very apparent how lucky we had been to be near the 'N and N', as we became frequent visitors.

In the summer of 2023, I noticed what I thought were symptoms of a mild UTI. I didn't do anything about it for a few weeks, but eventually I made an appointment with my GP. Following two urine samples which both contained traces of blood, I was referred to the Urology Department, and six weeks after my first visit to the GP, I was diagnosed with bladder cancer. This came as a total surprise to me; I knew that blood in my urine was not a good sign, but otherwise I really didn't feel unwell.

Trips to A&E

A day procedure to remove the two tumours was arranged for a month's time, but before that appointment, my condition became much more challenging when I suddenly realised that I couldn't pass any urine. A trip to A&E resulted in me being catheterised, and I soon understood the seriousness of my illness, as for ten difficult days I passed truly bloody urine.

I ended up at A&E several more times as my urine flow still wasn't right, and the worst point was when one of the doctors told me that she had seen the results of my CT scan, which showed that I also had an ovarian cyst. Luckily, this proved to be benign, so following my first (only partially successful) procedure to remove the bladder tumours, my ovaries and fallopian tubes were also removed.

Another operation

The second procedure on my bladder had to be delayed as I came down with COVID, but it took place before the end of the year.

In January 2024, I met with my consultant and we discussed the possibility of BCG vaccine treatment. But the option of removing my bladder had already been raised, and when the biopsy and CT scan indicated that the cancer had almost certainly begun to invade my bladder muscle, we all agreed that the best way forward would be an operation to remove my bladder and create a urostomy. This took place on 29 February 2024.

Adjusting at home

Eighteen months on and for the most part, my stoma – named Omar after my consultant, and with a nice ring to it – has been relatively straightforward to adjust to. My stoma nurse was invaluable in the early days after I returned home.

After a couple of weeks, I experienced some leaks, and she swiftly identified the issue, which was that I needed a convex bag with a barrier ring. I have continued using these same products with no problems.

> *"Eighteen months on, and for the most part my stoma - named Omar after my consultant - has been relatively straightforward to adjust to."*

Eventually, I began to recover my strength and started doing the things that I had been doing before my operation – Pilates and swimming weekly, walking and cycling locally and working in my local community bookshop.

Then, six months after my operation, I woke up one morning shivering, vomiting and with a high temperature. Thirty-six hours later and feeling no better, I was directed to A&E, where I learned that I had cellulitis. This necessitated three nights in hospital on intravenous antibiotics before I was allowed home. I recovered but, unfortunately, I had the same experience four months later – more days in hospital and lots of antibiotics.

Asking questions

This time, I started asking questions, such as was this second occurrence because the original infection had not fully cleared up? My GP agreed to do a blood test to check the infection markers

SILVER LININGS after surgery cont

really did indicate that the infection was gone, but he also looked at my leg and suggested that I might have lymphoedema. It turned out he was right. I knew that some lymph nodes had been removed by my operation, but I had had no idea of their function at the time.

Once I started to attend a lymphoedema clinic, it became obvious that I now had a condition that needed to be managed. They advised me that prophylactic antibiotics are recommended following two occurrences of cellulitis within 12 months, so I am now taking these.

Finding enjoyment again

Aside from adjusting to living with a stoma and side-effects from the operation, I have managed to go back to the hobbies and occupations I enjoyed before my cancer diagnosis, although of course, life will never be the same. One consequence has been that I have decided to retire from my job as a freelance archaeologist.

Sometimes, when I tell people of my experience, I reflect that the cancer diagnosis still doesn't seem real. I had no real pain, just discomfort for a few months, and it is hard to be grateful for the loss of an organ that had been working so well for me for 60-plus years that I had hardly ever thought about it. But what I can say is that I have discovered positive things about myself and others that I might not have done otherwise.

I was very touched that so many of my friends offered support and put themselves out for me. And I discovered that I didn't need to worry how my family would deal with my diagnosis – they have been magnificent.

I have been hugely lucky in getting other support for dealing with my health - literally five minutes' walk from my house is the Starthrowers Cancer Charity Centre, an amazing organisation. Thanks to the centre, I have had access to a nurse, a dietician, and a counsellor, as well as getting treatment for my lymphoedema. I can also take advantage of their other therapies and support services, such as Reiki, massage, and reflexology, all of which are free to both patients and carers.

Art as therapy

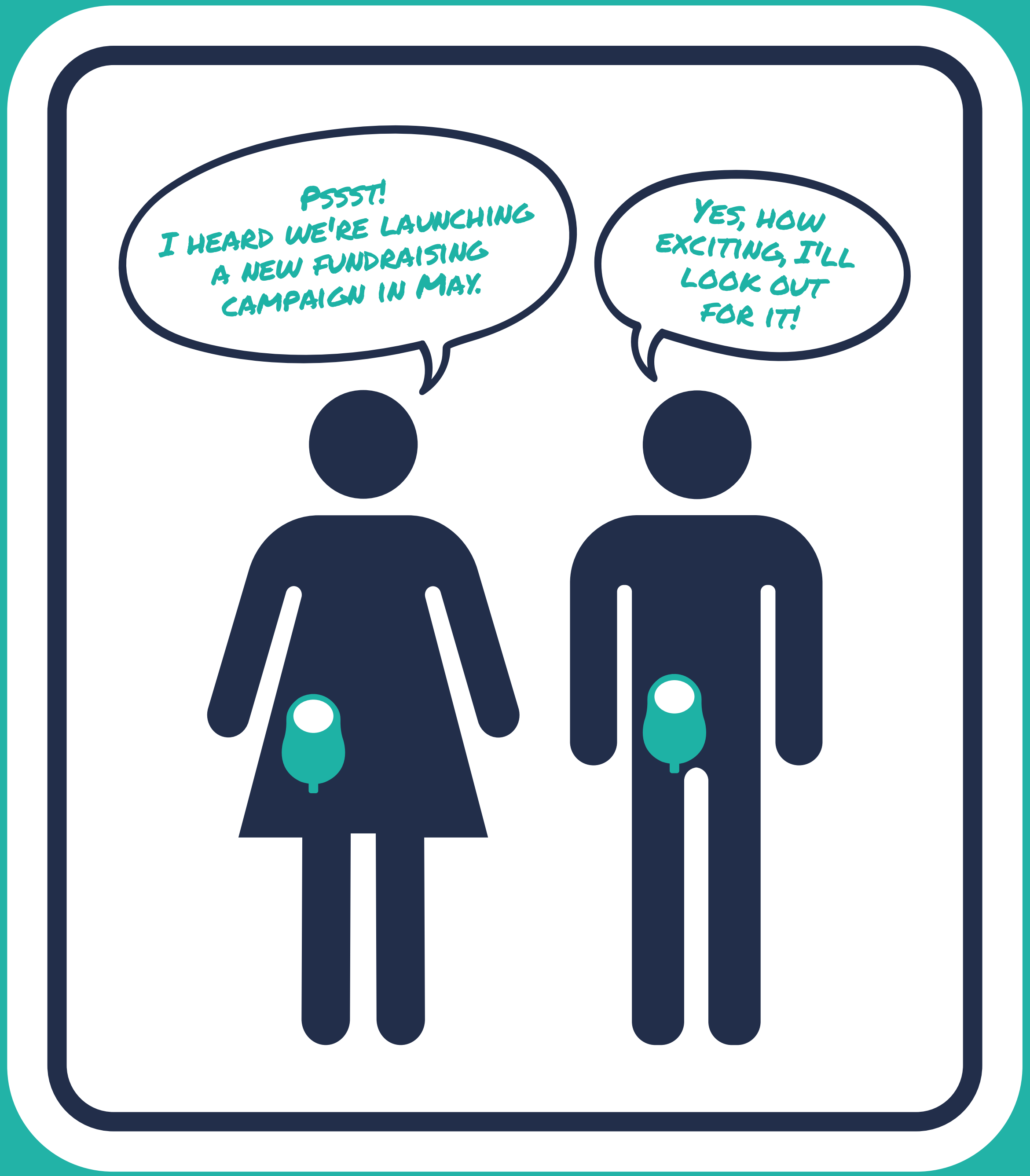
This has all been fantastic, but in addition I have been going to other types of therapy sessions. Every month I do an online writing for therapy class, and I have even had a short story published in my local magazine! I have also joined an art therapy class. As well as being a great place to talk and make friends with others who have been through similar experiences to me, I've discovered that, despite being written off at school as being 'hopeless at art', in fact – with encouragement – I can express my new self artistically in ways that I had never considered.

I was inspired to try doing some art at home, and I discovered a website where ostomates had decorated their pouches: ***www.bag-art.eu/.*** I have started to do something similar, and have found it very satisfying, even though I am no Tracy Emin! This just shows that anyone could do the same – just get some pens and paper. Or, if you want to decorate your pouches, you may need acrylic paints or fabric pens – then off you go!

"I have discovered positive things about myself and others that I might not have done otherwise."

My top tips

- **Find a local support group –** hopefully, there will be one somewhere near you, or you could join one of the UA's online support groups
- **Develop new interests –** you might surprise yourself
- **Most importantly –** love your stoma!



Many people are still unaware of what life with a urostomy truly involves. We provide vital support, information and reassurance to those preparing for and adjusting to life after surgery, helping people rebuild confidence and independence.

We rely on donations to continue this work, which is why, in the coming months, we'll be launching a brand new awareness and fundraising campaign to shine a light on this important cause and support even more people like you. We hope you'll feel able to support us when the time comes - every contribution, however small, makes a real difference.

Watch this space!

urostomyassociation.org.uk

UROSTOMY ASSOCIATION
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You can handle this

Adjusting to life with a urostomy means stepping into the unknown. Not only can big changes to your body take time to accept, there's lots of new information to absorb about managing life with your stoma.

> *"Most people find that within a few weeks, a bag change becomes just another part of their routine."*

It's normal for all of this to feel overwhelming, and your head may be full of questions, including those of the 'what if?' kind. You're probably wondering about what to do should any issues arise.

We hope it reassures you to know that after surgery, many people have few or no problems whatsoever. However, some do experience difficulties, so we're covering some of the most common 'what ifs' to help you feel as prepared and confident as possible should any of these happen to you.

What if I can't manage changing my bag?

Early on, changing your bag can feel fiddly. That's completely normal – after all, it's a new skill. There's no rush, so take your time. With practice, it becomes easier and quicker.

If you're struggling, ask your stoma nurse for a refresher demonstration. You can also try different products to see what works best for you.

Most people find that within a few weeks, a bag change becomes just another part of their routine.

> *"If you're struggling, ask your stoma nurse for a refresher demonstration. You can also try different products to see what works best for you."*

What if I experience a leak?

Anxiety about leaks is common among urostomates, particularly those new to living with their stoma. Almost every urostomate experiences a leak at some stage, but while they can feel upsetting, it's worth remembering that they are rarely a cause for concern.

Avoiding leakage

Check the fit regularly: Your stoma may change in size during the weeks and months after surgery. Measuring it routinely and making sure the baseplate opening fits closely around it can help create a better seal and reduce risk of leaks.

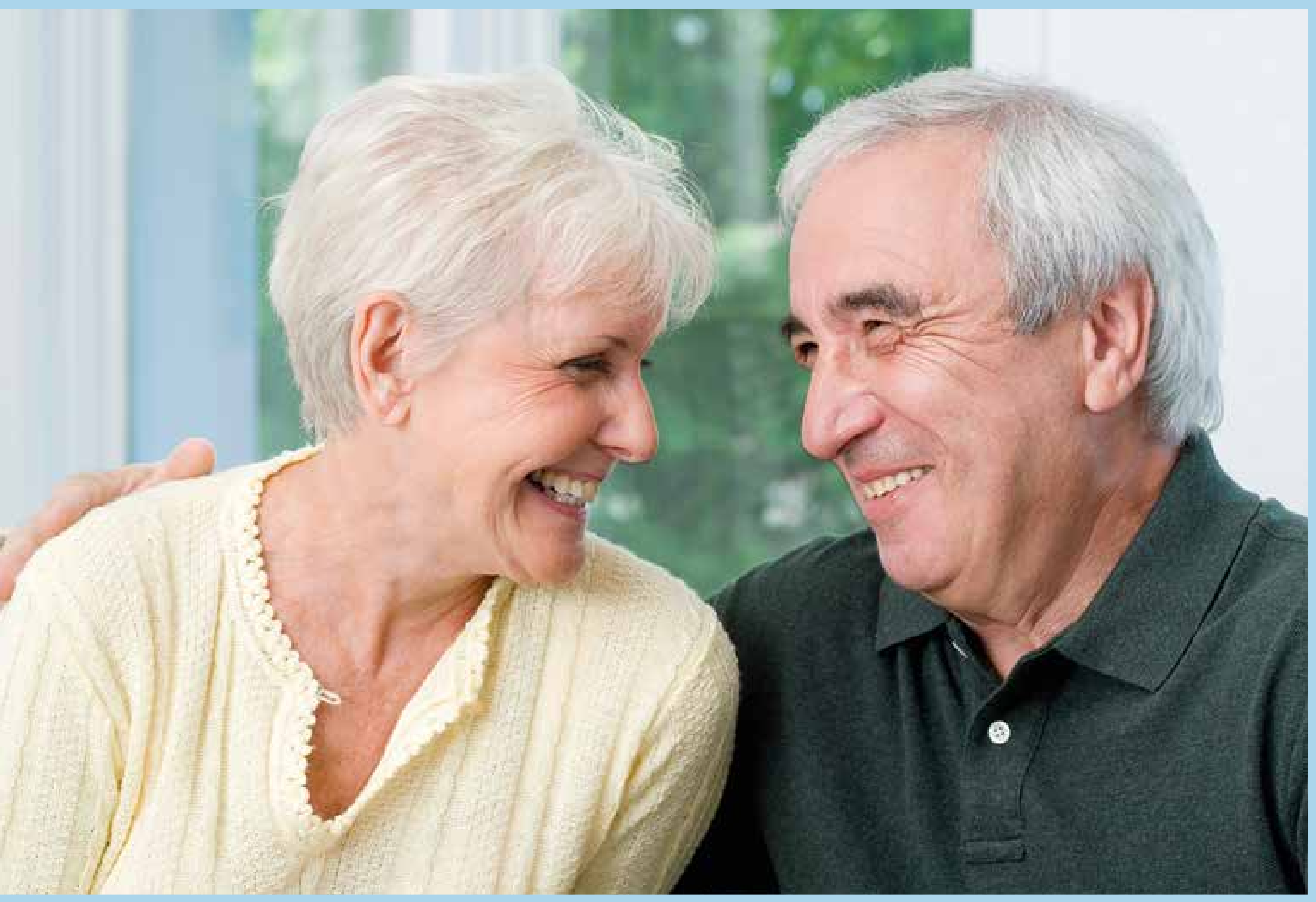
Keep the skin around your stoma clean and dry: Clean your skin with warm water and wipes, then allow it to dry completely before applying a new bag. Avoid oily products or soaps that leave residue, as these can affect how well the adhesive sticks.

Use accessories, if helpful: Barrier rings, strips, or paste can help smooth out uneven areas and improve the seal. If your stoma is flush with the skin or sits in a fold, a convex baseplate may be beneficial. Your stoma nurse can guide you on what's best for you.

Empty your bag regularly: Avoid letting your bag become too full, as extra weight can put pressure on the adhesive and increase the likelihood of leaks.

Take your time: Rushing a change can lead to poor adhesion. Taking a little extra time and applying gentle pressure to the baseplate after fitting can help ensure a secure, reliable seal.

You can handle this cont



> “Don’t struggle on with sore skin. Problems are common and very treatable with the right advice.”

Being prepared can give you peace of mind

- Carry spare supplies
- Keep a change of underwear or clothing if it reassures you
- Use a discreet bag to store your kit

If leaks continue, speak to your stoma care nurse, who can help you find a better-fitting product or help you with your technique.

What if my skin gets sore?

The skin around your stoma should look much like the rest of your abdomen. If it becomes red, itchy, or sore, it’s often due to urine coming into contact with your skin.

- Ensure your bag fits snugly around your stoma
- Change your bag promptly if there is any leakage
- Use products recommended by your stoma nurse to protect your skin

Don’t struggle on with sore skin. Problems are common and very treatable with the right advice.

What if I see mucus in my urine?

Because your urostomy is created using a piece of your bowel, it will naturally produce mucus. This can appear as cloudy strands in your urine.

This is completely normal. Drinking plenty of fluids can help keep your urine flowing and reduce mucus build-up. However, if you notice a strong smell, fever, or discomfort, it could indicate an infection, so speak to your stoma nurse promptly.

What if I get a urinary infection?

Following urostomy surgery, the changes in your body may leave you more susceptible to urinary tract infections (UTIs). In most cases, infections are mild and short lived, but they can sometimes become debilitating, affecting your quality of life. Not everyone will get a UTI so don’t worry too much, just be mindful.

Signs of a UTI include cloudy or strong-smelling urine, fever, or feeling unwell. If you notice these, contact your GP.

Helpful habits

- Drink enough fluids (usually around 1.5 - 2 litres daily, unless advised otherwise)
- Empty your bag regularly
- Maintain good hygiene when changing your appliance

What if my stoma bleeds?

Your stoma has many tiny blood vessels, so it is not unusual to see specks of blood when cleaning it. This is quite normal. Bleeding may also occur if your urostomy bag is rubbing against your stoma, so take care as ulceration of your stoma may develop.

If you find your bleeding is excessive, seek medical help as soon as possible, as one of your large blood vessels may have been damaged. If the bleeding is coming from inside your stoma, do get this investigated urgently. Sometimes urine infections, and stones, can cause slight bleeding.

> “Drink enough fluids (usually around 1.5 - 2 litres daily, unless advised otherwise).”

What if I feel low or anxious?

After your surgery, it’s normal to feel a range of emotions. Relief, frustration, fear and even grief are completely natural.

Adjusting emotionally is just as important as your physical recovery, and you don’t need to go through any of this alone. Share your feelings with trusted family or friends. You can also talk to your stoma nurse or GP, and please remember that the Urostomy Association is here for you too, however you may be feeling.

Many urostomates find comfort in connecting with others who have been through the same experience. We can put you in touch with one of our friendly volunteers in your area. Talking your feelings through with someone who truly understands because they have been where you are can make a big difference.

A final thought

Confidence comes with experience, and chances are, you’re doing better than you think. The early days after surgery can feel full of ‘what ifs’. But with patience, and over time, you’ll find yourself thinking, “I can handle this.”

Great odds, greater impact!
1 in 63 chance of winning

With a 1 in 63 chance of winning, our lottery gives you great odds of taking home cash prizes while making sure that no-one faces a urostomy alone.

When you play everyone wins

Weekly Lottery

There are lots of reasons to get involved:

- Win up to £25,000 in the weekly draw
- 52 draws a year – one every week!
- Half of every £1 you play directly funds our support services
- Great odds – you have a 1 in 63 chance of winning a prize each week
- Safe, secure and fully licensed by the Gambling Commission

Play for just £1

At just £1 per week, it's a simple and affordable way to support the work we do - from running our helpline and publishing facts sheets, to funding projects that improve everyday life for people living with a urostomy.

How to join

Joining couldn't be easier:

- **Online via our bespoke web page:** ***unitylottery.co.uk/causes/urostomy-association/***
- **By post:** Request a form by calling **0370 050 9240**, or download one via our bespoke web page (URL above)
- **By phone:** Call Samantha on 01223 910854

Each £1 entry gives you a unique six-digit number entered into the weekly draw.
Match digits in the right order to win one of four prize levels – including the **£25,000 jackpot!**

- 1st prize £25,000
- 2nd prize £1,000
- 3rd prize £25
- 4th prize 5 prize entries

From survival to self-acceptance

Written by Nicola Dames

Following last year's Association of Stoma Care Nurses Congress, I had the privilege of meeting Samantha Sherratt, Transformation Director of the Urostomy Association, and Brian Fretwell, a passionate patient advocate living with a urostomy. Our conversation touched on the incredible power of sharing real patient stories, not just to educate, but to inspire. I mentioned how fortunate I am, through my work and lived experience, to meet so many remarkable people willing to speak openly about life after stoma surgery.

> *"Naturism may not be for everyone, but Billy's journey reminds us that body confidence isn't about how you look, it's about how you live. By daring to strip away fear and judgement, he's shown that life after a urostomy can be not just full, but fearless. And that is something truly worth celebrating."*

Billy's journey with a ursostomy

It was in that spirit that I reached out to Billy Ritchie, someone I've known for several years. Billy's story struck me as one that perfectly embodies courage, humour, and the pursuit of confidence after life-changing surgery. What began as a simple Q&A soon became something much more, a testament to how survival can lead to rediscovery, and how self-acceptance sometimes comes from the most unexpected places.

A life changed overnight

Raised in St Andrews, Billy is a self-described outdoorsman; he loved cycling, hillwalking, and later developed a passion for indoor and outdoor climbing. By the time he was in his mid-40s, life seemed steady, a settled home in West Lothian, children, and weekends often spent chasing Scottish summits.

That all changed in December 2010, when Billy was diagnosed with cancer of the caecum. What he expected to be routine investigations quickly escalated. An MRI revealed the tumour had fused to his bladder. "They told me they might have to remove not just my large intestine, but also my bladder," he recalls. "To be honest, I wasn't really taking anything in. The medical team were positive and upbeat, but I couldn't see how I would survive. I just thought, they can do what they want, and I'll see how it ends."

Billy underwent surgery on 22 December 2010. It was extensive, removing his large intestine, part of his small intestine, bladder, and prostate, but crucially, it took all the cancer with it. Three days later, on Christmas day, he found himself in a hospital bed, reflecting on survival. "I realised I'd received the best Christmas present ever, life," he says.

Recovery was far from easy. Nearly three weeks in hospital, hallucinations from pain medication, endless tests, and visits from multiple specialist teams blurred into one. Instead of returning home, Billy went to stay with his ex-wife and two children. "That helped a lot," he says. "Along with my parents, siblings, and friends visiting, I felt there was light at the end of the tunnel."

Rebuilding body and spirit

In early 2011, Billy began six months of chemotherapy. It left him physically drained and emotionally isolated. "I locked myself away during that period," he admits. "I was living day to day."

When treatment finally ended, Billy slowly began reclaiming the parts of his life that had once defined him. The hills, the movement, the sense of freedom. "I took a full year off climbing and mountain biking," he says. "It

From **survival** to **self-acceptance** cont

was hard not to push too early, but I knew if I rushed it, I’d delay my recovery.”

Gradually, his confidence returned. A family wedding in August 2011 marked a turning point, the first time he felt like himself again. Over time, he learned to adapt his hobbies to his new reality. When he resumed climbing, he wore a Vanilla Blush support vest to protect his stoma. “At first I worried the harness would affect it,” he says. “But once I understood its moves, I was fine.”

Billy’s humour shines when he recalls a particularly memorable walk with his local Ramblers group. “We came across a fence and a stile, and as it was taking everyone ages, I decided to scissor-jump over. I landed perfectly, then felt my urostomy bag detach and whoosh! I was soaking wet.” Ever resourceful, Billy simply let the group go ahead, changed his bag discreetly, and carried on. "The funny bit was catching up with the others and seeing eight of the ladies squatting for a pee with bare bums on show!”

Facing the mirror

Despite his growing strength, another battle brewed quietly, one of body image. “I used to look at myself in the mirror and think, you look like a monster, a scar down your belly and a bag stuck to your side,” Billy said. “I thought, you’ll never get another girlfriend now.”

That self-criticism lingered even as his body healed. Then, one day, he read about naturist swimming, groups that swim naked, free from the social armour of clothing. “I thought, these people must be comfortable with their bodies. Maybe that’s what I need to try.”

Nineteen months after his surgery, he mustered the courage to visit a naturist swim 40 miles from home. The first time, he sat outside, panicked, and drove away. Four weeks later, he returned and walked in. “I told the receptionist, "I’m different, I wear a bag on my belly." She just said, "Everyone’s different. You’re welcome to swim."

That moment changed everything. “The scariest part is thinking you’ll be the only one naked,” Billy says. “Once I got in, nobody cared. Nobody stared. I wasn’t a freak, I was a person.”

After that night, he felt elated. He went back. Again and again. And with each visit, the weight of self-consciousness lifted.

Finding freedom

Today, Billy is Regional Vice Co-ordinator for the Scottish and North East England region of British Naturism, helping others experience the same liberation that transformed his life. “It’s an incredibly inclusive community,” he says. “I’ve met people with scars, mastectomies, amputations, and stomas and nobody judges anyone. We only have one life, and it’s short. Being socially naked isn’t scary; it’s freeing.”

Over the years, Billy has attended countless naturist events from formal Burns Suppers and ceilidhs to naked bike rides in York and Newcastle. He’s tried body painting in Blackpool, ten-pin bowling, even walked over hot ashes. “At one event I did a handstand on the glass floor of Blackpool Tower while a TV crew filmed us from below,” he says, grinning.

Naturism, for Billy, became more than just confidence-building, it reshaped how he saw humanity. “Clothing communicates identity,” he says. “It tells people what job you do, how much money you earn. But naturism removes all that. Nakedness is an equaliser. You realise we’re all just people.”

Even in naturist settings, Billy takes practical precautions, wearing a waistband when swimming so his bag stays protected. He often uses black or neutral bags like Salts Confidence BE, which blend naturally with his skin. “In the early days, my stoma nurse told me, "Don’t let it rule you." Back then, I didn’t understand. Now I do. My stoma doesn’t dictate my life – it’s just part of me.”

His adventurous streak hasn’t dulled either. “I still love hillwalking, climbing, and travel,” he says. “This year I was in Spain for a naturist holiday, then rock climbing in Kos. I recently had another hernia repaired, so I’m building back up, but I’ll get there.”

Confidence can be relearned

Billy’s story is as much about mental resilience as it is physical recovery. His honesty about fear, humour in mishap, and boldness in embracing naturism, all speak to something larger that true confidence doesn’t come from perfection, but from acceptance.

As he puts it: “It’s not the end of normality. Your lifestyle may need to adjust, but it doesn’t have to change completely; it can get better.”

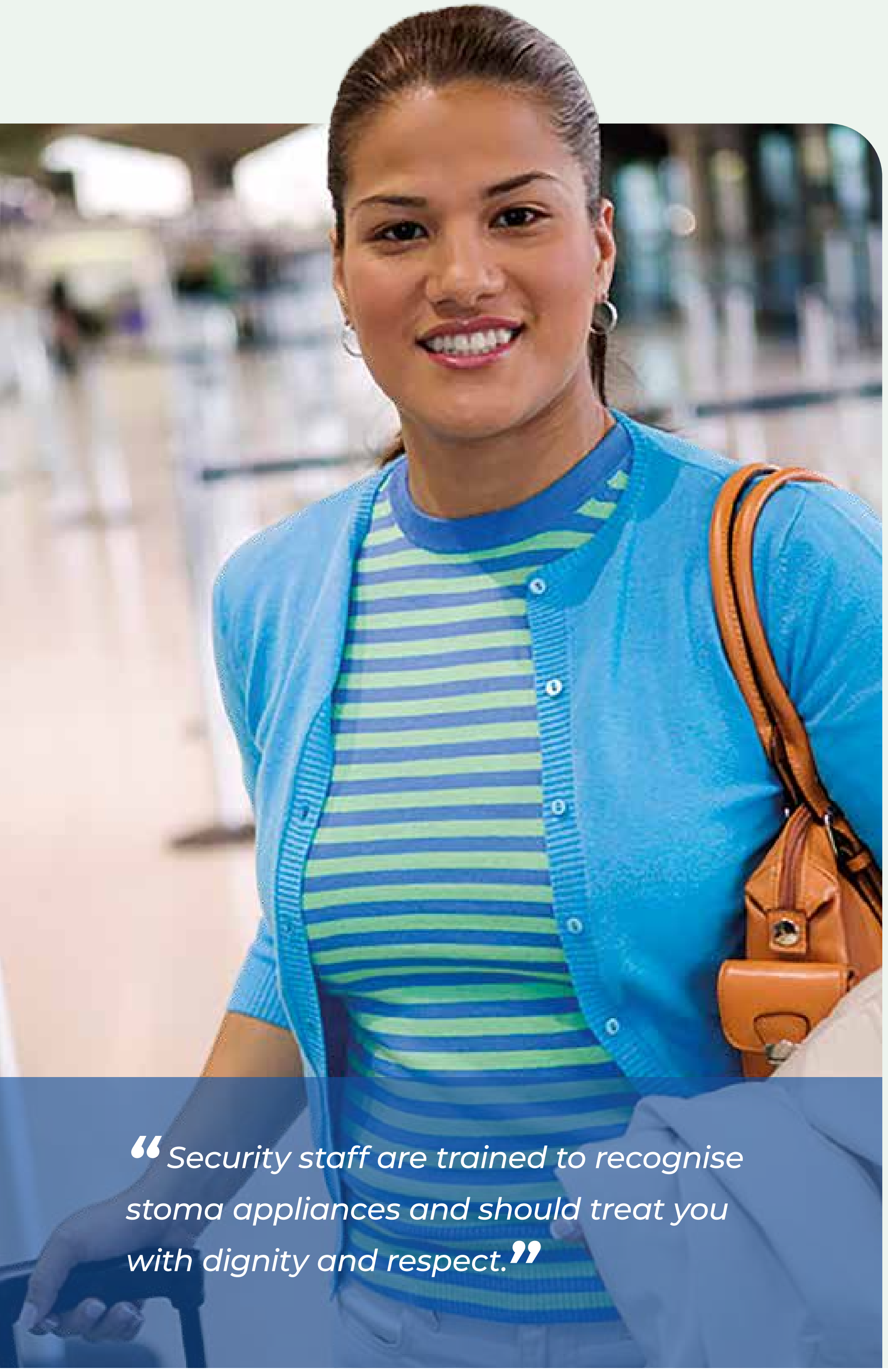
> *“Billy's willingness to be open, to find humour in awkward moments, and to face stigma head-on shows the strength that can come from vulnerability.”*

Nicola’s reflections

What struck me most about Billy’s story is that it challenges almost every stereotype about masculinity, body image, and living with a stoma. His willingness to be open, to find humour in awkward moments, and to face stigma head-on shows the strength that can come from vulnerability.

Flying with confidence

Planning a holiday should be an exciting time, but if you're flying for the first time since your operation, it's natural that you may be feeling some apprehension.



> “Security staff are trained to recognise stoma appliances and should treat you with dignity and respect.”

The good news is, your urostomy doesn't have to hold you back. Many urostomates tell us that once they've taken that first trip, their confidence grows.

Read our guide to help you plan ahead so that flying isn't just manageable but something you feel confident about - and even look forward to!

Preparing your supplies

A little preparation can make all the difference. A helpful rule is to take more supplies than you think you'll need - ideally double. Changes in routine, time zones, and climate can affect how often you need to change your bag. Delays can also happen, so having extra supplies can help you feel more relaxed.

Keeping essential items in your hand luggage means everything you need is always within reach.

Be sure to have a few pre-cut flanges in your cabin case. It also helps to remove any appliances from their boxes and put them in polythene bags as this saves space and weight.

Some people also choose to divide supplies between different bags for added peace of mind. It's also worth checking with your airline in advance, as many will allow an additional bag for medical supplies.

At the airport

You may like to carry a travel certificate, just in case you need to explain your situation.

Many airports offer extra support for people with hidden disabilities, which can make your journey through security and boarding feel much more relaxed. Most UK airports use the Sunflower lanyard scheme - wearing one lets staff know you might need a bit of extra support or understanding. You can get a lanyard from the UA – please visit our website or order via the form on page 45.

Travelling to Spain, or Spanish territories such as Ibiza or Tenerife? It's worth knowing that Aena airports now have their own 'invisible disabilities' badge, which works in a similar way. Find out more, via *www.aena.es/en/passengers/passengers.html.*

Finally, remember that if a search is needed, you can ask for it to be done in private and by a member of staff of the same gender. Security staff are trained to recognise stoma appliances and should treat you with dignity and respect.

During your flight

Once you're aboard, a few small steps can help you feel more at ease.

Choosing an aisle seat can make it easier to access the toilet.

Keeping a small kit of essential supplies within easy reach, rather than in the overhead locker, will give you extra reassurance.

Modern urostomy appliances are designed to cope well with changes in air pressure during flight. However, it's still a good idea to ensure your bag is secure before boarding and to empty it regularly during your journey.

Staying well hydrated is also important, especially on longer flights.

Travel insurance

Travel insurance is an essential part of being able to relax and enjoy your trip. Remember that if you take out an annual multi-trip policy, you must inform your insurer of any changes of circumstance or medical condition. The policy may be void if there's anything you do not declare.

Speak directly to a company agent to discuss your individual needs. They will then be able to look for a quote which will best suit your requirements. We recommend that you shop around – going through a broker should help you get the best rates.

It's good to talk

Flying for the first time, once you've recovered from surgery, feel like a big step. Simply speaking to a urostomate who understands your concerns and can share their experience of travel can make all the difference.

If you'd like to chat to a UA volunteer buddy, please contact us and we'll put you in touch.

Finally, remember that your urostomy doesn't define your limits. You can still travel, explore and fly with confidence.

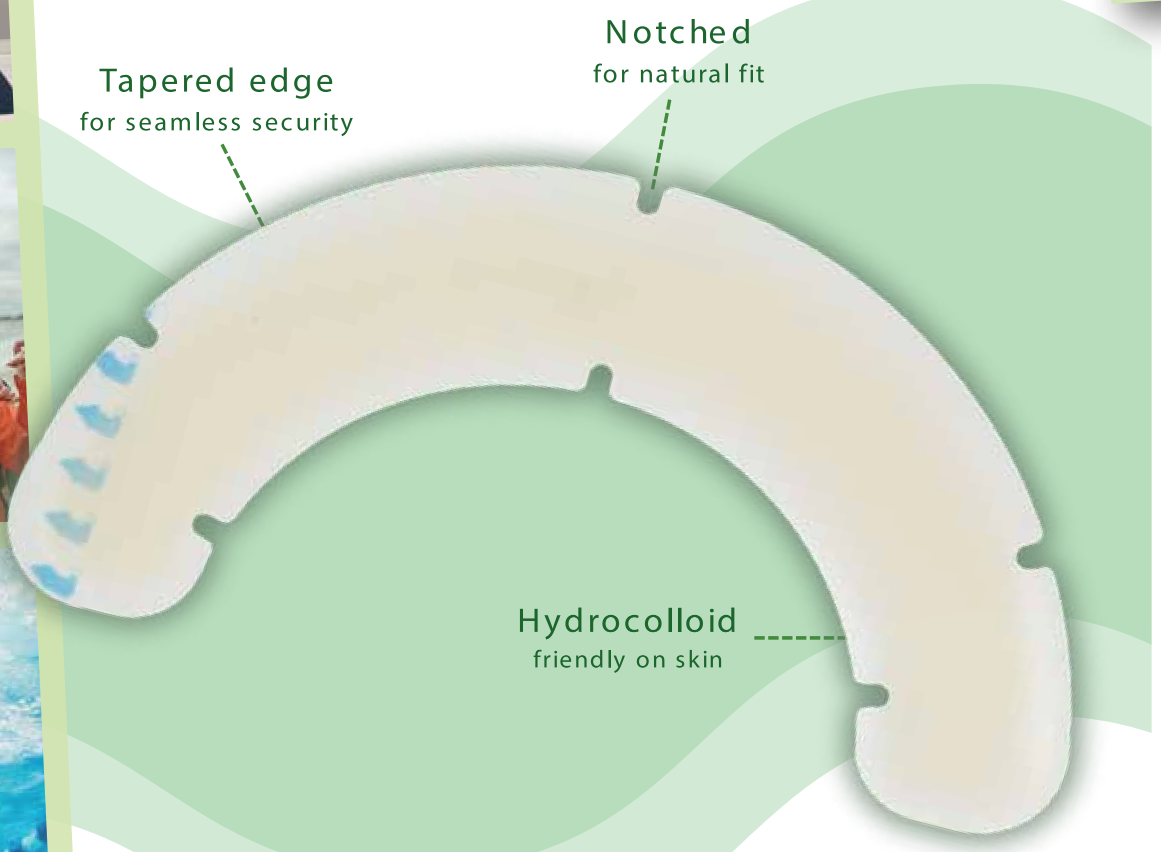
Make a difference

Whether you're looking for flights, booking a cruise or holidaying closer to home, there's a simple way to make a difference to anxious urostomates at the same time.

When you book via trusted sites *https://www.easyfundraising.org.uk/* or *giveasyoulive.com*, the companies – which include many well-known names, from Tui to Butlins - will make a donation to the UA without charging you a single extra penny!

Further information

On our website you'll find more top tips for travel, as well as a video in which UA volunteer Donna Watson shares her experience of flying with a urostomy.



SECURING your appliance

Are you experiencing issues with appliance adhesion, such as finding the edges lift too soon? Or perhaps you're generally anxious about the security of your urostomy bag? This can really knock your confidence. Your appliance should stay in place, regardless of your body shape, and not stop you going about your usual activities.

These useful tips will help you get a good seal.

1. Prepare your skin

Irritated or damaged peristomal skin can result in poor adhesion. This can then cause rubbing and/or leakage, which causes more skin irritation - it's a vicious cycle.

Make sure your skin is ready for bag changes by removing any hair in the area to prevent the adhesive from pulling it and causing inflammation. Clean your skin gently, avoid harsh products and do not scrub. Ensure your skin is completely dry before replacing your bag.

Don't ignore peristomal skin irritation, no matter how mild. Your stoma nurse can recommend products to help, such as a barrier film.

2. Prepare your appliance

Did you know that adhesives stick better when they are warm? Try warming the baseplate up in your hands before applying it. However, extreme heat can cause stoma products to degrade. If they have been kept in a very warm environment (like a hot car or near a radiator), this could also affect how well they stick.

Hold your hands over the baseplate when applying your bag and gently press on it for 30 - 60 seconds to help it bond to your skin. Ideally, leave it in place for about an hour before activities such as swimming, to allow it to properly adhere to your skin.

Ensure your baseplate fits snugly around your stoma. Your stoma can change size and shape over time, especially if your surgery was recent. Your stoma nurse can help with remeasuring if you are unsure.

3. Use the right products

To ease any anxiety about the security of your bag, try using supporting products, such as flange extenders. These increase the adhesive area so it feels more secure and is less likely to lift, whatever you get up to. This can help you get longer wear time from your bag, reduce stress and enable you to live your life to the full.

Make sure you opt for a skin-friendly option like StoCare Extend. These hydrocolloid flange extenders feature unique notches that allow them to flex to fit any body shape. Tapered edges mean they blend seamlessly with your skin, feel comfortable and won't catch on clothing.

Following these steps helps you leave adhesion anxiety behind and get on with life. After all, confidence sticks!

> *“Most parastomal hernias don’t need surgery, but they won’t go away on their own and can gradually worsen over time.”*

Preventing and **managing hernias**

You may already be familiar with the term ‘hernia’. This is when an internal part of the body pushes through a weak spot in the muscle or surrounding tissue, causing a lump or swelling.

Urostomates, along with people who have other types of stoma, can be more likely to develop a parastomal hernia. This type of hernia forms under or around the stoma. While they don’t usually cause serious medical problems, they can sometimes make stoma care more challenging - for example, by affecting how well your bag fits or how your stoma functions. Knowing what to look out for, how to reduce your risk, and when to speak to your stoma nurse can make a real difference.

What causes a parastomal hernia?

Parastomal hernias usually develop because of a combination of muscle weakness and strain around the stoma area. After urostomy surgery, your abdominal wall may not be as strong as it was before, which can make it more vulnerable.

A hernia might appear weeks, months, or even years after surgery, and the likelihood tends to increase with age. Other factors can include the way the surgery was carried out, existing muscle weakness, and having had more than one abdominal operation. Being overweight, straining, and even frequent coughing can also increase your risk.

Spotting the signs

Parastomal hernias often develop slowly and don’t always cause obvious symptoms. However, it’s worth keeping an eye out for:

- a bulge behind your stoma or swelling around it
- discomfort or pain around the stoma
- problems keeping your bag securely in place
- bloating
- pain when lifting things

If you notice any of these signs, it’s a good idea to get in touch with your stoma nurse, who can offer guidance and reassurance.

Most parastomal hernias don’t need surgery, but they won’t go away on their own and can gradually worsen over time. In rare cases, a hernia can cause twisting in the bowel, which usually requires surgical treatment.

Reducing your risk

After your surgery, try to avoid lifting anything heavier than 2.2 kg (5 lbs) for up to six weeks. If something feels too heavy, use a trolley or ask for help - it’s so important to protect your abdominal muscles.

Your stoma nurse can also advise you on gentle exercises before and after surgery to help you rebuild strength safely. Eating a balanced diet and maintaining a healthy weight can further reduce strain on your abdomen.

If extra support might help, your stoma nurse can talk to you about abdominal support garments and recommend one that suits your needs.

Staying active and exercising safely

Regular exercise can be great for both physical and emotional wellbeing, but it’s important to ease into it, especially after your surgery. Always check with your nurse before starting a new routine, and build up gradually.

- Walking and running are excellent ways to improve fitness; start with short distances and go at your own pace.
- Strengthening your core is particularly important after a urostomy. Pelvic tilts, hip lifts, and knee rolls are safer alternatives than traditional sit-ups.
- Yoga, Tai Chi, and Pilates are gentle on the body while helping build core strength and flexibility.
- Swimming is another excellent option, placing very little strain on your stoma while offering both strength and cardio benefits.

Living well with a hernia

The majority of urostomates who develop a parastomal hernia find that it causes few problems day to day. Others may need to make small adjustments but can still enjoy the activities they love.

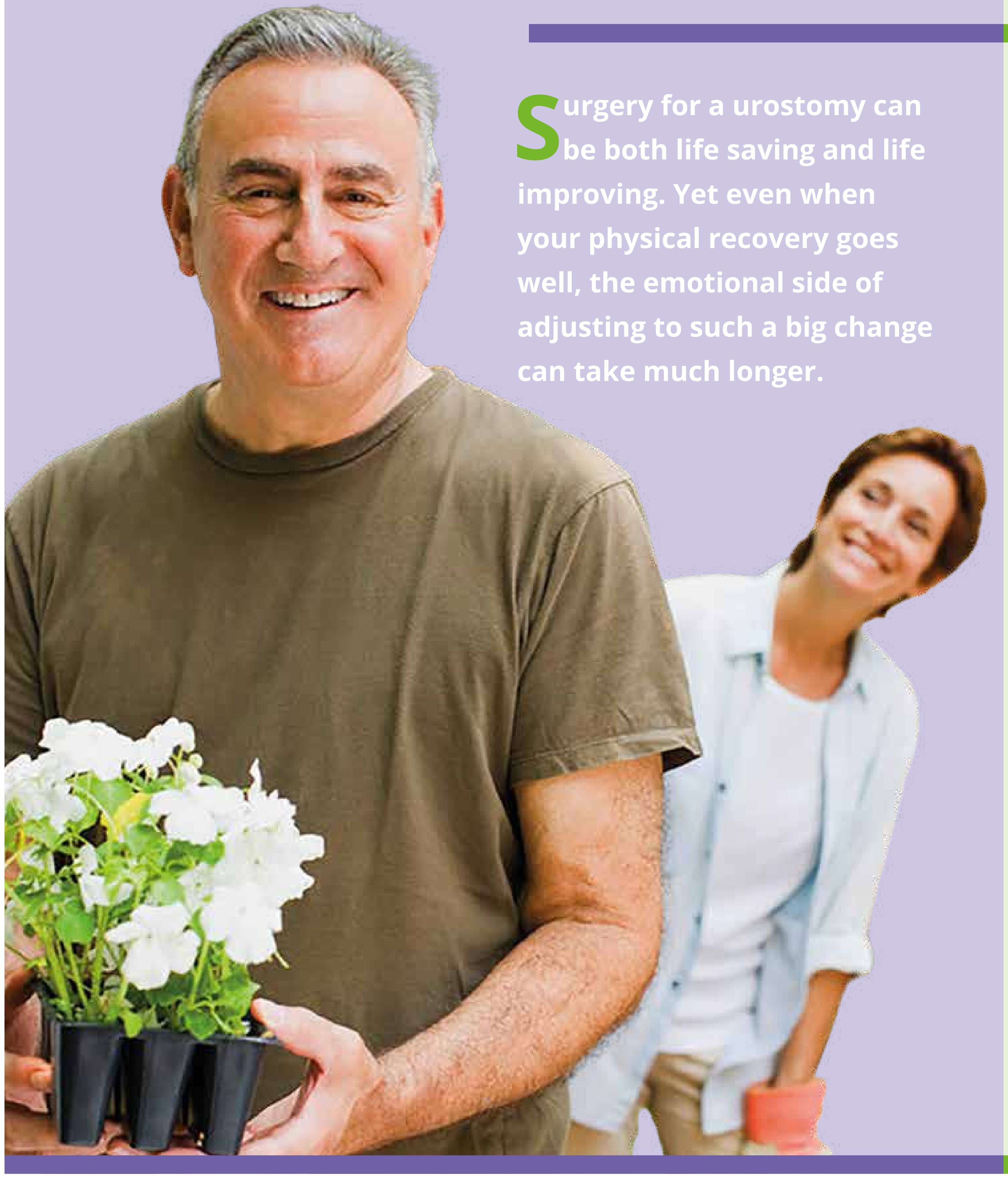
Gentle exercise, good nutrition, a reliable urostomy pouching system, and a supportive hernia belt or garment can all help you manage comfortably. Your stoma nurse can arrange a tailor-made support garment if needed and help you find alternative pouching options if your usual bag no longer works as well.

Surgery to repair a hernia may be an option, depending on your symptoms and how they affect your quality of life. This requires careful assessment by your surgeon.

We hope this article has been reassuring and informative. If you ever have concerns, don’t hesitate to speak to your stoma nurse - they are there to listen and support you every step of the way.

> *“Eating a balanced diet and maintaining a healthy weight can further reduce strain on your abdomen.”*

From **surviving** to **thriving**



Surgery for a urostomy can be both life saving and life improving. Yet even when your physical recovery goes well, the emotional side of adjusting to such a big change can take much longer.

If you've been wondering, "Why am I still struggling?", please know that you are not alone. The psychological impact of living with a stoma is often underestimated, and urostomates sometimes find emotional challenges persist beyond the early stages of their physical recovery.

More than physical

The truth is, adjusting to life with a urostomy is not just about learning practical skills. It is also about adapting to changes in how your body works, how you see yourself, and sometimes, how you feel in the world around you.

It's completely normal if you're feeling all sorts of emotions. Some people describe a sense of loss - loss of their previous body, their independence, or the life they expected. Others experience a drop in confidence, especially in social situations or within intimate relationships.

It's natural to worry about leaks, odour, whether others will notice your bag, and how it will feel being back at work. Some people experience low mood or feelings of isolation, particularly if they don't know anyone else with a urostomy. These reactions are not a sign that you are failing to cope - they are a human response to a major life change.

Adjustment takes time

Emotional adjustment after major surgery is a process, not a 'one-off'. In the early days, it can feel like you are simply getting through each day, focusing on the practicalities. Over time, most urostomates begin to regain a sense of control and confidence. But this doesn't happen overnight, and it doesn't follow a straight line. It's not unusual to have good days and then more difficult ones.

One of the key steps in moving forward is rebuilding trust in your body and in your ability to manage your stoma. As you become more familiar with your routine, things that once felt overwhelming can become more manageable. Small 'wins', such as changing your bag more confidently, going out for longer periods, or generally feeling less anxious, can gradually add up.

Be kind to yourself

Just as important is how you speak to yourself during this time. It can be easy to be self-critical, especially if you feel you 'should' be coping better. But remember that adjusting to a urostomy

> *"One of the key steps in moving forward is rebuilding trust in your body and in your ability to manage your stoma."*

From **surviving** to **thriving** CONT

is not something that can be rushed. Being patient and compassionate with yourself isn't just helpful, it's essential.

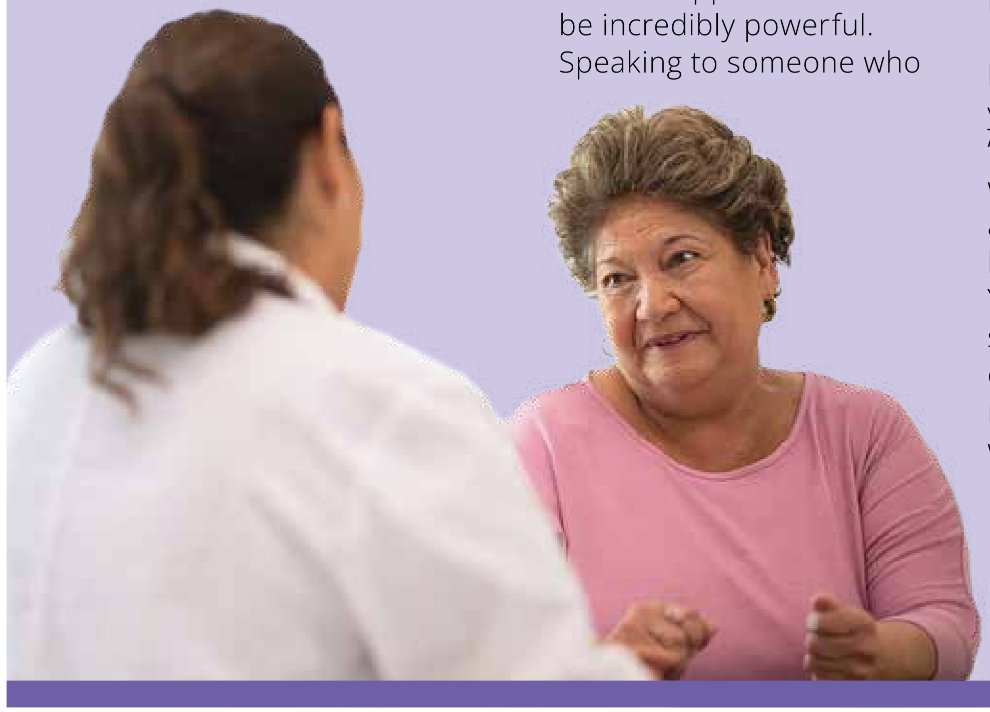
It's good to talk

Talking about how you feel can also make a difference. Some people hold their worries inward, especially when it comes to body image or intimacy. Yet sharing these thoughts, when you feel ready, can help you feel less alone. This might be with your partner, a trusted friend, or a healthcare professional.

Reaching out

If you are finding things particularly difficult, it is important to know that support is available. Your GP is a good place to start. They are there not just for physical health, but for emotional wellbeing too. They can listen, offer guidance, and, if needed, refer you for additional support, such as counselling or talking therapies. Many people find that having a space to talk openly with a trained professional helps them make sense of feelings and begin to move forward. Counselling or therapies such as cognitive behavioural therapy (CBT) can be especially helpful if you are dealing with anxiety or low mood, or struggling with self-image. These approaches can support you in developing coping strategies, rebuilding confidence, and adjusting to your new normal in a way that feels right for you.

Peer support can also be incredibly powerful. Speaking to someone who has been through a similar experience can bring a level of understanding that is hard to find elsewhere. The Urostomy Association offers information, support networks, and opportunities to connect with others living with a urostomy. People often find comfort and reassurance in hearing how others have navigated similar challenges.



Looking ahead

Over time, most urostomates find that life becomes more manageable and, importantly, more meaningful again. They often describe going from surviving to thriving.

This doesn't mean that everything becomes perfect, or that challenges disappear entirely. Rather, it's a gradual rebuilding of confidence, identity, and quality of life. Rest assured, you can begin to feel more like yourself again, even if that 'self' has changed in some ways. You may find that activities you once avoided become possible again. You may discover new strengths, a deeper sense of resilience, and perhaps new connections too. It's also worth remembering that progress can be quiet and easy to overlook. Simply getting through a difficult day, trying something new, or reaching out for support are all meaningful steps forward.

A gentle reminder

If you are struggling right now, it might not feel like things will improve. But many people who have been in that place do find that, with time, support and self-compassion, life feels lighter and more fulfilling again.

You deserve support, understanding and the time it takes to adjust.

Helpful contacts

MIND

Telephone: 0300 123 3393

www.mind.org.uk

Samaritans

Telephone (24-hour helpline): 116 123

www.samaritans.org

The British Association for Counselling and Psychotherapy

www.bacp.co.uk

In their own words

"It can sometimes feel like a long road to travel when you're learning to live with a urostomy, but in my experience, finding an activity you enjoy can make all the difference. And not just to how you feel about yourself but the world around you too.

"Don't be afraid to ask for support if you need it, and always try to get the best out of life."

Jonathan Fry

"My message is one of hope. You are worth fighting for, so never give up. I'm very fortunate to have people who've encouraged and supported me all the way, from my husband Gareth and my family to the hospital team and my UA peer supporter. But ultimately, it's been down to my own determination to keep going."

Dani Hughes

Read Jonathan and Dani's stories on our website, where you'll find many other inspiring examples of urostomates leading fulfilling, active lives.

Support online and in person

Urostomates often tell us how valuable it is to speak with people who truly understand what life is like with a urostomy. That's why we offer online support group meetings to make it as straightforward as possible to hear from experts, share experiences and tips, and seek advice from others who truly understand.

Each meeting starts with a short topical presentation from a stoma care specialist, followed by insights from a product supplier. After that, participants have around 40 minutes to connect in small groups to share experiences, tips, and seek advice in the company of those who understand what it's like living with a urostomy.

We look forward to welcoming you to our meetings. For dates and further details, please visit the events calendar on our website.

Local groups

There are also support groups across the UK offering shared experiences, friendly advice, and helpful information. Run by volunteers, these groups may meet in person or online and often welcome guest speakers on both stoma-specific and everyday topics. Many also organise social events and fundraising activities.

Some groups are local branches of the Urostomy Association, focusing on people with urostomies or other urinary diversions.

Others are broader stoma support groups, which may include people with different types of ostomies. These groups are run independently, sometimes by other charities or hospitals, so please note that we're not responsible for their activities or events.

You'll find details of local groups on our website at *urostomyassociation.org.uk/local-groups.*

These support sessions complement our popular 'Meet the experts' webinars, recordings of which you can find in our video library.

> *"We look forward to welcoming you to our meetings."*

Join our friendly community
- there's no fee!

Having a urinary diversion doesn't need to hold you back from doing what you want to do, whether that's enjoying days out, getting back into exercise or travelling overseas. Sign up to join our friendly, inclusive community for tips, resources and support to help you keep well, stay active and get the most out of life.

It's straightforward and free of charge to join the Urostomy Association and we're here for you whether you're facing surgery, recovering afterwards or have been living with a urinary diversion for many years. We're here for your family and carers too.

- Telephone helpline
- One-to-one support*
- Regular magazine and e-newsletter
- Downloadable resources
- Expert-led webinars
- Local get-togethers
- Private Facebook group

**Our trained volunteers know from their own experience what it is like facing surgery for a urinary diversion, as well as how it feels adapting to life beyond it. If you're in need of support, we'll link you up with someone in your local area. Wherever possible, this will be someone who has the same type of urinary diversion as you.*

Join today

Simply call us on 01223 910854 or go online at *urostomyassociation.org.uk*. Alternatively, complete the form (opposite) and post it to us at the address given on the second page.

We look forward to welcoming you!

Join the UROSTOMY ASSOCIATION

SIDE 1 OF 2

The Urostomy Association (UA) is the national charity for people with a urinary diversion or preparing to have one, and their family and carers too. **It's free and easy to join** and you can choose to be as involved as much or as little as you wish.

Please complete your details below and we'll be in touch. Alternatively, you can scan the QR code **or** visit *urostomyassociation.org.uk/join-now*.
We look forward to welcoming you!

Your details

Title:
First name:
Last name:
Date of birth:
Main telephone number:
Email address:
Address line 1:
Address line 2:
Town / City:
Postcode:

Type of operation

☐ Ileal conduit / urostomy
☐ Bladder reconstruction / neo-bladder
☐ Continent diversion (eg: Mitrofanoff)
☐ Other
☐ Not applicable

Reason for operation:
Hospital:

Please turn over to complete the second part of this form

UROSTOMY
ASSOCIATION

How did you hear about the Urostomy Association?

☐ Nurse / GP /Other healthcare ☐ Advert ☐ Open Day ☐ Facebook

☐ Google / Bing /etc ☐ Other (please specify) ☐

Keeping in touch

As part of our community, you'll receive our popular magazine, The Journal, by email three times a year. We'll also send our e-newsletter, giving you bite sized updates once a month. If you would like to receive a paper copy of the Journal, please contact the office for subscription details. We may also post you updates every now and again on our news, events, fundraising and campaigns.

We have a few local branches, and would be happy to put you in touch if we have one in your area.

I consent for the UA to send my details to the committee officials of a local UA branch (if there is one near me)

☐ Yes ☐ No

If you'd like to receive occasional communications from stoma product suppliers, please tick the box below (please note, these will be sent to you by post from the Urostomy Association's mailing house, as we do not share your details with third parties).

I give my consent for the UA to send me details from stoma product suppliers:

☐ Yes ☐ No

By submitting this form, you are consenting to the UA holding and processing your data in accordance with our privacy policy, which is available on our website or upon request.

Signature: Date:

Kind donations help us to run our helpline and keep supporters up to date through our regular magazine, e-newsletters, webinars, group meetings, social media and fact sheets. Thanks to donors, we can increase awareness across healthcare and the general public, and influence urostomy policy and practice. Will you make a donation today? Simply visit ***urostomyassociation.org.uk/donate.*** *Thank you.*

Scan to donate

Office 205, No 9 Journey Campus, Castle Park, Cambridge, CB3 0AX, 01223 910854
urostomyassociation.org.uk, *info@urostomyassociation.org.uk*

Registered charity nos: 1131072 (England and Wales) SCO47740 (Scotland)

Let's get **social**

Following the UA on social media is an easy way to keep up to date with our latest news, events and campaigns. You can find us on...

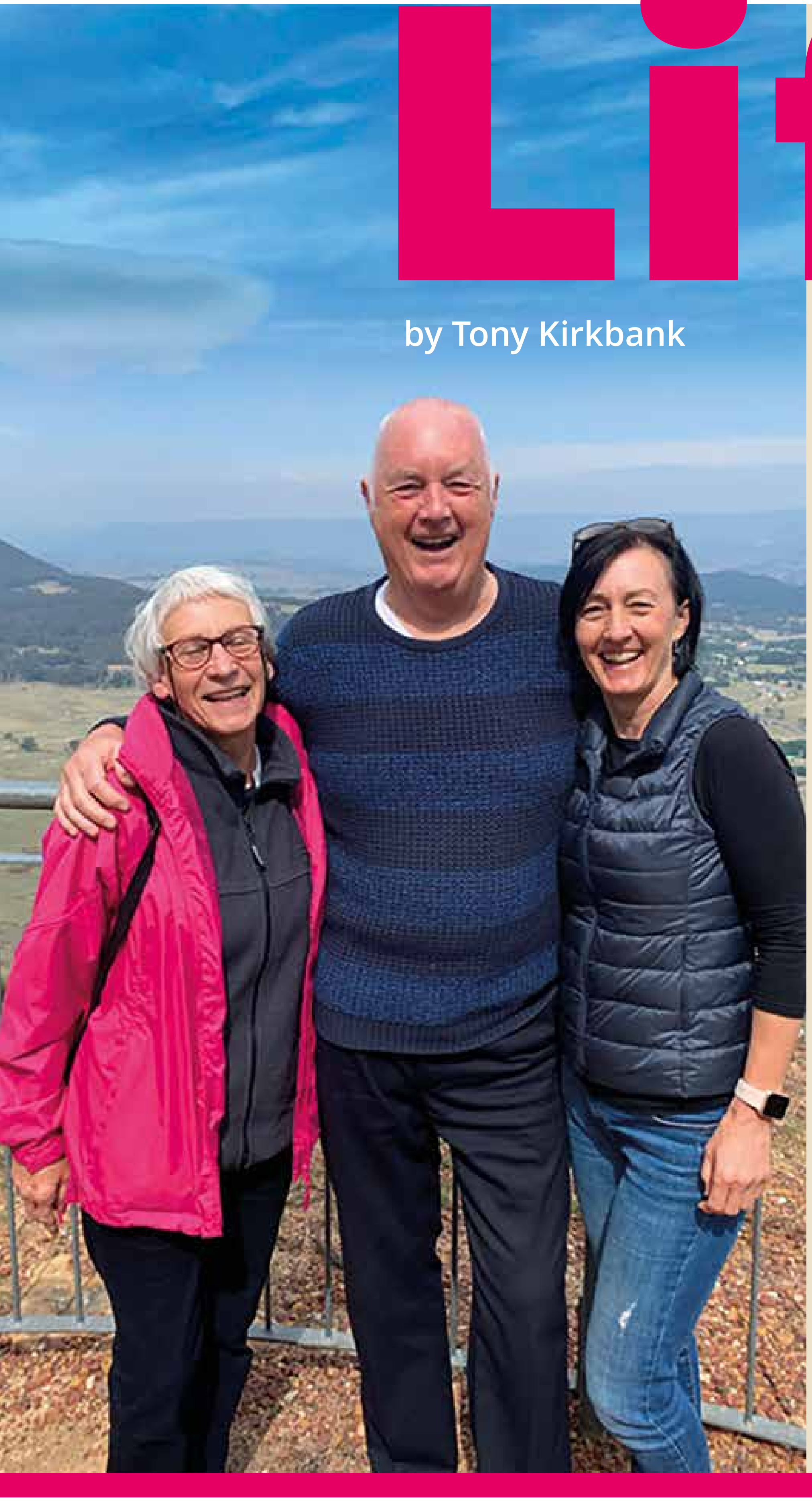
- **facebook.com/urostomyassn**
- **Instagram.com/urostomyassn**
- **x.com/urostomyassn**
- **youtube.com/@UrostomyAssn**
- **linkedin.com/urostomy-association**

There's also our Help and Support Group on Facebook, a supportive community for people living with a urinary diversion or preparing for their surgery, wherever they are in the world.

facebook.com/groups/158052257866449/

Life IS GOOD

by Tony Kirkbank



My name is Tony and I've been happily married to Diane for more than 60 years. We live in Canterbury and have two daughters and three grandchildren. At 82, I'm still fit and active, but I know how it feels to have your life interrupted due to serious illness, and I can still remember how it felt when I suddenly noticed blood in my urine back in 2000.

I was a police officer for 30 years, retiring in 1992, before becoming a self-employed insurance claims investigator, working from home. It was a successful venture, brought abruptly into doubt by the sight of that blood. Doctors told me it was 'probably only polyps', and their advice was to 'wait and see'. That Christmas, I was unable to pass any urine at all and, finally, the medics decided to act.

Appointments and examinations eventually revealed that I had advanced bladder cancer. The situation was so serious that I needed to have my bladder removed, and the operation went ahead in April 2001, some six months after the unusual bleeding had started.

I sometimes wonder if, had I been more forceful with my local GP surgery, an examination early on might have caught the cancer sooner, avoiding the need for such drastic action.

> *"It's not only patients who go through anxiety and sleepless nights – it's often the family around them too."*

Six months on

Six months from spotting such a worrying sign to eventually having the life-saving surgery I needed seemed like an inordinate amount of time to have to wait. But at least the wheels turned and the scale of my problem was finally revealed.

My hope is that, these days, things move quicker for people needing to get a diagnosis and treatment. It's not only patients who go through anxiety and sleepless nights – it's often the family around them too.

Now, the good bit. I had a fantastic urology consultant who successfully completed the operation to remove my bladder, prostate, appendix and infected lymph glands. He fashioned a stoma in the requested spot on my abdomen, and I underwent four months of chemotherapy. Having chemo after the operation is unusual now, as surgeons prefer to shrink tumours before operating as a last resort, but in my case, the regime worked satisfactorily and, to date, I have been cancer-free.

My new start

I thus commenced a new life with a urostomy. There was plenty of assistance from an excellent stoma team at East Kent Hospitals. The availability of suppliers and products was made known to me, and I

Life IS GOOD cont

sought out contacts with first-hand knowledge of living with a stoma.

The first 'hardware' attached to my body was a two-piece stoma bag where the adhesive area was fixed to my abdominal skin and a new bag was fitted to the circular flange each day. The adhesive part was changed weekly, or earlier if it failed! The problem was that when bending down, the joint popped away from the flange. But I soon discovered the one-piece bag and, after many years of trials, have settled on one that I can trust better than most.

Work and volunteering

A few months into my recovery, I resumed my work as an investigator within the automotive world. I also began taking an interest in hospital volunteering, within the area of urology support. I was invited to serve as a patient advisor on medical administrative committees, such as that related to the national computerisation of patient records, which was creating a lot of discussion.

Patient volunteer

Also as a volunteer, I got involved with Action on Bladder Cancer (now Action Bladder Cancer UK) and became a trustee.

This led to invitations to serve as a patient representative on cancer-related clinical trials, which in turn led to the opportunity to go to Westminster and speak to interested MPs about post-operative costs. In other words, the huge cost to the NHS of stoma products, such as bags, adhesives and wipes, for thousands of ostomates, some of which could perhaps be avoided if patients received their diagnosis – and hence, treatment – sooner.

Bladder removal had left me with total reliance on all manner of expensive hardware. Following my talk at Westminster, I was invited to Brussels to give my presentation to MEPs.

All of this greatly increased my interest in cancer medicine, and gave me the opportunity to meet many leading figures involved in pioneering research and treatments at centres across the UK.

After my own experience of cancer, it felt good to be doing something positive for people facing their own challenges with the disease. I also try to do my bit for those who, like me, have recovered and are living with a urostomy. Since my operation, I have had the chance to speak at stoma-related groups and social organisations locally.

I was also cajoled into writing, and self-publishing, a book covering my first 15 years in the Kent police force. 'A Uniformed Response' was published in 2012, and then – as now – I donate my book royalties to the Urostomy Association. It's my way of showing support for the charity, which does so much to reassure and support those having to adjust to urostomy life.

Living life to the full

Our eldest daughter emigrated to Australia in 1998, and Diane and I have had several opportunities to visit both her and other relations 'down under'. Such trips need a bit more careful planning as a urostomate, but I have found the Australian medical services remarkably kind and efficient when, on rare occasions, I have needed their help. In fact, I have rarely experienced any difficulties when travelling abroad.

I'm not ashamed of my 'bump' – after all, my urostomy saved my life! I'm a keen bowler and enjoy my days like anyone else. Having to consider bag-related matters is just part of my routine.

Of course, I do have occasional stoma-related blips, but I take them in my stride.

My latest innovation is to always have a night bag under the driver's seat in case the M25 comes to a complete standstill for too long. It saves worrying about when the next chance to 'empty' will be.

Is my life any worse because of bladder cancer? No, not really, and from my story I hope you can tell that I don't let my urostomy hold me back. There are times when I must take more care, which is sensible, but generally, life is good!

> *"I'm not ashamed of my 'bump' – after all, my urostomy saved my life!"*

> *"After my own experience of cancer, it felt good to be doing something positive for people facing their own challenges with the disease."*

Point of **view**

We welcome your contributions to, and feedback on, The Journal. Please get in touch via *editor@urostomyassociation.org.uk*, or send your letter to our office for consideration.

Urostomy vs neobladder

I was particularly interested in the article by Mr Paul Stewart in the Winter 2025 Journal, describing his experience of a neobladder, because I too was once offered this option.

It was about 12 years ago that I noticed blood in my urine. Despite knowing this should not be ignored, I proceeded to do just that. The heart would not believe what the head was telling it.

Suffice it to say that things went from bad to worse. Six months later, I found myself in front of a urology surgeon, who told me there was a large, cancerous tumour in my bladder. He said, "If I don't take your bladder out, it'll kill you." He then explained the surgery available.

After describing the standard operation for a urostomy, he went on to discuss a neobladder, in which urine continues to be discharged through the natural outlet but takes a different route to get there. He emphasised that whereas a urostomy does what is required of it (most of the time, I ought to add), a neobladder demands much more perseverance on the part of the patient, especially in the early months. He said he would only offer this alternative to patients whom he judged capable of managing it. He also confirmed that if I accepted the neobladder but found it unsatisfactory, he would willingly exchange it for a urostomy at a later date.

After much deliberation, I settled for a urostomy. (I suspect the surgeon was a little disappointed at not having the opportunity to exercise his neobladder skills, but if so, he did not show it.) The prospect of a urostomy and night drainage bag allowing a good night's sleep at last was too much to resist. But I was also concerned about the incontinence associated with a neobladder, as related in Mr Stewart's article.

From time to time, I have wrestled with the question of whether I should have been more adventurous and tried a neobladder. Mr Stewart's experience, however, set my mind at rest that I probably made the right decision. There are obviously those for whom a neobladder is successful, so I do not mean to discourage its use, but perhaps not for me.

P R Brown (Mr)
Bristol

My Miles of **Hope** challenge

by Paul Stewart

My name is Paul, and I have been taking part in the Miles of Hope challenge to help raise funds for the UA. With the charity being such a trusted source of support for urostomates needing advice or a listening ear, it is my way of giving something back.

I'm 75 and live in Sheffield with my wife, Morag. I have been retired for 11 years, having worked as a university librarian. I was diagnosed with bladder cancer in September 2018, when I was 68.

When I first experienced symptoms, such as needing to pee but not being able to pass much urine, and traces of blood appearing in my urine, it was initially put down to my having an enlarged prostate. My GP did keep referring me to the Urology Department at the Royal Hallamshire Hospital, and eventually, after cystoscopies indicated a possible problem on my bladder wall, I had a biopsy, which revealed my diagnosis.

Staying positive

I have been very fortunate to be under the care of a brilliant surgeon, Professor Derek Rosario. Even when he had to give me 'bad' news, his positive manner was infectious, and this has certainly helped me to maintain a positive attitude. When offered the choice of having a neobladder or a urostomy, I opted for the former, although I was warned that recovering my continence after surgery could take quite some time.

My operation went ahead in October 2018, about five weeks after my diagnosis. After surgery to remove my bladder and have the neobladder (made from part of my small intestine), I was keen to recover my fitness, although I recognised that this could be a long journey. In hospital you are encouraged to walk around the ward. Once back home, starting with short walks around the block, and gradually extending them, I was able to go for longer walks close to home.

"I have been very fortunate to be under the care of a brilliant surgeon, Professor Derek Rosario. Even when he had to give me 'bad' news, his positive manner was infectious, and this has certainly helped me to maintain a positive attitude."

Walking back to fitness

I have been a keen walker for much of my life, and first met Morag while out in the Peak District. Walking in the lovely countryside is our main form of recreation and staying active. Particularly in the company of friends, it is a great way of keeping your spirits up. For me, it has been

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UROSTOMY
ASSOCIATION

Merchandise

UA-branded **sunflower badges** and **lanyards**

Our Urostomy Association-branded badges and lanyards are officially sanctioned by the Hidden Disabilities Sunflower Scheme Limited: *hdsunflower.com*

The **official** Radar **KEY**

Our Radar keys are the genuine article – other keys purchased online may not be genuine and may not work.

All prices include p&p within the UK

To place your order by credit/debit card, please call **01223 910854** or visit *urostomyassociation.org.uk/shop.* Alternatively, please complete the form below and send it, together with a cheque made payable to the Urostomy Association, to: **The Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge CB3 0AX**

Please send me:

Sunflower lanyard and badge* £6.25** ***Quantity

Radar key* £5.75** ***Quantity

I would like to make a donation to the UA's work ***Amount***

Title: First name: Last name:

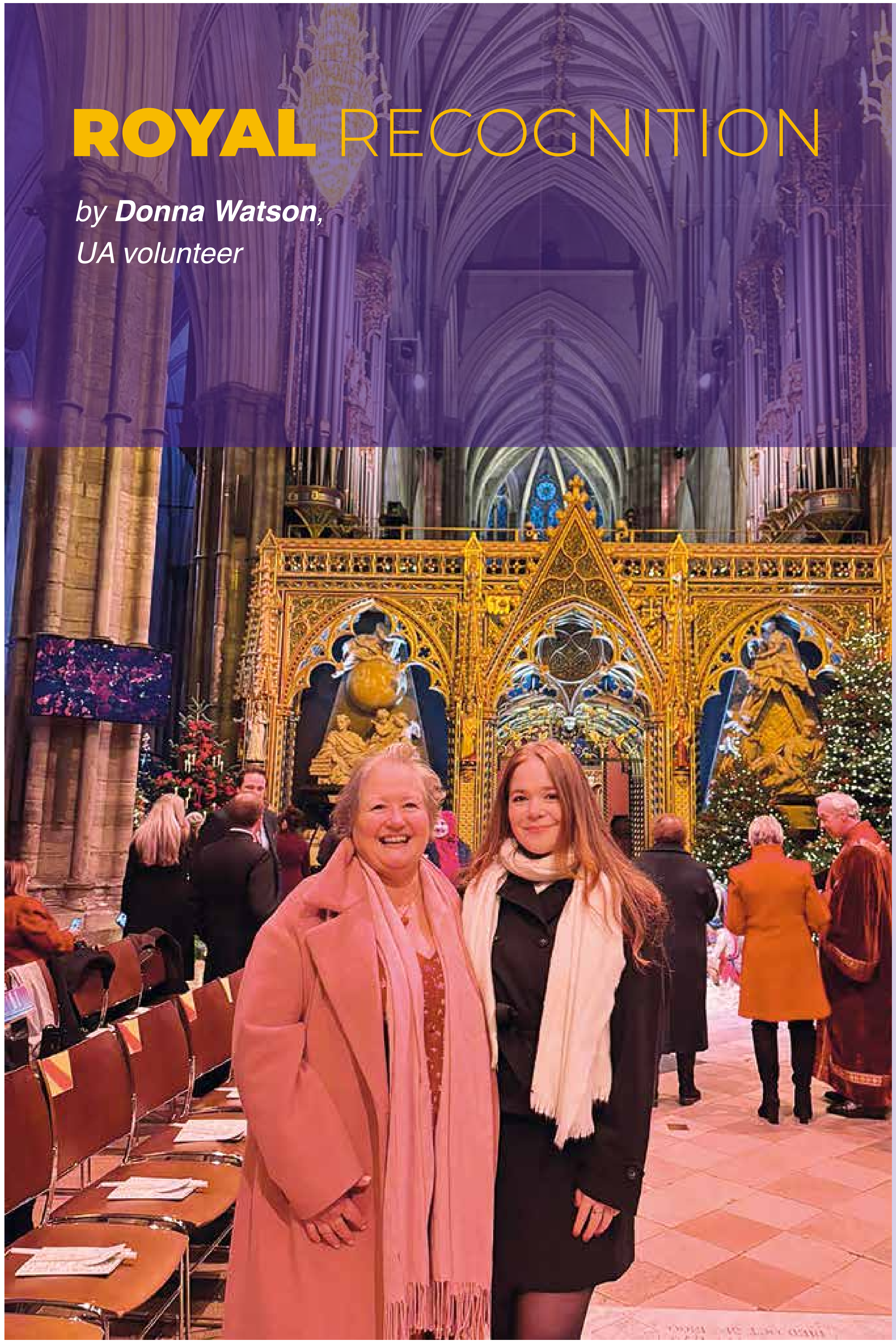
Address:

Postcode:

Email: Tel:

ROYAL RECOGNITION

by **Donna Watson**, UA volunteer



Last December, I was honoured to be among some 1,500 people invited to the Together at Christmas carol service hosted by the Princess of Wales at Westminster Abbey. The event, which is supported by the Royal Foundation, included guests from across the UK who have been recognised for bringing people together in their communities.

Her Royal Highness The Princess of Wales,
supported by The Royal Foundation and with grateful thanks
to the Dean and Chapter of Westminster Abbey,
requests the pleasure of the company of
Mrs. Donna Watson
Carol Service at Westminster Abbey, 20 Dean's Yard, London, SW1P 3PA
on Friday 5th December, 2025 at 5 p.m.

Arrivals from 3.30 p.m.
Carol Service 5 p.m. – 6 p.m.

Dress Code: Smart (no hats)

Please note that photo identification and your admit ticket are mandatory on entry.

To me, the invitation to this star-studded carol service - broadcast on ITV on Christmas Eve - was recognition of the work of the Urostomy Association, not just in Northern Ireland, where I live, but across the UK.

In her letter to guests, Her Royal Highness said, "The time, care and compassion you give, often quietly and unspoken, and without any expectation or recognition, make an extraordinary difference to the lives of others."

Happily, the invitation enabled me to take along my granddaughter, Kate, who has her heart set on an acting career. She was delighted to meet celebrities, such as actors Hannah Waddington, Joe Locke and Chiwetel Ejiofor, as well as Mary Berry. Others who contributed to the service included Kate Winslet, Katie Melua and singer-songwriters Griff and Dan Smith.

The work of the UA is largely undertaken by volunteers, and in Northern Ireland I have not only been involved in assisting urostomates but also in training security staff at our two main airports. I do this alongside community stoma nurse Helen Coulter, and together we endeavour to make travelling a less stressful and easier experience for people with a stoma.

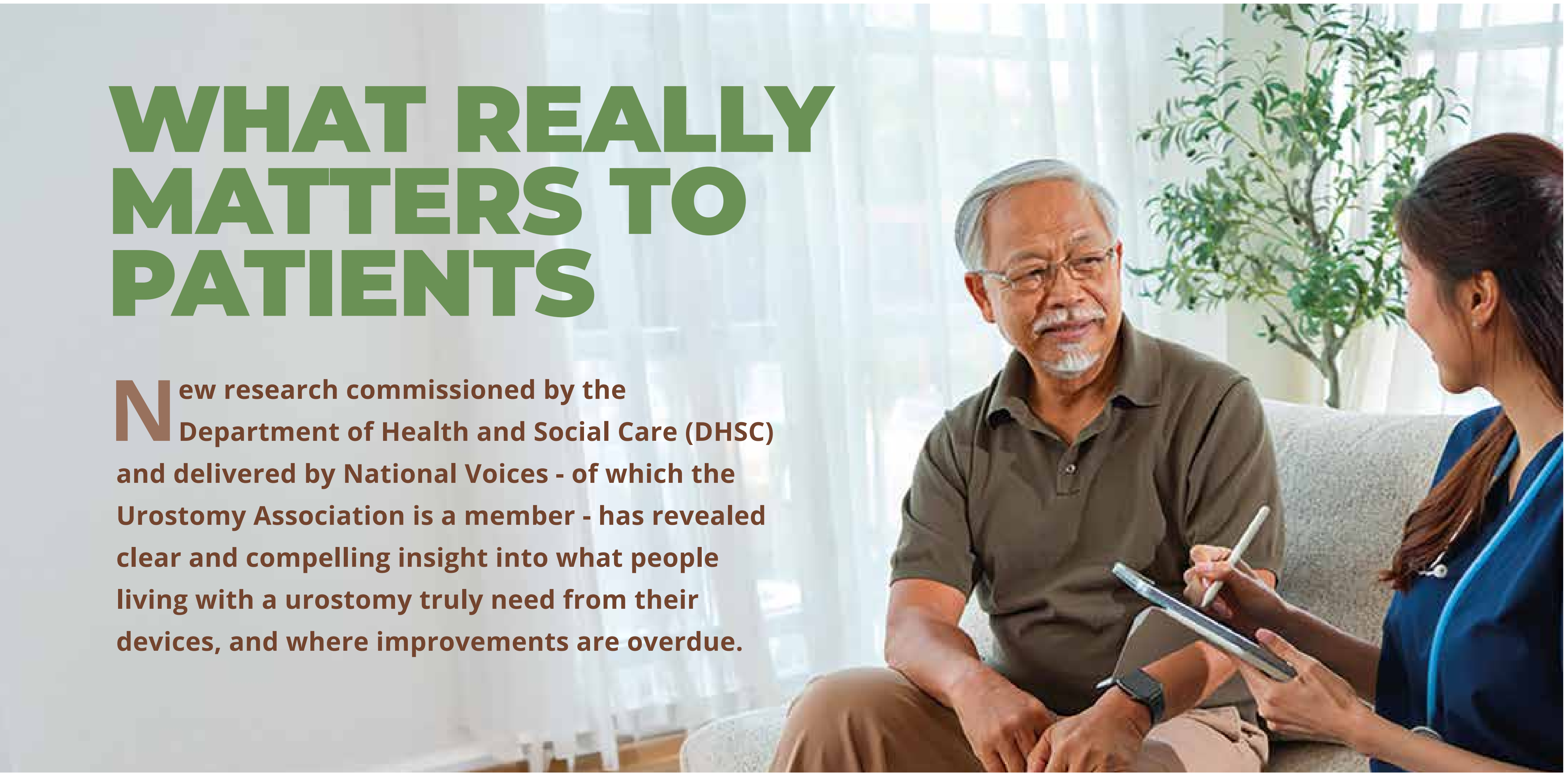
Helen educates security personnel about the medical side of stomas, while I demonstrate what a stoma and bag look like and explain the anxieties that passengers with an ostomy may have. For people who live with a bag, travel can sometimes feel daunting, especially early on. Helen and I aim to ensure that staff working to keep our airline journeys safe have a clear and sympathetic understanding of both the physical and emotional concerns. My work also involves keeping special assistance staff at airports aware of ostomates' needs.

I am in contact with the Head of Transport Policy for the Consumer Council for Northern Ireland, and through this I have provided guidance to one of our main ferry operators, Stena Line. Again, the aim is to help make travel easier for fellow urostomates.

All this work is extremely rewarding, and I would encourage others in a similar situation to consider how they might give of their time voluntarily to their local airports or seaports. It's a really meaningful way to make a difference.

WHAT REALLY MATTERS TO PATIENTS

New research commissioned by the Department of Health and Social Care (DHSC) and delivered by National Voices - of which the Urostomy Association is a member - has revealed clear and compelling insight into what people living with a urostomy truly need from their devices, and where improvements are overdue.



The study forms part of a wider review into patient experiences of 60,000 medical devices prescribed through Part IX of the NHS Drug Tariff. Between November 2024 and March 2025, National Voices gathered nearly 700 survey responses, alongside in-depth interviews and focus groups. This included 99 people using urostomy products. The aim was to better understand what patients value most and ensure these insights inform how devices are assessed and categorised in future.

The message is unmistakable. Urostomy devices are not simply medical products - they are fundamental to people's independence, confidence and quality of life.

Features that make a difference

Details matter. Time and again, participants pointed to a core set of features that define a good device.

Comfort and skin protection are essential, with base plates needing to be both gentle and reliable.

Leak prevention is equally critical, with secure adhesion and well-designed convex options helping people feel safe and in control.

Ease of use, such as pre-cut pouches, clear visibility during application and accessible taps, can make all the difference, particularly for those with reduced dexterity or sight loss.

> “Choice, quality and good information are not ‘extras’ – they are essential.”

Devices must work seamlessly with night drainage systems and be durable enough to stay secure throughout the day, even when full. When these elements come together, they enable people to sleep better, and take part fully in daily life.

Where things fall short

Yet the research also highlights ongoing frustrations. Many participants described adhesives failing in heat or during physical activity, leading to leaks. Others reported base plates breaking down too quickly or struggling with poorly designed flanges, taps and pouches.

Compatibility between products was another issue, as was visible bulging of pouches. For many, these challenges go beyond inconvenience - they can erode confidence and have a lasting impact on mental wellbeing.

> “Urostomy devices are not simply medical products - they are fundamental to people’s independence, confidence and quality of life.”

There is also growing awareness of environmental concerns, with patients expressing a desire for more sustainable options where clinically appropriate.

Choice and fairness

Perhaps most striking is how many people are unaware they have a choice at all. Some participants believed the product they were given after surgery was their only option.

The report also underscores the importance of inclusive design. Devices must work for a diverse population, including people from different ethnic backgrounds, those with disabilities, and individuals with limited dexterity or sensory impairments. Seemingly small details, such as colour and ease of handling, can have a big impact in everyday life.

What’s next?

In response, the DHSC has set out a series of commitments, including maintaining a wide range of available devices, improving patient information, and addressing regional variation in access. There are also plans to strengthen patient involvement in decision-making and encourage manufacturers to tackle health inequalities through better design.

Manufacturers are being urged to work closely with users to create products that prioritise comfort, discretion and independence, while local decision-makers are encouraged to look beyond clinical function and consider the emotional and practical realities of living with a urostomy.

Samantha Sherratt, the Urostomy Association’s Transformation Director, said: “This research validates what people with urostomies have been telling us for some time: the right device can be life-changing, and the wrong one can be devastating. Choice, quality and good information are not ‘extras’ – they are essential.

“We welcome the DHSC’s commitment to embedding patient voice and tackling inequalities, and we will continue to work with partners, like National Voices, to ensure urostomy patients are heard, respected and supported.”

CELEBRATE good times!

Giving in celebration is a joyful way to raise funds and make a real difference to the lives of people living with a urostomy.

Whether it's a birthday, wedding or another special milestone, why not support the Urostomy Association as part of your celebration? By inviting friends and family to make a charitable donation in place of gifts, you'll be helping to share positivity while supporting our vital work.

There are several simple ways to get involved - just choose what feels right for you. If you have any questions, we'd be delighted to help.

Set up an online collection

The easiest way for people to donate is online via a JustGiving "fundraising in celebration" page. It automatically keeps track of donations, and your friends and family can leave thoughtful messages to mark your occasion. Even better, donations come straight to us - so you can relax and enjoy every moment of your celebration!

To find out how to set up your page, visit: *https://urostomyassociation.org.uk/support-our-work/giving-in-celebration/*

Request donation envelopes

We're pleased to offer personalised envelopes that you can include with invitations or place on tables at your event - an easy and thoughtful way for guests to give if they wish.

Each envelope contains a donation form, and you simply return everything to us afterwards. Just call the office to let us know what you'd like printed on the front: 01223 910854.

Donate online

You can also visit our online 'make a donation' page to make a one-off or regular gift.

By post

To send an "in celebration" donation by cheque, please make it payable to the Urostomy Association and include the donation form from the back of this Journal.

By phone

You can call and make your donation over the phone; just have your payment card handy. Our telephone number is 01223 910854. Lines are open between 9:30am and 5:30pm, Monday to Friday.

Whatever the occasion, we hope your celebrations go with a swing!

NEWS FROM OUR BRANCHES

A round-up of news from our regional branches and local groups

Cambridge

Venue: Cambridge Cancer Help Centre, Scotsdales Garden Centre, Great Shelford, CB22 5JT

Secretary: Jane Phillips

Email: *secretary.cambridge@urostomyassociation.org.uk*

When you have a urostomy, getting a good night's sleep isn't always straightforward. For some of our members, sleep is a big problem so we were delighted to get lots of helpful advice from the two Coloplast nurses who kindly gave us a talk in March. It was very well attended and extremely worthwhile, with the nurses staying to answer questions afterwards. A big thank you to them for their time and expert input.

Our previous Chair, Alan, was voted back in at our December meeting. The rest of our committee officers remain the same, but we now have five additional committee members to help arrange meetings and talks for our branch. In the coming months we are looking forward to talks about cidermaking, AI and addressing concerns around it, and the history behind fairs and markets.

We will also be arranging a coach trip – destination to be confirmed – and we are searching for a venue for this year's Christmas lunch. At last year's lunch, we raised over £200 from raffle ticket sales towards branch funds. I think we were drawing tickets for the prizes, all donated by members, for half an hour after our meal!

We are proud to be one of the UA branches that still has regular face-to-face meetings, and pride ourselves on being welcoming and supportive. Whether you are facing surgery, on the road to recovery after your operation or have had your urostomy for many years and want to connect with others in a similar situation, please do come along to a meeting.

Our meeting venue is very comfortable, and there's plenty of space for parking.

Jane Phillips

DIARY DATES

We meet at 10.30am on the first Tuesday of the month. Please see venue details above.

Newcastle

Venue: The Freeman Hospital, Newcastle-upon-Tyne, NE7 7NU

Secretary: Brian Fretwell

Email: *chairman@urostomyassociation.org.uk*

We are continuing to meet on a regular basis, welcoming familiar faces as well as people who are new to living with a urostomy or simply didn't know until recently that our branch exists.

Our meetings are as informative as they are uplifting, usually with a talk from a stoma care professional sharing advice on living well with your urostomy, and company reps showing us their latest products.

There's plenty of time for questions and catching up on news, and always lots of encouragement for anyone who might find themselves going through a tough patch. There's nothing like being in the company of those who understand what you are going through and can offer reassurance and tips from their own experience.

We are still seeking a volunteer to help organise our meetings. In the meantime, I will continue standing in to keep things running smoothly.

Please keep an eye on the events page of the UA's website for meeting dates and details. If you are in the area, do come along to a meeting to find out more about us, or drop me a line at the email address above.

We'd love to welcome you.

Brian Fretwell

Sheffield & District

Venue: Tapton Hall, Shore Lane, Sheffield, S10 3BU

Branch Secretary: Mary Milner

Email: *secretary.sheffield@urostomyassociation.org.uk*

We will be holding three meetings at Tapton Hall throughout 2026 – please see 'Diary dates' below for details.

Our branch committee is currently finalising our plans for these meetings. Sometimes we have a guest speaker or perhaps a quiz but, whatever we do, we can promise you a warm welcome with tea, coffee and possibly cake!

Usually around 40 – 50 people attend our meetings, which offer a lovely opportunity to meet with others who have a urostomy to share experiences and tips, with fun and laughter along the way. We are also very fortunate to have the support of a number of representatives from the different appliance and delivery companies, so you can take a look at their appliances and accessories, and have a chat if you have any queries.

We look forward to welcoming you.

Mary Milner

DIARY DATES

11 April: Spring get-together;
4 July: Summer meeting.

Yorkshire & Humberside

Venue: Salvation Army Church Hall, Hunslet Road, Leeds, LS11 6QB

Secretary: David Legood

Email: *secretary.yorkshire@urostomyassociation.org.uk*

We had a busy end to last year, representing the UA at York Hospital's Stoma Day and also at Pinderfields Hospital's Wellbeing Day, the latter sponsored by companies Hollister, Dansac and Fittleworth. Both were well attended and gave us the opportunity to meet people who don't currently attend our branch meetings.

Our Branch Treasurer was invited to give a presentation about UA activities, including the Facebook Support Group. We shared our table with one of our members who makes discreet bag covers - for further information, contact mickholmes1@ntlworld.com.

Our Christmas 'Urostomeet' at Garforth Golf Club was also well attended. Special thanks to all who helped make the day such a success, including the stoma nurses from Leeds and Pinderfields Hospitals, Helen from Salts, Lou from Dansac, Lorraine from Comfizz, Huw from Hollister, and all at the Golf Club.

Entertainment was provided by branch member John Turner, who is the Town Crier for Pontefract, who gave a light-hearted talk.

With our branch covering such a large area, the Committee is concerned about how we can best support the Humberside region, in particular. For example, do the hospitals have stoma days or would members like a branch meeting in Humberside? Please let me know your thoughts via my email address above.

David Legood

DIARY DATES

8 June: 'Urostomeet' at Garforth Golf Club, Leeds.

We are pleased to include reports from Gloucestershire and Northern Ireland, although they are not formal Urostomy Association bodies.

Northern Ireland group

In January, we were delighted to be joined by Joanna Kerr, Salts Territorial Manager. She showed us all the company's urostomy products, gave a great talk, and provided a lovely lunch, so a big thank you to her.

We are also grateful to the Macmillan Cancer Information and Support Centre in Belfast for use of their premises for our meet-ups and for kindly providing tea, coffee and biscuits.

We warmly welcome new members to join us for mutual support and encouragement, so do come and meet us if you are in the area. To find out more, please contact me via *donna.watson@urostomyassociation.org.uk.*

Donna Watson

Gloucester & District group

Venue: Churchdown Community Centre, Parton Road, Churchdown, Gloucester GL3 2JH

Group Co-ordinator: Nicky Berry

Email: *urostomysupport5000@icloud.com.*

Our local group, covering Gloucestershire and surrounding areas, continues to thrive, welcoming new members and looking to the future.

At our most recent meeting in February, our long-standing organisers Val and Alex (see photo) handed over the baton after running the group for many years. Having done a fantastic job of successfully steering the group through testing times, they are now going to focus on other things but certainly not putting their feet up!

We then spent time considering future plans and seeking views on what people most wanted to gain from the group, We now have a long list of wishes to be fulfilled, so no resting on our laurels!

Using a dummy she brought with her to demonstrate, group member Stacey kindly talked us through the various benefits of using a leg bag, issues that can arise and how they can be tackled with a little bit of lateral thinking. Special thanks to Hollister for helping with sample supplies.

Via our most recent Freedom of Information request to the local NHS, we know that at least 60 people had urostomy surgery in Gloucestershire last year. So, we know there's lots more to do to help us reach all those people and let them know about the support and camaraderie our group provides.

You can find out more about our group via our website: *www.gloucestershireurostomygroup.org/.*

DIARY DATES

18 June: Group meeting.

Nick Berry

UROSTOMY
ASSOCIATION

Your support makes such a difference

Regular, monthly donations are crucial to the Urostomy Association because life with a urinary diversion can feel daunting. It's vital that people have somewhere to turn for reassurance at every stage, from diagnosis to living life to the full again. We provide that support at the UA. But we can only do so thanks to your donations.

With your kindness, we can continue running our helpline and keep people informed and supported through our magazine, The Journal, e-newsletters, plus group meetings, social media, fact sheets and more. We can also keep on campaigning, making sure the voices of the community we represent are heard wherever they need to be.

By giving regularly, you'll help people with a urinary diversion grow in confidence so life can feel more like normal again – or even better than before.

- **£10 a month** could help ensure our helpline is there for anxious callers.
- **£15 a month** could fund a 'meet the expert' webinar so urostomates can directly speak to those in the know.
- **£25 a month** could help ensure there's a local buddy available to provide one-to-one support, drawing on their own experiences of living with a urinary diversion.

It's straightforward to set up a regular donation via our website at *www.urostomyassociation.org.uk.*

If you prefer, please complete the form at the back of this magazine and post it to us at the address given there.

Thank you so much for your support.

Complete this side to support the Urostomy Association with a single gift

UROSTOMY
ASSOCIATION

SIDE 1 OF 2

Thank you for making a real difference to the lives of people facing, or living with, a urinary diversion across the UK. To make a donation, you can either use this form or scan the QR code below to donate online.

Alternatively, by donating monthly you can provide a consistent source of funding that enables us to plan and deliver our support programmes. Please use the form overleaf to give a regular gift.

Thank you for your kindness.

Scan to donate online or call **01223 910854**

1 Your donation

I would like to give a single gift of: ☐ **£30** ☐ **£60** ☐ **£175**

OR other amount £

☐ I am enclosing a cheque payable to **The Urostomy Association**

☐ I would like to donate by debit/credit card

Card no: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ *(Maestro only)* ☐☐☐

Expiry date ☐☐☐☐ CVV number* ☐☐☐ *Maestro issue no:* ☐☐

Signature: Date:

**If you're uncomfortable completing your CVV number here, please leave us your phone number so we can call you and complete your donation by phone. Thank you.*

2 Your details

Title: First name: Last name:

Address:

Postcode:

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We may post you occasional updates about our events and fundraising and how support like yours transforms lives. Please indicate if you're happy to stay in touch by:

☐ Email ☐ Phone ☐ SMS

Make your gift worth **25% more** at **no extra cost to you!**

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Signature: Date:

☐ I am a UK tax payer

I am a UK taxpayer, and wish you to treat all gifts I have given in the past four years, and all future gifts I make, as Gift Aid donations. By ticking this box I am confirming that I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it is my responsibility to pay any difference.

You can see our donor privacy policy on our website at ***urostomyassociation.org.uk***. If you want to change the way we communicate with you or wish cancel your Gift Aid declaration, please let us know.

Registered charity nos: 1131072 (England and Wales) SCO47740 (Scotland)

Please return this form to:

Urostomy Association,
Office 205,
No 9 Journey Campus,
Castle Park,
Cambridge,
CB3 0AX.

Thank you!

Registered with
FR
FUNDRAISING REGULATOR

Complete this side to support the Urostomy Association with a regular **monthly gift**

UROSTOMY
ASSOCIATION

SIDE 2 OF 2

Thank you for making a real difference to the lives of people facing, or living with, a urinary diversion; we appreciate your generosity and commitment. By making a monthly gift, you can help ensure a consistent source of funding that enables us to more effectively plan and deliver our support programmes. If you prefer to give as single donation today, please complete the other side of this form.

Thank you so much for your kindness.

Scan to donate online or call **01223 910854**

1 Your donation

I would like to give a monthly gift of: ☐ **£10** ☐ **£15** ☐ **£25**

OR other amount £ ______ via my debit/credit card.

Please take my monthly gift on the 1st of the month or the 15th of the month.
Please circle which you prefer. If no date is selected, we will process your gift onthe 1st of the month.

Card no: *(Maestro only)*

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐

Expiry date ☐☐☐☐ CVV number* ☐☐☐ *Maestro issue no:* ☐☐

Signature: Date:

**If you're uncomfortable completing your CVV number here, please leave us your phone number so we can call you and complete your donation by phone. Thank you.*

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Thank you!