UROSTOMY
ASSOCIATION
Incorporating all types of urinary diversion

journal

Winter 2025 Issue 135

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Innovating to improve patient care

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Be in it to win it

Play our exciting new lottery

Welcome to our winter Journal

With the end of the year in sight, it’s been a time of looking back at the past 12 months, including the personal stories we’ve featured in the Journal. It takes courage to share your journey, so thank you to every urostomate who has contributed from their own experience - from diagnosis through to living an active life again. There’s real power in your words, and the tips you pass on are greatly appreciated – the feedback we receive from readers tells us so!

In this edition, Paul, Dani and Aimee explain how they’ve navigated big challenges and come out stronger, appreciating life more than ever. If, like Paul, you feel inspired to take on a challenge of a different kind to show your support for the UA, why not seize the day? Committing to clocking up your own Miles of Hope in 2026 could be a great way to start the new year! Details of how to get involved are on page 12.

I hope you enjoy reading all our articles and feel encouraged, whether you’re facing surgery, recovering after your operation, or have been living with your urostomy for years.

If you'd like to share your story - or any top tips - with Journal readers, please get in touch via *editor@urostomyassociation.org.uk.*

Finally, please remember that you are not alone. You are part of our UA community and we are here with support, however your life is unfolding.

Warm wishes

Paola

Paola Simoneschi
Journal Editor

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 spring edition should arrive no later than **13 February**.

Thank you.

On the cover

Urostomate Paul has turned his health challenges into Miles of Hope, raising vital funds for the UA. Turn to page 8 to read his story.

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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.

Disclaimer

The views expressed by contributors are not necessarily those of the Urostomy Association. Great care has been taken to ensure accuracy, but we cannot accept responsibility for errors or omissions. The display or description of products or services, or the inclusion of advertisements or inserts within this magazine, does not constitute an endorsement or recommendation by the Association.

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
Incorporating all types of urinary diversion

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.**

Resources at your fingertips

Whether you're new to living with a urostomy, or experiencing any issues further along, you need information you can trust, and advice that's jargon-free. Practical tips from those in the know can also be invaluable, helping you face the future with more confidence.

At the Urostomy Association, we understand the questions you might have, and we're here to help you feel supported whenever you need us. Our website, *urostomyassociation.org.uk*, is full of free resources - all available at the click of a button - to guide you through every stage of life with a urostomy.

You'll find clear information guides and leaflets, covering everything from looking after your stoma and staying well to navigating relationships, returning to work and managing travel.

We also have a growing library of videos and webinars, where you can hear from stoma care specialists, learn from others living with a urostomy, and pick up useful tips for daily life.

For reassurance, encouragement and inspiration, there are personal stories from urostomates who share their journeys - how they felt, what helped them most, and how they've regained the confidence to live life to the full.

Our resources are available to you free of charge, ready whenever you need them via your phone, laptop or computer. Thank you to everyone who donates to, or fundraises for, the UA – it's your generous support that makes this possible.

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 about getting back to living as full a life as possible.

Just over two months from my operation, I was able to go out walking again. Life wasn't without its difficulties though, and continence was definitely a problem. I had to rely on continence products to help, although this wasn't really approved by my surgeon. Doing pelvic floor exercises is an essential part of recovery, but it's not easy to regain one's continence with a neobladder, and I admit that I didn't manage that well.

Travel has been an important part of life to Morag and me, particularly in retirement. So, a little over a year after surgery, we went on a walking holiday to Patagonia in South America. We have been on many holidays together, both in the UK and abroad. Again, part of living life to the full!

Embracing challenges

One of the challenges I set myself was to walk the Coast-to-Coast path, 190 miles from St Bees in Cumbria to Robin Hood's Bay in North Yorkshire. I set this goal when I was recovering in hospital, and it was originally planned for May 2020, but COVID changed this. Eventually, I managed to achieve my goal, doing it in two parts: from St Bees to Kirkby Stephen in July 2022, and then from Kirkby Stephen to Robin Hood's Bay in June/July 2024.

Between these trips, in June 2023 I had to have another major op, changing my neobladder to a urostomy, and also having my right kidney removed because of the spread of cancerous cells. Again, I was determined to get my fitness back, and I followed a programme of exercises to strengthen my core. I found that my urostomy was easier to manage than the neobladder, and being able to use a night drainage bag meant I no longer had to get up twice in the night. Incontinence was no longer a problem, although I have had to cope with the occasional 'accident'.

My Miles of Hope challenge this year was prompted by being reprieved from further surgery. Having had a serious UTI in February, which had to be treated in hospital, it was thought that cancer may have spread to my remaining kidney and ureter. However, a biopsy has shown that, fortunately, this has not been the case – at least not so far.

Having walked the Coast-to-Coast with me, my friend David was keen to do the Offa's Dyke Path (177 miles) along the England and Wales border. We had booked to walk the first part, from Chepstow to Knighton (80 miles), in September. It didn't look as if this would happen, as I might have been tied to a dialysis machine, but I have been able to do this first part, with the remaining 97 miles from Knighton to Prestatyn in North Wales to be completed next year, hopefully.

Urostomy life

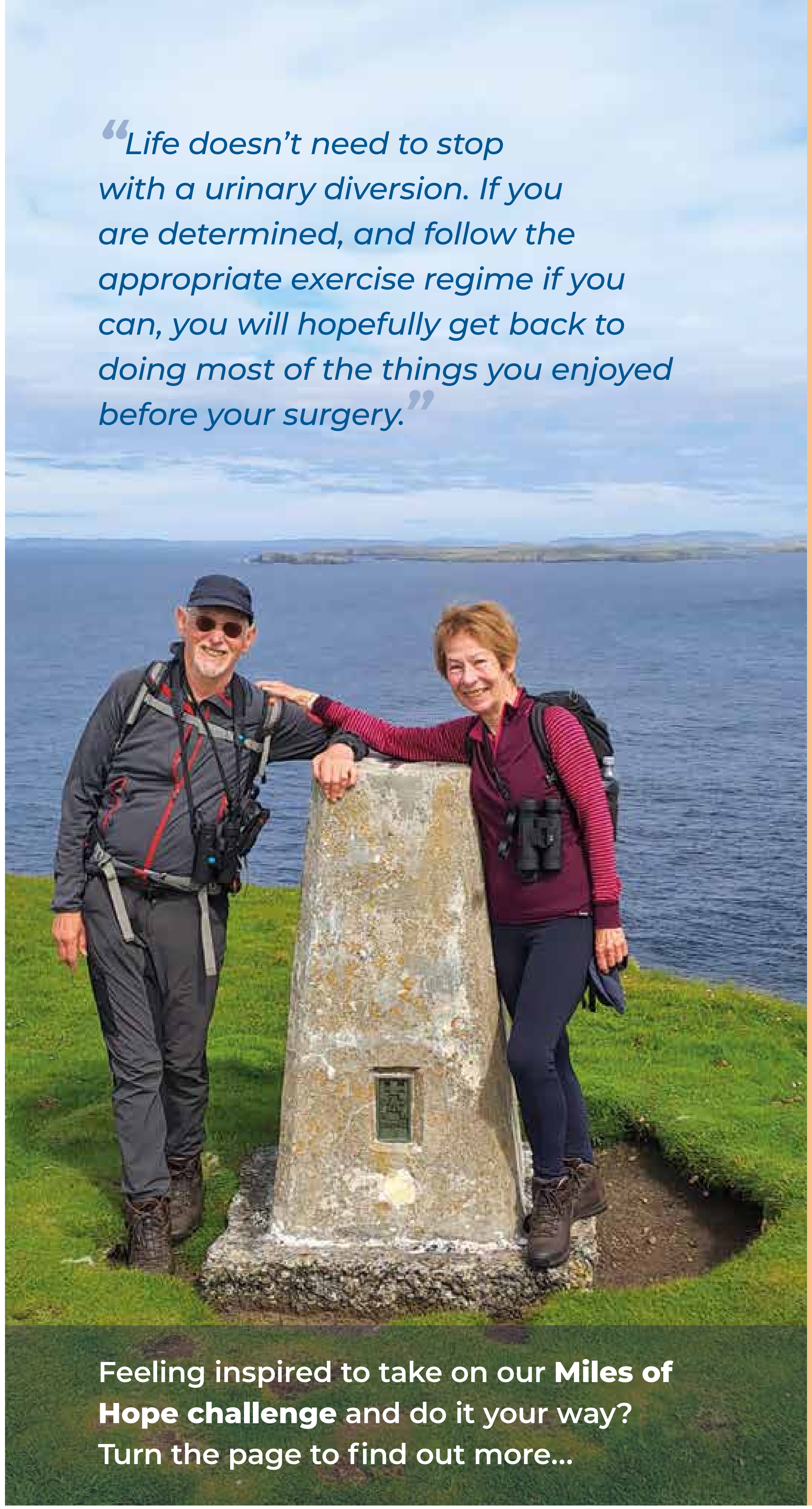
Having a urostomy doesn't mean there is any extra planning for a trip like this. We stay in small hotels, pubs and b&bs, and our luggage gets taken on to the next overnight stop. As for any trip, it's important to have sufficient stoma supplies, including night drainage bags with a plastic stand. I carry a spare urostomy bag set in my rucksack, but I haven't had to use that. It's important to keep well hydrated, so you need to carry enough water.

Thanks to the wonderful generosity of my friends and family, I have so far raised £1,155 for the UA by taking on the Miles of Hope challenge. I first got to know the Association through going to a meeting of the Sheffield branch. They provide great support, and the meetings are an opportunity to get together with people who are in a similar situation. I have found the UA's Facebook support group really helpful, as is the information on the UA website and via the webinars.

Life doesn't need to stop with a urinary diversion. If you are determined, and follow the appropriate exercise regime if you can, you will hopefully get back to doing most of the things you enjoyed before your surgery. It doesn't have to involve walking long distances. Keeping active is the main thing. When I got home after my first operation, I thought that I would spend a lot of time sitting in my armchair, reading and listening to music. Although these are things I enjoy, I try to get out most days for a walk, maybe just around the neighbourhood.

I wouldn't have been able to cope with my health issues without the support of Morag, my sons, Dave and Jon, and my friends. My message for anyone setting out on this road: just keep going!

> *"Life doesn't need to stop with a urinary diversion. If you are determined, and follow the appropriate exercise regime if you can, you will hopefully get back to doing most of the things you enjoyed before your surgery."*



Feeling inspired to take on our **Miles of Hope challenge** and do it your way? Turn the page to find out more...

Miles of Hope: your challenge, your way

With winter comes the temptation to hunker down at home, waiting for warmer days before spending time outside. But getting outdoors for a burst of movement can work wonders, not just for body but for state of mind too. That's why, this season, we're inviting you to take part in our Miles of Hope Challenge. It's an uplifting way to stay active, embrace fresh air, and raise funds to help bring hope to someone facing surgery, or adjusting to life with a urostomy or other type of urinary diversion.

Do something you enjoy

How you choose to clock up your miles is entirely up to you. Hike, stroll, cycle, row or jog – every mile you complete helps raise awareness and vital funds for the UA's work. You don't have to go far – unless you want to! Just take it at your own pace. Go solo or make it a social activity, joining with friends or family to travel your Miles of Hope to a coffee shop for some well-earned cake.

Prefer to stay under cover? You could complete your miles at your local swimming baths, or on a treadmill, exercise bike, or rowing machine.

Wherever you put in your miles and however far you go, you'll be making an important difference. The funds you raise will help us bring comfort, reassurance and hope to others.

Join the challenge and share your progress

To get started, simply download our participant pack *urostomyassociation.org.uk/help-provide-hope/miles-of-hope-challenge/*. It's full of tips, inspiration, and everything you need to set your challenge in motion. If you'd prefer a paper copy, please call Samantha at the office on **01223 910854.**

Thank you for making your miles matter!

SAMANTHA'S **STEPS**

Our Transformation Director Samantha Sherratt walked more than 100 Miles of Hope in the autumn, raising £220 for our charity. Thank you for going the distance, Samantha!

There are many 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.

Local support for you

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. We're happy to share their details so you can find the support that suits you best, but please note that we're not responsible for their activities or events.

Find connection

You'll find details about branches and groups on our website at *urostomyassociation.org.uk/local-groups/*. If you're part of a group we've not yet listed there, please let us know by filling in the brief form on that page.

We hope you find a group nearby - you're very welcome to contact them directly.

If there isn't a group in your area and you'd like to talk to someone who understands life with a urinary diversion, please get in touch with us. We'll connect you with one of our trained volunteers for friendly, one-to-one support.

You might also like to take a look at our events page which gives details of activities coming up in the months ahead.

> *"We hope you find a group nearby - you're very welcome to contact them directly"*

Talking about your urostomy

> “Having a supportive network around you can do so much to help your recovery.”

When you’re adjusting to life after surgery, it can feel hard knowing how, or if, you want to tell others about your urostomy. It’s natural to feel unsure at first. You may wonder who needs to know, how much you should share, or whether people will understand.

There’s no right or wrong. You are in control of who you tell, when you tell them, and how much detail to go into. It’s important to take things at your own pace, and know that the right people will meet you with kindness and support.

Choosing who to tell

It’s understandable to feel apprehensive about having conversations about your urostomy. But you may find that sharing with certain people lifts some of the weight off your shoulders. For many urostomates, this means talking to close family and trusted friends – people who love you and want to walk alongside you as you adjust.

It might also be helpful to let a few others in on your situation and how it is affecting you. Perhaps your manager at work or a supportive colleague, so you don’t feel you’re carrying everything alone.

Understanding goes both ways

Talking about your urostomy can be a step towards creating understanding and helping you find support when you need it. When you’re ready to talk, think about what feels comfortable for you. Do you want to share just the basics, or open up about your feelings too? There’s no wrong answer.

Not everyone will know much about stomas, so try to give people time and space to process. They may have questions, but it’s up to you how much you choose to share. Many urostomates find that honest, open conversations help clear up any confusion and often make bonds even stronger.

Talking to friends and family

Having a supportive network around you can do so much to help your recovery. Given what you have been through with your health, you may have friends and family members who already know about your urostomy.

Explaining how you are feeling, and letting them know how best they can support you – both practically and emotionally – can help reduce your anxiety as you adapt to life with your urostomy.

If some of your relatives and friends don’t yet know about your stoma but you want them to, you could ask those who do to give them the basics until you feel ready for a proper conversation.

Talking to your partner

Perhaps the most personal conversation of all is with your partner. If you’re already in a relationship, honesty can deepen your connection. It’s normal for your partner to have questions, but most of the time, they’ll simply want to know how they can support you. This is an opportunity to share your feelings, your worries, and your hopes. Facing this together can help you feel closer.

If you’re thinking about dating or starting a new relationship, it’s natural to feel nervous about when to mention your urostomy. There’s no rulebook, so trust your instincts. Some people like to share early on, while others prefer to wait until the relationship feels more established and secure. The right person will see you first, not your urostomy.

Conversations with young children

If you have little ones in your life, it makes sense to keep things simple and reassuring. A short, clear explanation is often enough. Answer any questions as they come up; how you respond is likely to affect the way your child thinks about people’s differences and treats others as they grow up.

Finding it difficult to know where to start? Take a look at our children’s book, ‘Bags, Bags, Bags’, and download a copy free of charge.

Created with under-7s in mind, it’s full of fun and bursting with colour, helping to spark conversations naturally.

> “If you have little ones in your life, it makes sense to keep things simple and reassuring.”

Speaking to your employer and colleagues

For many urostomates, work is a big part of daily life. It’s normal to feel nervous about how a stoma might fit into that. Having an open conversation with your employer can ease some of those worries. Whether it’s about taking breaks, adjusting schedules, or just knowing they’re aware, being upfront can pave the way for a smoother return to work.

As for colleagues, you may decide that telling just one or two people you trust is enough. Many people are surprised by how understanding their colleagues are once they open up.

Talking about your urostomy cont

You're never alone

Adapting to life with a bag takes time, patience and self-compassion, but having a urostomy does not need to define who you are.

With time, these conversations will feel easier, and you'll find that the people who matter most will stand beside you with love and understanding.

The Urostomy Association is here for you, too. Our trained volunteers can provide reassuring, confidential one-to-one support, by telephone, face-to-face or through our branches. All our volunteers are urostomates themselves, or family members, so can understand your concerns.

To be put in touch with a volunteer do contact us by phoning our helpline on ***01223 910854***, or via *urostomyassociation.org.uk/contact/*. We also host a private Facebook Group – *Urostomy Association Help and Support Group* – a safe space for you to get to know and learn from others who are facing similar situations, or have done so in the past.

> "All our volunteers are urostomates themselves, or family members, so can understand your concerns."

In their own words

"My advice to anyone struggling to find the confidence to tell those close to them about their urostomy is take your time but don't overthink it. Your urostomy is a reminder of how strong you are and what you've had to overcome. You've done the hard part, so don't forget that.

"When it comes to work, be open with your manager so they have a good understanding of your situation. Ask for a catch-up with them to discuss it, and perhaps take some literature along with you to help you explain."

Lorna Coates

"I do feel that health conditions and disabilities are so much more talked about now than when I had my urostomy operation 15 years ago.

"At first, I found it a bit daunting telling people about my stoma, but I was surprised at how accepting and understanding they were. Many people say, "Really? I would not have known if you hadn't told me." I thought having a urostomy made me stand out as different, but people see it as just one aspect of me."

Allen Rowlinson

Win 25k!

Our exciting **new** Unity Lottery – more chances to **win**, more ways to **support!**

For many years, our 200+ Club has been a fun and friendly way for supporters to get involved with fundraising - and perhaps win a little extra along the way! Thanks to your participation, it's helped raise vital funds for our work supporting urostomates and those who care for them.

Now, we're taking that success a step further by launching something even bigger: the Urostomy Association Unity Lottery!

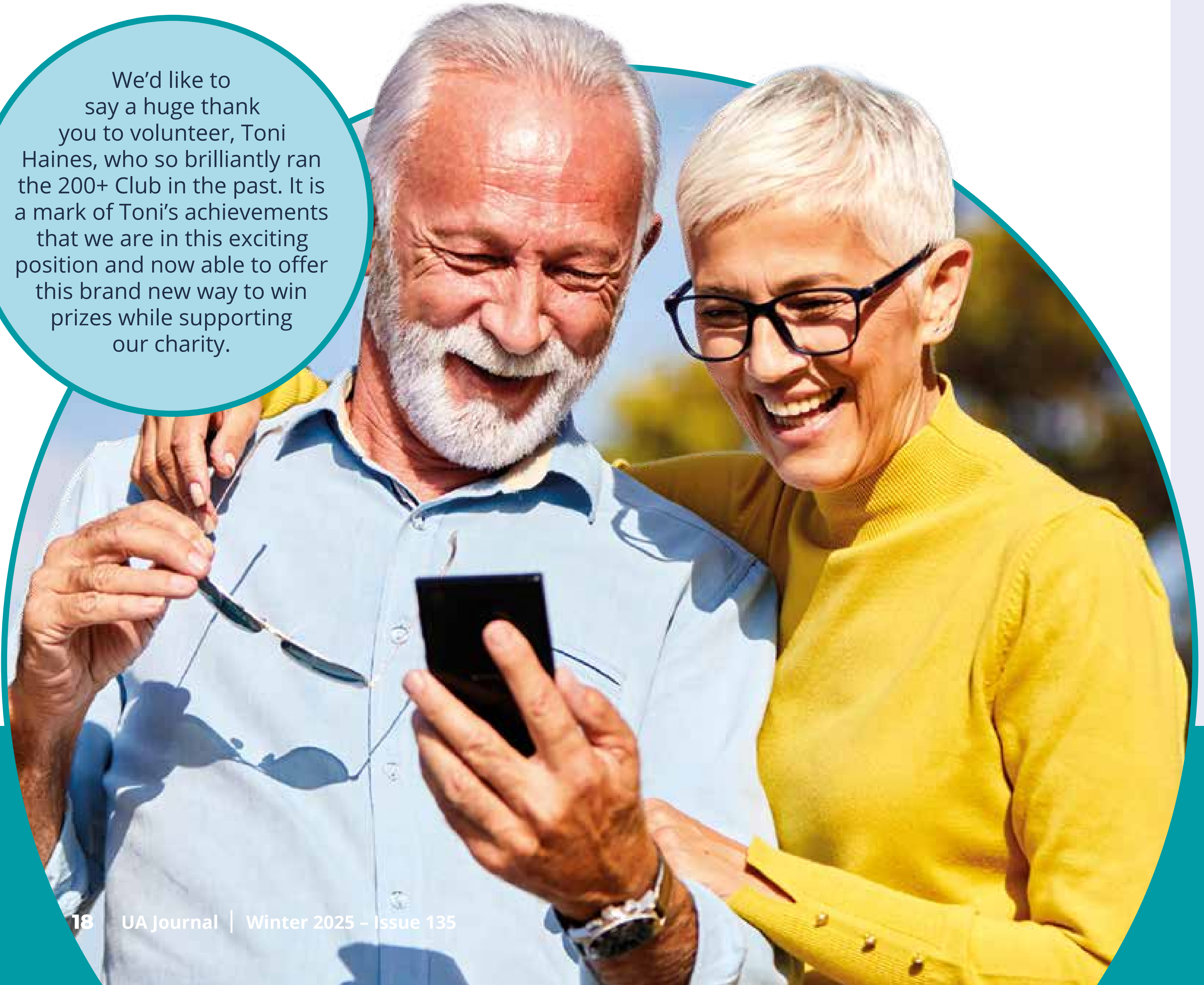
A new chapter in fundraising

From 1 January 2026, all our draws will take place through the Unity Lottery, a national scheme run by Sterling Lotteries - one of the UK's most trusted lottery providers for charities.

This exciting change means we can offer more prizes, more chances to win, and a simpler way to play - all while ensuring the highest standards of security and compliance.

If you've enjoyed being part of the 200+ Club, you'll love the Unity Lottery!

We'd like to say a huge thank you to volunteer, Toni Haines, who so brilliantly ran the 200+ Club in the past. It is a mark of Toni's achievements that we are in this exciting position and now able to offer this brand new way to win prizes while supporting our charity.



Why join the Urostomy Association Unity 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 goes directly to the Urostomy Association (the same percentage as the 200+ Club)
- **Great odds** – you have a 1 in 63 chance of winning a prize each week
- **Safe, secure and fully licensed** by the Gambling Commission

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

Farewell to the 200+ Club

Our long-standing 200+ Club will come to an end on 31 December 2025. We're so grateful to everyone who's taken part over the years - you've helped raise essential funds and built a wonderful community of supporters. If you're a 200+ Club player, you should have received an email or letter from us already but, if not, then do contact Samantha at Head Office.

To make sure you don't miss future prize draws, we encourage all 200+ Club members to sign up to the new Unity Lottery before the first draw takes place in January 2026.

How to join

Joining couldn't be easier:

- **Online via our bespoke web page:** *unitylottery.co.uk/causes/urostomy-association/*
- **By phone:** Call **0370 050 9240**
- **By post:** Request a form by calling the number above, or download one via our bespoke web page

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

Your support makes a difference

Every ticket you buy helps fund our mission to support, inform and empower people living with a urostomy.

Together, we can continue to:

- Offer advice and reassurance through our helpline and one-to-one buddies
- Produce trusted information for new and experienced urostomates
- Raise awareness and advocate for better care

So why not join today?

You could be our next big winner - while helping us make sure no one has to face living with a urostomy alone.

Find out more Visit *unitylottery.co.uk/causes/urostomy-association/* or contact Samantha Sherratt at *Samantha.sherratt@urostomyassociation.org.uk* / **07812 495907** for more details.

ASCN 2025:
connection and collaboration

As the national charity specifically for urostomates and their carers, we are part of the wider community of care and support organisations for people living with any type of ostomy. So, it was great to be back at the Association of Stoma Care Nurses (ASCN) annual conference in October, sharing our latest developments with stoma health professionals and product suppliers, and hearing from them too.

Working together keeps us in step with how the sector is evolving, and helps ensure the information and advice the UA provides for people with a urinary diversion is always up to date.

Collaboration is the key to providing the very best, joined-up services for patients. That's why we took the opportunity to connect with stoma care nurses to discuss how we can work together to better support young people requiring urinary diversions as a result of Ketamine Bladder.

The UA has launched a new study to investigate the incidence and impact of this devastating condition, both on the users themselves, and the services which support them. Details about this vital work appeared in our Summer Journal, and you can also read about it on our website, *urostomyassociation.org.uk/news/rising-pressures-complex-cases/.*

Boosting your defence against UTIs

Living with a urostomy, you're probably aware that urinary tract infections (UTIs) can be an unwelcome part of the journey. In most cases, UTIs are mild and short lived but they can sometimes be debilitating, affecting your quality of life.

While antibiotics are an effective treatment for most urinary infections, you might want to explore over-the-counter supplements that could reduce your risk of recurrent UTIs.

Read our guide to the most common options and what to consider before trying them.

Vitamin C (ascorbic acid)

Vitamin C makes your wee more acidic. Many UTI-causing bacteria, such as E. coli, prefer a neutral – or slightly alkaline environment – so a lower pH could make it harder for them to flourish. Vitamin C is also an antioxidant and supports immune function.

Pros:

- Can discourage some bacterial growth
- Supports the immune system and reduces inflammation
- Affordable and easy to find

Cons:

- Effect varies from person to person
- High doses over time can lead to kidney stones in susceptible people

Cranberries and cranberry products

Cranberries contain proanthocyanidins (PACs), which may prevent bacteria – especially *E. coli* – sticking to the urinary tract lining.

While some studies show a modest benefit, particularly for women with recurrent UTIs, others find little effect.

Please note that if you have been prescribed Warfarin, you should avoid cranberries and cranberry products. This is because they may increase the effect of your medication, putting you at higher risk of bleeding.

Cranberry juice

Pros:

- Easily available and when consumed in large amounts, may bring relief for UTI symptoms by flushing the urinary tract

> *"Whole cranberries also contain other beneficial nutrients, plus fibre."*

Boosting your defence against UTIs cont

Cons:

- Shop-bought cranberry juices are diluted with other juices and contain high amounts of added sugars. This can counteract the benefits and contribute to other health issues like weight gain or diabetes.

Cranberry capsules or powders

Pros:

- These can provide a concentrated form of cranberries without the added sugars found in juice. They're also standardised, so they contain specific amounts of active ingredients known to inhibit bacteria from adhering to the bladder wall.

Cons:

- Quality can vary between brands. Be sure to choose products from reputable manufacturers who provide information about PAC content.

Whole or dried cranberries

Pros:

- Eating whole cranberries or dried cranberries (with no added sugar) can be a healthy way to ingest bacteria-preventing PACs naturally. Whole cranberries also contain other beneficial nutrients, plus fibre.

Cons:

- Dried cranberries often contain added sugar, negating some health benefits. As whole cranberries are tart, some people find them unpalatable.

D-Mannose

D-Mannose is a naturally occurring sugar that binds to E. coli, stopping the bacteria from attaching to the urinary tract so they can be flushed out in your urine.

A 2013 study found it as effective as a common antibiotic for preventing recurrent UTIs, with fewer side effects. However, a 2024 UK trial in primary care found daily D-Mannose didn't significantly reduce confirmed UTIs, though results may differ in more complex patients.

Pros:

- Generally well-tolerated
- May be helpful for some people with recurrent E. coli infections

> *“A lesser-known benefit of probiotics is their impact on the immune system.”*

Cons:

- Not effective against all bacteria
- May cause mild bloating or diarrhoea
- Often more expensive than other supplements

Probiotics

Probiotics are live micro-organisms. Often referred to as 'good' gut bacteria, they play a key role in supporting gut health by helping to balance the digestive system.

A lesser-known benefit of probiotics is their impact on the immune system. Around 70% of the body's immune cells reside in the gut, making gut health a key player in immune defence and therefore beneficial for urinary health.

Pros:

- Generally safe for most people
- Can be taken as supplements or through fermented foods like yogurt, kefir, or sauerkraut

Cons:

- Strain-specific benefits mean not all products are equally effective
- Can take time to see results

Vaginal oestrogen

Falling oestrogen levels after menopause can alter vaginal flora, making it easier for harmful bacteria to thrive. Topical oestrogen can help restore the natural balance and reduce the risk of UTIs.

Widely supported in clinical research, vaginal oestrogen is often recommended for women with recurrent UTIs linked to menopause. You may be able to get it on prescription from your GP, and it is also available over the counter.

Pros:

- Can be very effective for some women
- Available as cream or pessary

Cons:

- Needs ongoing use to maintain benefits

> *“While supplements can be part of a prevention plan, they are not a substitute for professional care.”*

Maintain a healthy diet

Supplements may help protect you from UTIs, but they should not be taken as a substitute for the healthy, balanced diet you need to stay well. Including plenty of vegetables, fruits, whole grains and lean proteins should supply you with the necessary nutrients to protect your immunity.

Keep well hydrated

As well as being vital to daily living, keeping your fluid levels up is one of the most effective ways to reduce your chances of developing a urinary infection.

Depending on your size, level of activity and the weather, aim for two to three litres of water each day. This will help to flush out any bacteria.

Read the 'Keep hydrated to stay healthy' page on our website for more information.

When to seek medical advice

While supplements can be part of a prevention plan, they are not a substitute for professional care.

> *“Keeping your fluid levels up is one of the most effective ways to reduce your chances of developing a urinary infection.”*

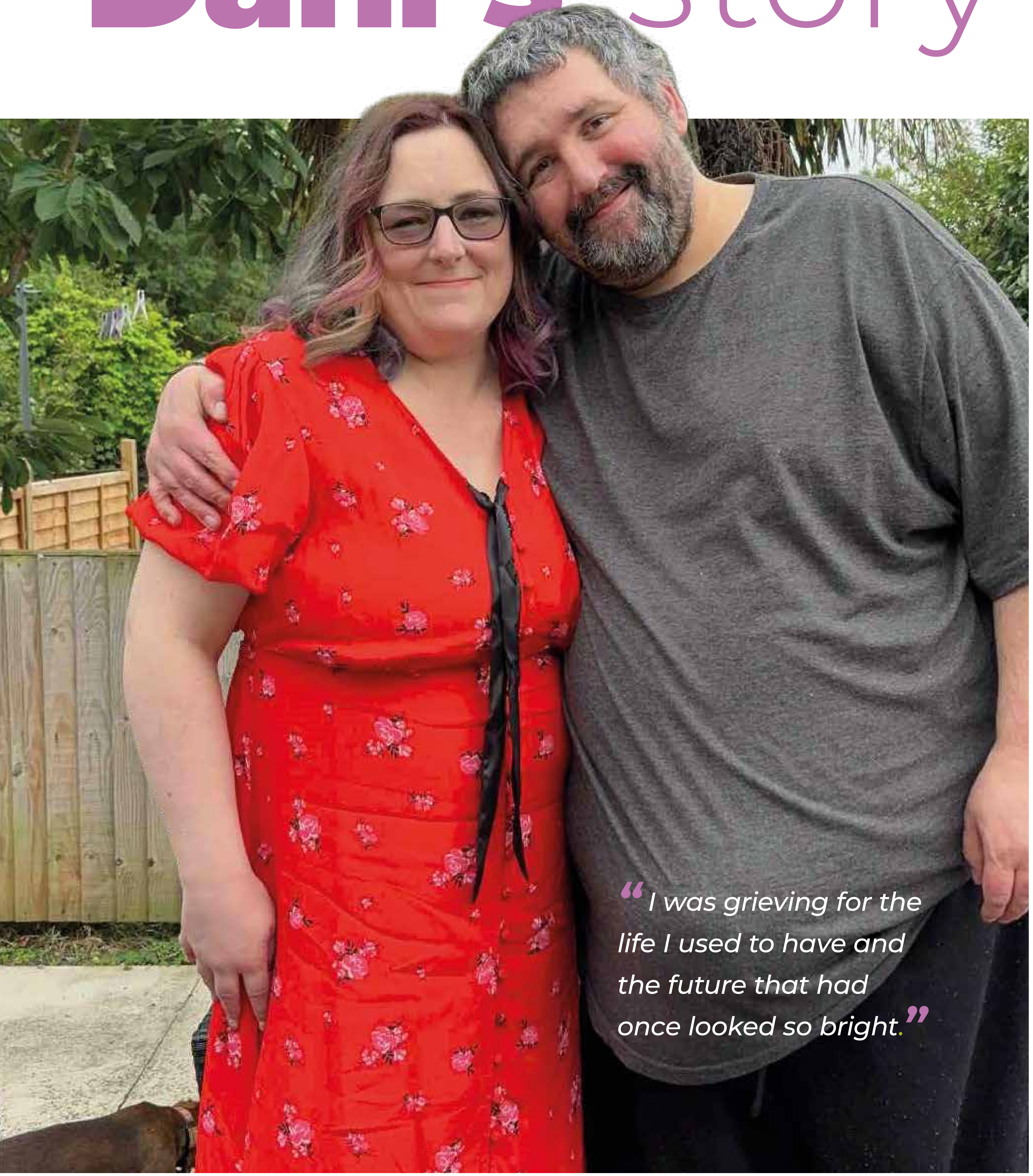
Look out for UTI symptoms, which might include those listed below. Speak to your GP if you notice these signs, as you may need to be treated with an antibiotic.

- Dark, cloudy or strong-smelling wee
- Wee tinged with blood
- Pain around your stoma or kidney area (the flank or back)
- Raised temperature, feeling feverish or clammy
- Feeling confused
- Feeling tired and 'out of sorts'

And finally ...

When it comes to supplements, what works well for one person may do little for another. Be open to a bit of trial and error, guided by your healthcare team.

Dani's story of hope



“I was grieving for the life I used to have and the future that had once looked so bright.”

By Dani Hughes

I'm Dani and I live in Doncaster with my husband Gareth and my three sausage dogs Vader, Spider and Wicket. My family and my ‘fur babies’ are my world.

I am still quite early on in my journey of living with a urostomy – my operation was in May this year. I'm sharing my story because I know just how it feels living with chronic health conditions and how scary it is to be told that your bladder needs to be removed.

The UA was there for me when I needed support, and this is my way of giving something back. I hope my words will help anyone facing surgery feel less frightened about what lies ahead and more confident that, with patience and support, they can overcome any challenges that come up along the way.

Unexplained symptoms

In 2012 I was working as a cardiac nurse. It was a role I loved and a big part of who I was. I also had lots of hobbies and adored horse riding. Life was busy and exciting. I'd just got engaged to Gareth, and as we settled into the home we'd bought together, we talked about getting married and the kids we hoped to have one day. It felt as if everything was falling into place.

Unfortunately, I was about to find out that life had other plans! I was 26 when I started feeling really unwell. Not only was I in pain, I'd developed a limp too. With each new test I hoped for a definite diagnosis. It felt heartbreaking not getting any answers, and the longer this went on, the harder it was to stay positive. Eventually, I was told I had a neurological disorder. But more than that, they couldn't say – until many years later, that is.

I felt very low. My symptoms became so debilitating that I had to give up the job I loved, and we had to sell our home and find a bungalow because I could no longer cope with stairs. On top of this, and one by one, my friends began drifting away.

It was such a tough time. I was grieving for the life I used to have and the future that had once looked so bright. “Focus on the positives”, I'd tell myself, as I thought of Gareth and my family. I still had them, and deep down inside, I knew I was still me despite everything I'd lost.

Bladder diagnosis

Something that was established early on was that my bladder was no longer functioning properly, and that I'd need to be catheterised to stop me going into retention.

I was referred to a urology consultant, Mr Kumar, at Doncaster Royal Infirmary. Little did I know then that he would be on the journey with me for the next 15 years. Having diagnosed me with neurogenic bladder, which is when the bladder no longer works properly due to nerve damage or dysfunction, he fitted my first suprapubic catheter (a surgical catheter through my abdomen).

Mr Kumar tried everything to keep my catheter and bladder going. I had regular Botox injections in my bladder

Dani's story of hope cont

every six months for years as we tried to keep the symptoms under control. But eventually, the pain became so severe that in February 2025, the decision was made to remove my bladder and create a urostomy.

I came out of that appointment feeling conflicted. On the one hand, I felt relieved there was a plan, but at the same time, the thought of such life-changing surgery made me incredibly nervous. I did not waver from my decision to go ahead though. By now, I knew they'd done everything possible to save my bladder and that I simply couldn't continue being in pain that was worsening by the day.

Amazing team

With my operation booked for three months' time, I tried to keep looking forward. The urology team was amazing, and the nurses were really supportive. They understood how much I was struggling and arranged for me to have telephone appointments so that I didn't have to travel back and forth to the hospital. They also worked with my consultant to bring my operation forward when I explained how very difficult it was to move around. I won't lie, it was a miserable time. However, it led me to the Urostomy Association, for which I'm forever grateful.

Unwavering support

Accessing the peer support the charity provides was a game-changer. It was a relief to talk to people who understood exactly how I was feeling and could make it sound less scary.

From my very first conversation with my UA peer supporter, I began feeling more at ease. Living with a urostomy herself, she understood my fears and could explain what to expect. She said it wasn't at all strange that I'd picked a name for my stoma already (Jeff) as it's something many urostomates do. For the first time in a long while, I had a laugh and felt that here was someone who really understood.

Gareth and my family are fantastic and do their best to understand, but this lady had the lived experience to be able to truly empathise. Talking to her, I felt completely at ease. I came away from our chat feeling "Yes, I can actually do this", and I can never thank her enough.

The big day

When operation day came on 6 May, Mr Kumar talked everything through with me. It was agreed that as well as having a urostomy, I'd undergo a hysterectomy to spare me any complications further down the line.

> *"It was a relief to talk to people who understood exactly how I was feeling and could make it sound less scary."*

About half an hour later, they took me to theatre.

Everyone there understood how anxious I was, and they were lovely. Before I knew it, I was asleep and then the next thing I knew, I was on my way to the ward. Gareth was there, waiting for me - I was so happy to see his face! The first few days after surgery are all a bit of a blur. I struggled most with my emotions because the hysterectomy had sent me straight into early menopause, despite the surgeon leaving my ovaries in place.

Patience and encouragement

Thank goodness for such fantastic support from the hospital team and the UA support group. They frequently checked in with me to see how I was doing, and their kindness was just what I needed. Throughout my health struggles, my medical and surgical teams have been brilliant. I've been extremely fortunate to have such a great bunch of stoma care nurses. They have been wonderful, literally holding my hand right the way through, from siting my stoma to recovering on the ward and going back home. They have patiently guided me through any panics and given me pep talks whenever they were needed. I so appreciate their confidence in me when I couldn't feel it for myself. I can't thank them enough.

Recovery hasn't been plain sailing, especially as I live with asthma, Hypermobile Ehlers- Danlos Syndrome and functional neurological disorder, to name just three of my health conditions.

Finding freedom

Sometimes, it's felt really hard but each day is getting better. 'Jeff' the stoma has changed my life completely - for the better! I'm no longer stuck in bed, and while my mobility is restricted because of my other health conditions, I can at least sit down to shower, and I can cook and bake from a chair.

Recently, I even bought a new dress for my nephew's 18th birthday party. Being able to wear what I want feels great – nobody has to know I have a stoma unless I want to tell them, and I no longer feel bad about myself. I have freedom to move around on my crutches, unlike before when my catheter was permanently attached to a night bag. It really does feel liberating!

To anyone reading this, 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 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.

Here's to the future!

> *"To anyone reading this, my message is one of hope. You are worth fighting for, so never give up."*

Regaining body CONFIDENCE after surgery

Coming home after your operation, there's a lot to take in – from how and when to empty your bag to cleaning and caring for your stoma. Getting used to each of these practical steps is vital to your health, but there's another side to recovery that's not talked about as much: learning to feel comfortable in your own skin again.

Your urostomy doesn't just change how your body works. It can also change how you feel about your body – how you dress, how confident you feel, and how you relate to others. The emotional side of recovery can take longer, but it's every bit as important. Our advice here is aimed at helping you to feel at home in your body again.

When your reflection feels different

Body image isn't only about appearance. It's about how at ease you feel being you. After surgery, your body can feel unfamiliar, even when you're healing well. Many people describe a period of adjustment. You may feel self-conscious, unsure what to wear, or anxious about how others might react to the new you. These feelings are completely normal.

Sadly, outdated ideas about stomas can add to the challenge. Some people still hold misconceptions about what life with a stoma looks like, which can make you more hesitant to show or talk about yours. Even with love and support around you, it's only natural to grieve for the body you used to have.

None of this means you're getting anything wrong. It just means your mind is adjusting to change and 'newness' – and you are far from alone in that.

What shapes how we see ourselves

No two people experience life with a stoma in exactly the same way. How you feel about your body depends on many things, from your age and life stage to the reason for your surgery.

Age and stage of life

Adapting to a big change in your body can feel difficult at any age, but it can be younger adults who find this particularly challenging. Young adulthood is often a time of exploring identity and self-expression, so a visible or physical change may feel especially jarring.

You might find yourself checking your bag in the mirror or worrying whether it shows under your clothes. These thoughts can chip away at your confidence, especially if you're not used to seeing other people with stomas in the world around you.

Reason for surgery

If your surgery was lifesaving – because of cancer, for example – you may see your stoma as a symbol of survival and strength. As with others, whose operation put an end to long-term health

> *"Even with love and support around you, it's only natural to grieve for the body you used to have."*

Regaining body CONFIDENCE after surgery cont

conditions, there can be feelings of gratitude and relief.

However you feel, your emotions are valid. And how you see your stoma can change over time, from something that feels confronting to something that represents resilience.

Temporary or permanent

If your stoma is temporary, you might feel as if you're in limbo, waiting for 'normal' to return. For some, that makes acceptance harder. With a permanent stoma, there can be a sense of clarity - chance to rebuild life around something certain, rather than waiting for what comes next.

Rebuilding confidence – step by step

Find products that feel right for you

It's hard to feel confident when you don't trust your pouching system. Worrying about leaks or irritation can affect how you feel throughout the day.

Modern products are designed with comfort and discretion in mind. There are bags in different shapes and colours, softer materials that move with your body, and accessories to help prevent soreness. Finding what works for you, and getting advice from your stoma care nurse, can make a huge difference.

When your pouching system feels secure, it frees up energy for the things that really matter.

Notice what your body is doing right

After major surgery, it's easy to focus on scars or changes. But take a moment to recognise how much your body still does for you. It heals, adapts, and keeps you alive. Your stoma allows your body to function and gives you the chance to live well again. That's something to celebrate.

Hold on to joy

When body image feels tough, try to reconnect with things that remind you who you are beyond your body. Ask yourself:

- What helps me feel most like myself?
- What brings a spark of joy, even on quiet days?

Maybe it's a cup of tea in the garden, a walk with your dog, or a chat with a friend who listens without judgement. These moments help you remember that life is bigger than managing your urostomy.

Take your time

There's no deadline for feeling comfortable in your body. Some days will feel lighter; others might not. That's perfectly normal. Progress isn't about how quickly you 'get over' things. It's about continuing to move forward, one step at a time, even when it feels tough.

Top tips

- Explore product options: Ask your stoma care nurse about different bag styles, colours, and materials. Comfort makes confidence easier.
- Wear what makes you feel good: Try different fabrics and fits until you find what feels most 'you'. There's no right or wrong - only what works best for you.
- Connect with others: Hearing from other urostomates who truly understand can be reassuring. The Urostomy Association's support groups, online and in person, are a great place to start.
- Be patient with yourself: Emotional recovery takes time, just as physical healing does.

> *"Modern products are designed with comfort and discretion in mind."*

Still whole

After stoma surgery, your body isn't broken - it's simply changed. You don't have to feel grateful every moment or positive every day. What matters is recognising that you are still whole, still capable, and still deserving of kindness and joy.

Acceptance doesn't happen overnight. Often, it grows in quiet ways: in choosing clothes that make you smile, sharing your story with someone new, or realising that you can go for a walk or run without worrying about your bag.

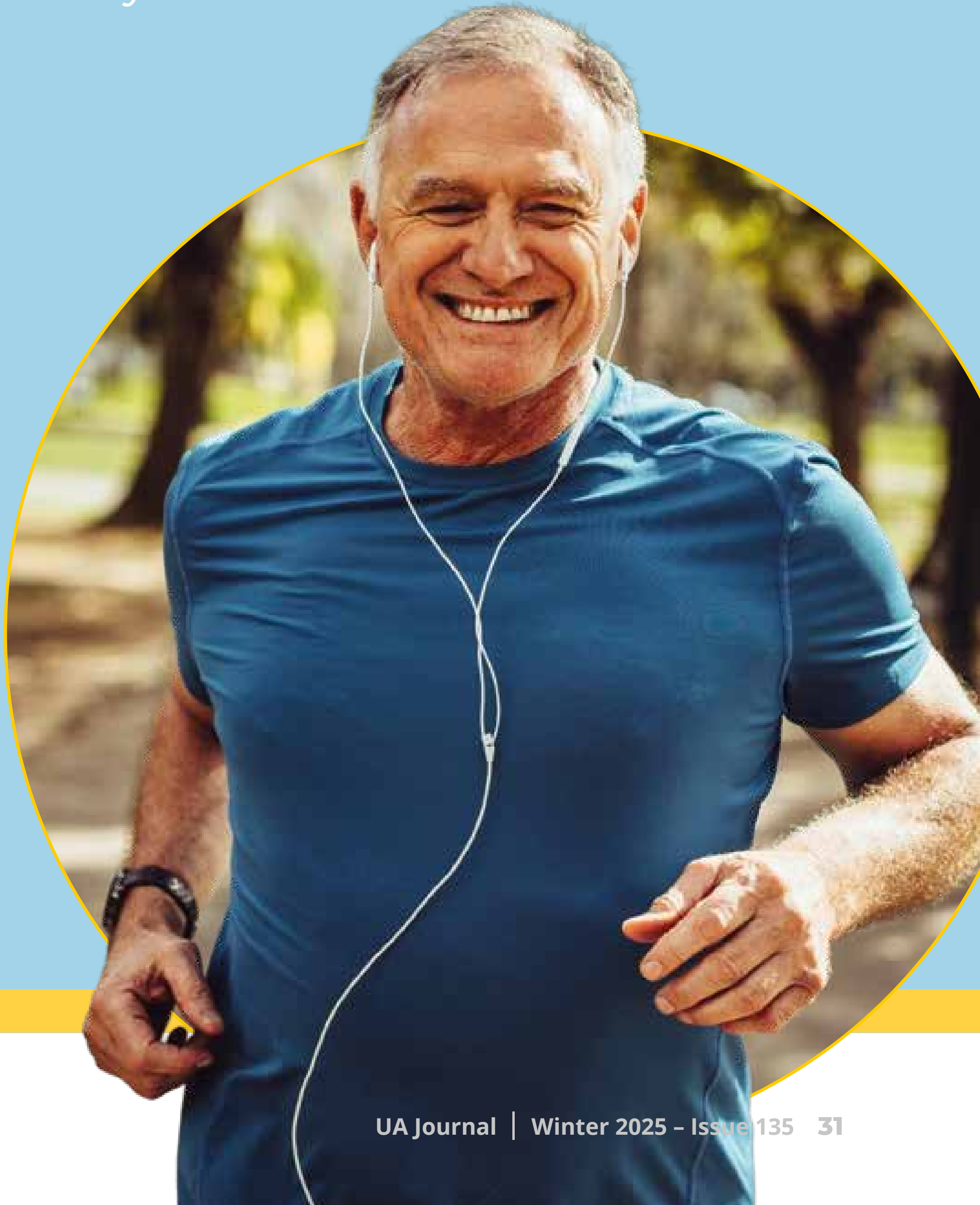
Remember, your body has carried you through enormous change.
It's stronger than you realise.
It may not be the body you expected, but it's a body that's survived, adapted, and found a new way to live. That's something to be proud of!

Moving forward

Living with a urostomy isn't about getting back to who you were before; it's about moving forward as who you are now.
Every day brings new opportunities to live fully and find confidence in the life you have. You're not defined by your surgery or your stoma. You're defined by your courage, your humour, and your ability to keep going - even when it's hard.

So, be gentle with yourself. Take each day as it comes. And remember: you are more than your stoma.

> *"Remember, your body has carried you through enormous change. It's stronger than you realise."*



Shop to **show** your **support**

Did you know that you can support the Urostomy Association every time you shop online – without spending a penny more?

By shopping through easyfundraising or Give as you Live, thousands of your favourite brands - from M&S, Tesco and Amazon to John Lewis. Argos and Boots - will donate a percentage of what you spend directly to us. It's quick, simple, and completely free!

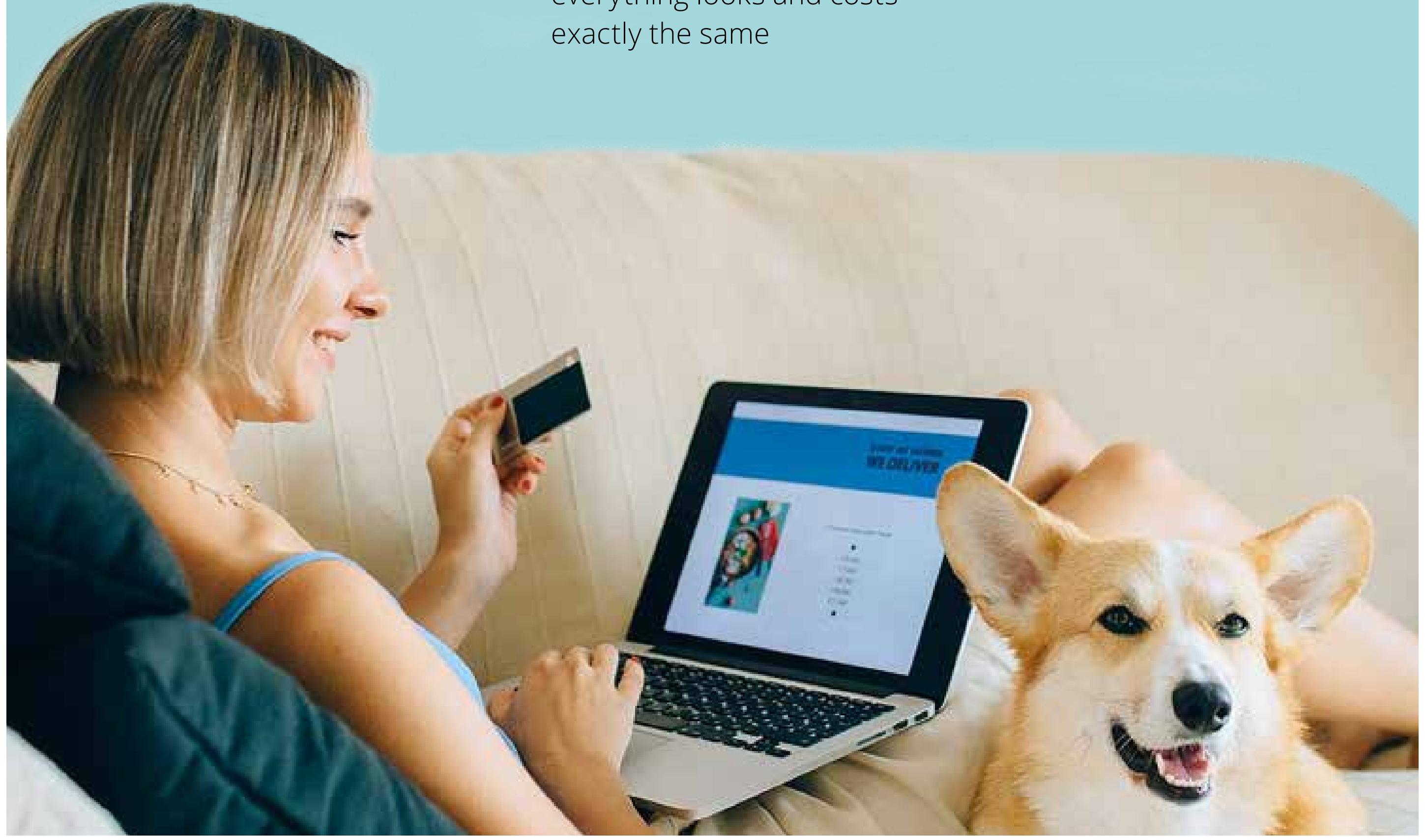
How it works

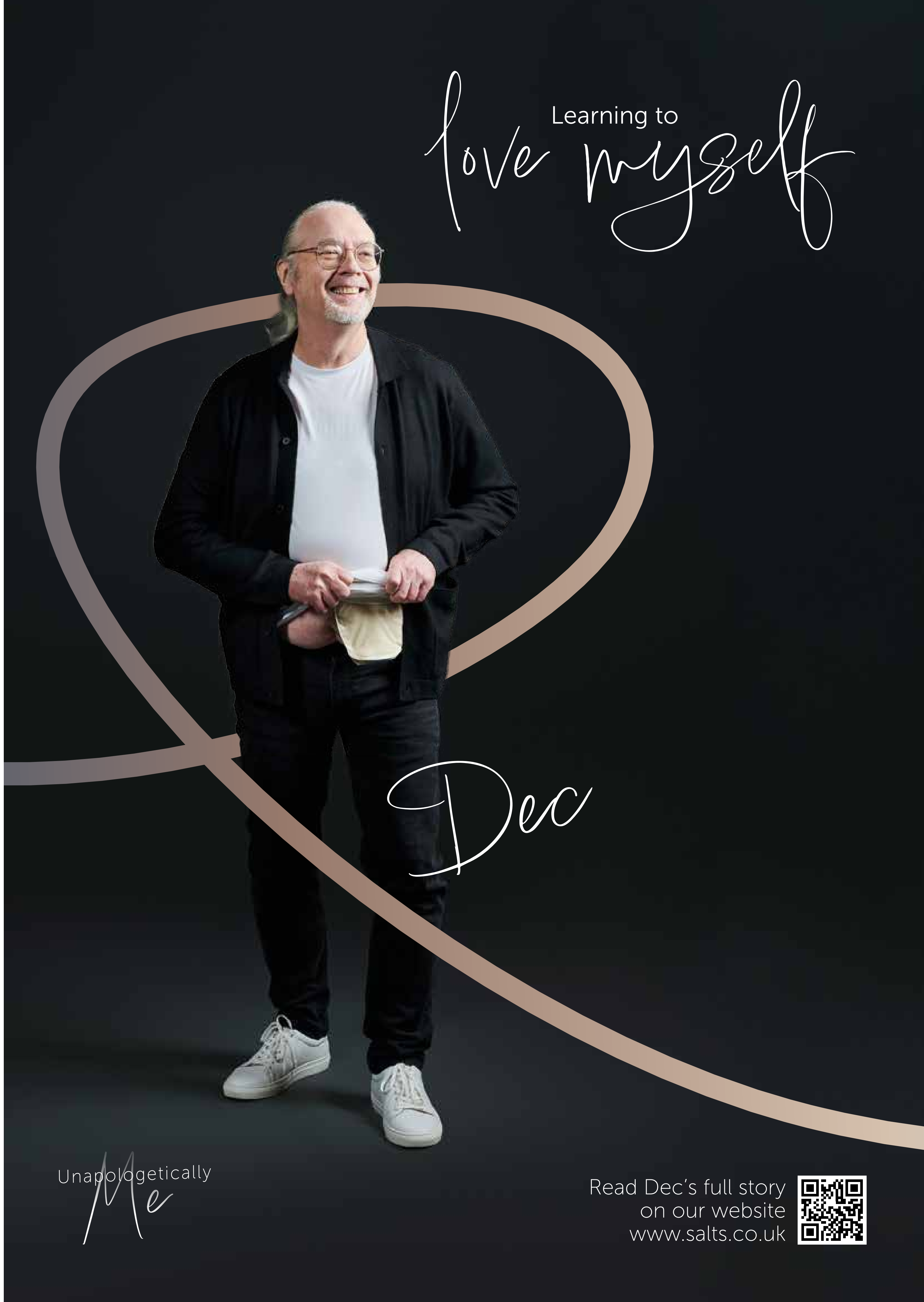
It couldn't be easier to shop and do good for urostomates at the same time.

- Start your shop via *easyfundraising.org.uk/* or *giveasyoulive.com/.*
- Choose the Urostomy Association as your cause
- Shop as normal with your favourite retailers – everything looks and costs exactly the same
- A free donation is automatically sent to us by the retailer

That's it – every purchase helps make a difference. From groceries to gifts, holidays to homeware, shopping can bring hope and support to people with urostomies – wherever they are on their personal journey.

Thank you for your support.

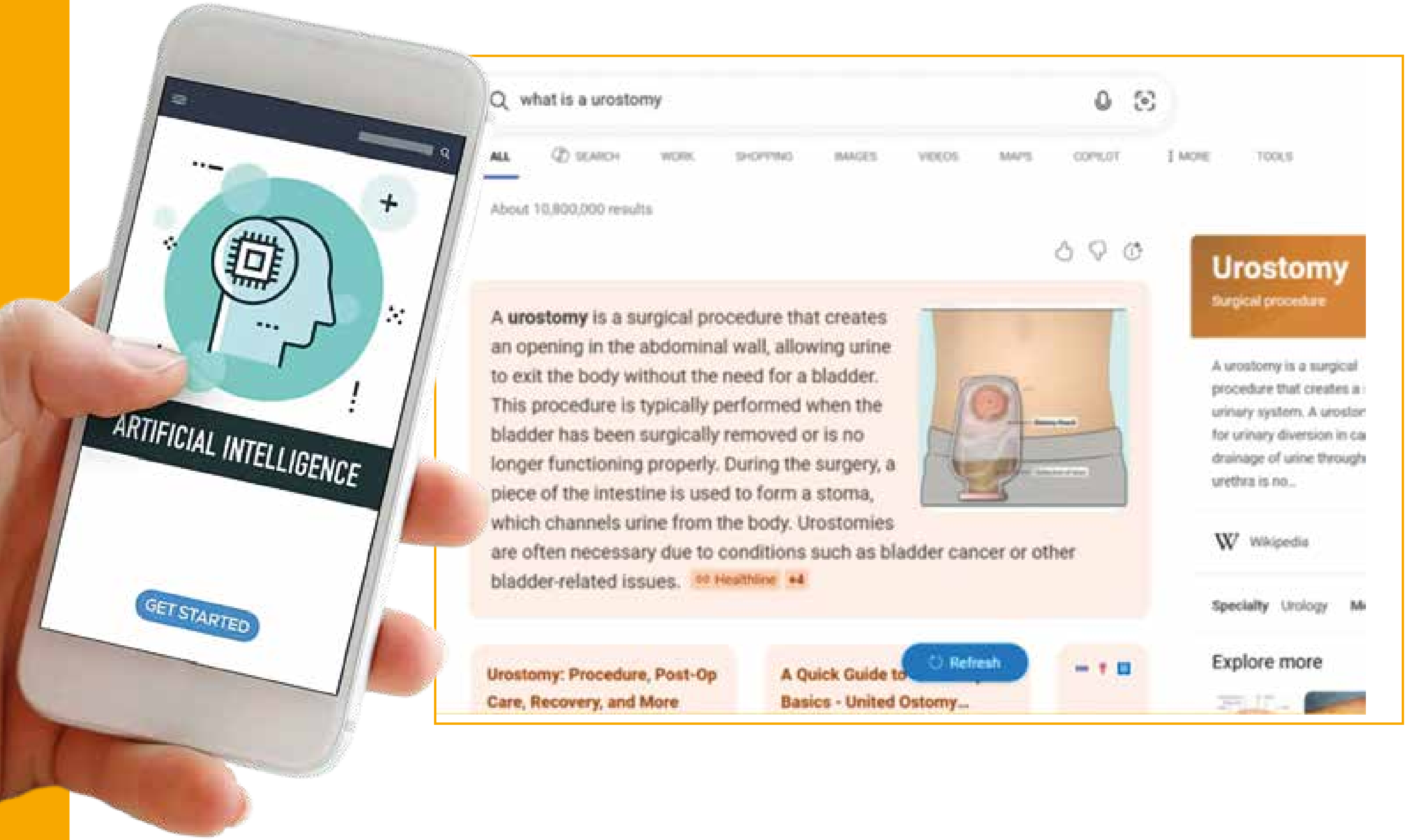




Should you trust **artificial intelligence** for urostomy advice?

by **Eve Sherratt-Cross**, AI Safety Advocate

Artificial intelligences (AIs) like ChatGPT or Microsoft Copilot have changed the way many people access information online, providing an interactive search-engine that feels like a conversation. But what does online AI-generated advice for urostomates look like and is it reliable?



About 10,800,000 results

A **urostomy** is a surgical procedure that creates an opening in the abdominal wall, allowing urine to exit the body without the need for a bladder. This procedure is typically performed when the bladder has been surgically removed or is no longer functioning properly. During the surgery, a piece of the intestine is used to form a stoma, which channels urine from the body. Urostomies are often necessary due to conditions such as bladder cancer or other bladder-related issues. Healthline +4

Urostomy
Surgical procedure
A urostomy is a surgical
procedure that creates a
urinary system. A urostor
for urinary diversion in ca
drainage of urine through
urethra is no...

Wikipedia

Specialty Urology

Explore more

Urostomy: Procedure, Post-Op Care, Recovery, and More

A Quick Guide to Basics - United Ostomy...

What does an AI do and when might I end up interacting with one?

Some AI programs, like ChatGPT, are standalone websites, and work like a chatty conversation between you and the computer. This is the sort of AI you actively need to find, so you know when you visit the website that you are engaging with artificial intelligence.

But in other instances, you may be engaging with AI without realising it. For example, some search engines, like Bing, have introduced a summary box at the top of search results (see example above), which aims to answer your query but is generated by AI, not written by a human. You may not have even noticed this. This can be handy, but review it with a touch of caution.

Is AI-generated information reliable?

AI tools pull together data from all over the internet, in the blink of an eye, and much of this is not about urostomies or urostomates. This means the content AI produces is, in essence a broad summary of available information, and this can be stoma generic, rather than urostomy specific.

And the answers can be confusing, incorrect, and worrying. For example, an AI-generated response from Google to the statement 'I think I've seen bits of food in my urostomy bag' suggests that seeing undigested food in your urostomy bag is not uncommon when, in fact, it is. This response actually relates to people with colostomy bags.

Additionally, AI is currently very US centric. For instance, in the Bing example on the previous page, the links that come up all relate to American resources, rather than UK ones. The danger here is that services and support for urostomates in the UK are different to the US, particularly when it comes to the NHS and sourcing supplies.

What do the professionals think?

Paul Russell-Roberts is a Stoma Care Nurse Specialist and is passionate about developing protocols, policies and digital platforms that make a difference in urostomates' lives:

"I've always believed that patients should have access to clear and reliable information. AI can make learning quicker and easier, and that's a real positive, but it should never replace trusted sources. If you're looking for information, check against places like the Urostomy Association or the NHS website. And if you're ever unsure or worried about your urostomy, the safest step is always to speak to your stoma nurse.

"AI is becoming part of everyday life, and it can be a great way to pull information together quickly. That's helpful, but it's important to remember it isn't always specific or accurate for urostomies. Use it as a starting point, then check what you find against reliable sources or with your stoma care team."

Can I switch off AI summaries from my search engines?

If you don't want to see AI summaries in your search engine results, you can do the following:

- On **Google**, you can add **-ai** to the end of a search query to stop the summary box at the top of your search results appearing.
- For **Bing**, click the three horizontal lines in the top right hand side of the page and turn off the "Copilot response on results page" setting
- **Yahoo** doesn't currently have an AI summary box. Keep in mind, some organisations may use AI on their own websites. The UA does not.

In conclusion

Paul Russell-Roberts sums it up:

"AI is exciting because it puts knowledge at our fingertips, but in stoma care context matters. It can point you in the right direction, but the detail and reassurance still comes from trusted professionals and organisations. Always be mindful and use the steps below to be SURE you're getting the correct facts.

"AI can be a fantastic tool, but your stoma nurse is irreplaceable."

S	**Speak** to your stoma nurse for advice about your own situation
U	**Understand** before acting
R	**Review** the facts using sources you trust
E	**Evaluate critically** – don't believe everything you read

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

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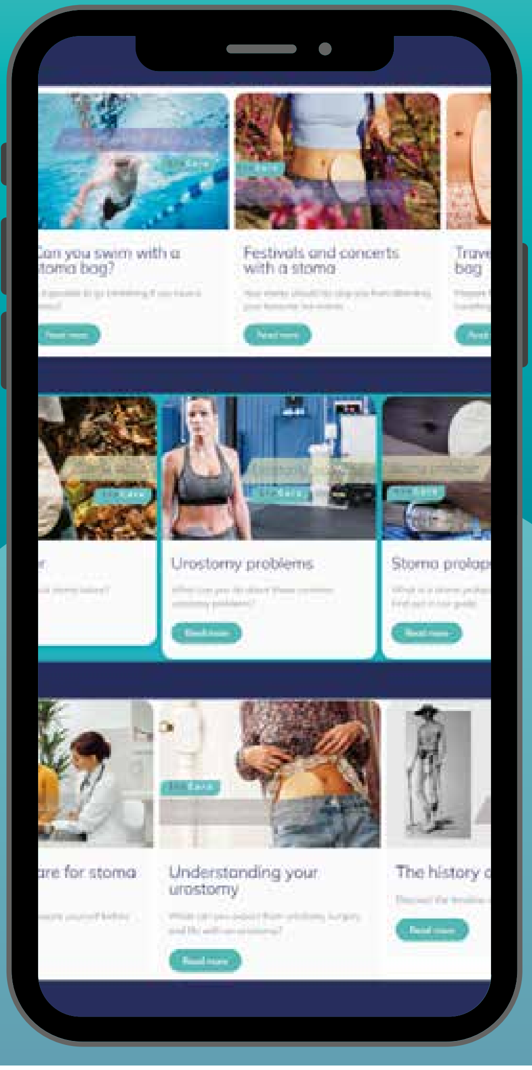

Let's get **social**

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/

INNOVATING to improve patients' care and confidence

We know that hospital care for urostomy patients can vary considerably, depending on where you live. From the number of specialist nurses available to the quality of discharge planning and follow-up support, experiences can differ between regions, and even between hospitals within the same county.

This 'postcode lottery' can have a profound effect on patients' health, confidence, and quality of life. So, when we heard that University Hospitals Coventry and Warwickshire (UHCW) is taking a particularly forward-thinking approach to improving outcomes for urostomy patients, we were keen to find out more.

Doing things differently

Lead Urology Nurse, Josh Hearne-Wilkins, said: “Traditionally, UHCW's urostomy patients were cared for by both stoma nurses and urology nurses. But then we began to feel that this patient group would benefit from more urological input from someone with the skills to teach them – while in hospital - about the practicalities of looking after their urostomy and adapting to a bag.

“Innovating to provide the best possible care and support, we introduced the new role of Urostomy Practitioner in May 2024. Sitting within the Urology team, and dedicated to the specific needs of urostomy patients, we believe this may be the first post of its kind within the UK. And in Donna Wilson, who we recruited to the role, we have someone with not only relevant skills and experience, but the warmth and compassion to help patients feel as at ease as possible before and after their operation. This is so important, particularly given that many have already been through a really tough time, from diagnosis and invasive tests to chemotherapy.

“Listening to patients, answering their questions and liaising with the consultants and nurses, Donna is the 'glue' that helps ensure each patient's care is properly joined up. Having her as their point of contact within the hospital, all the way through their stay, is making an important difference.

“Our surgeons have witnessed the rapport Donna builds with patients, and that when she is able to meet them before they have their operation, they are that much more relaxed about what's to come. Consequently, surgeons are now organising their schedules to enable her to do this. It's such a testament to Donna and we are massively proud of her.”

> *“Donna is the 'glue' that helps ensure each patient's care is properly joined up.”*

Donna and her role

Having worked in the NHS for 28 years – including in gastroenterology as well as urology – Donna is relishing her role in helping to make what can feel overwhelming more manageable for patients. She said: “Having a urostomy is lifesaving, but it is also life-changing and there's a lot to get to grips with. That's why I contact patients early, visiting them on the ward together with Urology Specialist Nurse Margo Reynolds. It's a chance to introduce myself, get to know a bit about them and answer any questions that come up.

“I show them a urostomy bag so that they can see what one looks like and get a feel for it. I also let them know that I'll make several further visits before they are discharged home. It's about reassuring them that they're not facing it all on their own, and that I'll be there to teach them, step by step, how to look after their stoma and how to fit, empty and change their bag, with time for them to practise while in hospital.

“The next time I see them is after their surgery. It's usually while they're still on the critical care ward but feeling well enough for a short visit.

“I put their bag on for them and - briefly - talk through what I'm doing. I don't want them to feel rushed, so it's not until they're on a regular ward that I go through how to remove the bag and clean their stoma with warm water. I also teach them how to cut their base plate to the right size and attach the bag. If their partner is there while I go through all of this, that's great. It means they're clued up if ever they need to provide some help with bag changes at home.

“During my next visits, I observe while the patient practises changing their bag. This is how they gradually gather more confidence about

INNOVATING to improve **patients' care** and **confidence** cont

what they need to do and how to do it. I'm also there to advise about any issues, such as dealing with leakage and managing night-times, both common concerns.

"On average, I'll see a patient five times in all. Once I'm confident that they're managing well, I relay this to their consultant and the nurses. Then, providing the patient is medically fit, they'll be discharged home.

Getting ready to go home

"I know going home can be a daunting prospect when you're still in the early stages of recovery. That's why I remind them that while it will be a district nurse who comes out to see them if they're encountering any issues, it's also fine for them to phone me with any queries or concerns.

"At the hospital, we stock the UA's patient pack full of useful information about what to expect during recovery, and tips to keep well. It's good to know patients have got this to hand at home. We also let them know there are further resources available on the Association's website, and make them aware of the one-to-one support the charity provides through its trained volunteers, who are urostomates themselves.

"Most patients find that their urostomy gives them back quality of life. It's really rewarding knowing I've played a part in helping them adjust to the big changes they've gone through, and it's always heartwarming when I hear that they're back to getting on with their lives."

Josh added: "Our goal is more seamless, holistic care that helps empower patients to self-manage and thrive, and even though it's been less than two years since we introduced the Urostomy Practitioner role, we're really encouraged by the results we're seeing. We hope that hearing about our approach - and how it seems to be benefiting patients in terms of recovery, confidence and wellbeing – might inspire others to think more outside the box too."

> *"Our goal is more seamless, holistic care that helps empower patients to self-manage and thrive."*

> *"I know going home can be a daunting prospect when you're still in the early stages of recovery."*

UROSTOMY ASSOCIATION

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My journey to a urostomy

By Aimee Heenan

It all began in April 2023. I'd just celebrated my birthday and was excited for a day trip to London. But as I got ready that morning, something felt off – I couldn't wee. I didn't think much of it at first and carried on with my day, drinking extra fluids to try and 'break the seal'.

As the hours passed, discomfort turned into pain, and I became increasingly unwell. Still unable to wee, I cut the trip short and got picked up by a family member. I tried all the tricks: hot showers, warm baths, running taps, but nothing worked.

Eventually, encouraged by my partner and family, I went to A&E. A bladder scan revealed I was holding over a litre of urine. I was catheterised and sent home with an indwelling catheter. I was terrified. No guidance, no diagnosis, and no idea if, or when, I'd be able to wee again.

Searching for answers

Just three days later, I had a scheduled laparoscopy for suspected endometriosis. We hoped it might explain the sudden urinary retention, but no endometriosis was found on my bladder. While I was diagnosed with endometriosis in other areas, it left us with even more questions.

It was overwhelming. I was recovering from my first proper surgery, trying to process a new chronic diagnosis, and had a bladder that had essentially stopped working. I felt completely lost.

> *"He taught me how to self-catheterise using intermittent catheters. It felt like a small win."*

My gynaecologist supported my first TWOC (trial without catheter), but I still had no bladder control. He taught me how to self-catheterise using intermittent catheters. It felt like a small win. At least I didn't need the indwelling catheter anymore. I was hopeful my bladder would 'wake up' in time.

Hospital admission

By July 2023, things took another turn. The self-catheters started getting stuck, and one day I couldn't get a catheter in at all. I couldn't tell how full my bladder was, and the pain was unbearable. With no help from the district nurses, I ended up in A&E again, in severe pain.

A scan showed at least 1.3L in my bladder. When they catheterised me, over 2L was drained. A nurse, concerned for my kidneys, pushed for me to be admitted. While in hospital, another failed attempt at self-catheterisation led us back to an indwelling catheter.

A doctor attempted to place it, struggled, and called me 'difficult to catheterise'. He used a larger catheter size, which caused awful urethral spasms and pain. I couldn't get out of bed.

Then came my turning point: a doctor named Mr Naffi. After witnessing the pain I was in, he urgently arranged for a suprapubic catheter (SPC). I had surgery the next day. It was such a relief!

Diagnosis at last

The following months blurred together. I underwent urodynamics testing, which showed my detrusor muscle had failed. I had no bladder sensation and couldn't urinate at all.

I was referred to Leicester General Hospital to see Dr Obloza, a urogynaecologist who was a breath of fresh air.

She performed a urethral pressure profile test and confirmed my urethra was 'in overdrive'. Combined with the urodynamics, a clear cystoscopy, and my laparoscopy results, I was finally diagnosed with Fowler's Syndrome in January 2024. It's a rare, little-known condition – just two people in a million are diagnosed each year. Finally, having a name for what was happening to me was validating, but it also came with a sense of isolation. There isn't much research, and treatment options are limited.

> *"Finally, having a name for what was happening to me was validating, but it also came with a sense of isolation."*

My journey to a urostomy cont

Infections and complexities

The SPC was a definite improvement, but the infections were relentless. By mid-2024, I'd had over 35 courses of antibiotics. I was becoming resistant, and we knew this couldn't be a long-term solution.

My medical history isn't straightforward, and neither were my treatment options. I tried multiple medications and was assessed for various surgical interventions. After another multidisciplinary team review and a second opinion, it was agreed I would have urostomy surgery.

A new beginning

In December 2024, just 20 months after my bladder stopped working, I had an open supratrigonal cystectomy and ileal conduit surgery. I spent five days in ICU/HDU and was discharged after 12 days – on Christmas Eve, no less. It was physically and emotionally intense: 30 staples, a wound infection, and a re-admission on Christmas Day due to bowel issues.

My partner Jack was my rock. He visited every day, held my hand through the darkest moments, and helped me keep going. I can't thank him enough for all his support.

For most people, recovery after this type of surgery is relatively smooth. But for me, it wasn't straightforward. It took seven weeks for my wound to heal, and fatigue hit me hard. But despite everything, my urostomy felt like a blessing. Since surgery, I've only had one infection – something I couldn't have imagined a year earlier.

Finding my voice

My urethral pain may be chronic or lifelong, but I'm now being referred to a pelvic floor physio and pain specialist. I finally feel like there's a team behind me.

Through it all, I've found purpose. Sharing my journey as @nobladderbabe online has connected me with so many others. I've heard from people who say my story gave them hope. That alone makes this all feel worthwhile.

I'm now a Salts Healthcare Brand Ambassador, and I recently took part in a charity photoshoot with Fowler's Syndrome UK. I even got to meet Professor Fowler herself. These moments have been powerful reminders that we are not alone.

Looking forward

Now seven months post-op, I feel more hopeful than I have in a long time.

Yes, I still have worries, about my health, my future, but I also have so much gratitude for my urostomy.

Since surgery, I've been diagnosed with two more conditions, which we now think might be linked to Fowler's. On bad days, I rely on a wheelchair or stay in bed all day. But I'm slowly regaining strength. I've rediscovered hobbies like cooking, scrapbooking, and sharing on social media.

Most of all, I feel more confident in my body. I want to keep raising awareness – about Fowler's Syndrome, about urostomies, and for every young person navigating chronic illness without a map.

My urostomy has given me my life back. And while this isn't the path I expected, I'm embracing it with open arms.

> *"Now seven months post-op, I feel more hopeful than I have in a long time."*

Your will could do wonders

Writing a will isn't for you. It's for the people and causes closest to you. Having a will doesn't just save your loved ones time, money and stress, but it can do wonders.

Being told that you will never wee normally again is overwhelming but, with your kindness, we can be there for those facing this life-changing news - offering reassurance before surgery and vital support as they rebuild their lives without a functioning bladder.

A gift in your will, however big or small, could bring comfort, hope, and strength when it's needed most.

That's why we've partnered with experts, Octopus Legacy, to offer you the chance to write or update your will for free with one of their will writers or solicitors.

Claim your free will today:
Online: Scan the QR code
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Weight loss medicines and your urostomy

by **Paul Russell-Roberts**,
Stoma Nurse Specialist

> *“Weight loss can change the shape or softness of the tissue around your stoma.”*

Many people will have heard of newer injectable or tablet medicines used to help with weight loss or to manage diabetes. These include a group of drugs called GLP-1 receptor agonists. They work by helping the body feel full sooner, slowing digestion, and supporting safer blood sugar levels. They are now being prescribed very widely, often for several months or longer.

Because these medicines act mainly on the bowel, most of the information available relates to people without a stoma or to those with an ileostomy or colostomy. However, even with a urostomy, there are still some practical reasons why it can be helpful to understand how they work.

How GLP-1 medicines work

GLP-1 medicines slow the movement of food from the stomach into the gut. This means people feel satisfied after smaller portions. Over time this can lead to weight loss. Some people also notice nausea, changes in appetite, or that they drink less without realising.

Although these effects act on the bowel rather than the urinary system, the knock-on impact – particularly around hydration and body shape – can still be relevant for urostomates.

Why this can matter with a urostomy

Because a urostomy drains urine, GLP-1 drugs do not change the stoma output in the same way they might for someone passing stool through their stoma. However, they can still influence your routine in other ways:

- Weight loss can change the shape or softness of the tissue around your stoma, making an appliance that once fitted well feel different or lift at the edges.
- Reduced intake or dehydration can make urine darker or thicker and may increase the risk of crystals or infection around the stoma.
- Nausea or loss of appetite may affect how confidently you eat and drink, which can then influence hydration and general comfort.

These effects are not harmful in themselves, but they are easier to manage when noticed early.

> *“GLP-1 medicines slow the movement of food from the stomach into the gut.”*

What to look out for:

- A change in how your pouch sits or sticks to the skin
- Needing to change your pouch more often than usual
- Itching, redness, or soreness around the stoma
- Darker or thicker urine than normal
- A noticeable change in your body shape or weight

What you can do:

- Take small, frequent drinks across the day
- Keep an eye on urine colour as a guide to hydration
- Ask for a review if your appliance feels less secure after weight change
- Let your stoma care nurse know if anything feels different or less predictable

Do not stop your GLP-1 medicine without medical advice.

In summary

GLP-1 medicines are now a common part of diabetes and weight management care. For urostomates, their main effects are indirect – through changes in hydration and body shape – rather than through urine output itself. Understanding these predictable changes means you can notice them early, adapt if needed, and continue treatment with confidence. Your stoma care nurse can advise on any adjustments to keep your appliance comfortable and secure.

For more information, or if anything in your routine has changed since starting GLP-1 medication, please contact your stoma care nurse, GP or the Urostomy Association for support and guidance.

Grab your diaries
FOR OUR NEW ONLINE SUPPORT GROUP!

Urostomates often tell us how valuable it is to speak with people who truly understand what life is like with a urostomy. But with local meetings becoming less common, these opportunities can be hard to find.

So, in October, we launched our first online support group, with thanks to sponsorship from our friends at Coloplast. Participants had the opportunity to hear from experts, share experiences and tips, and seek advice from others who truly understand. 100% of those who fed back after the meeting said that they'd like to see more next year!

So we've pencilled in six dates for 2026.
Do check our online events calendar for the details: ***urostomyassociation.org.uk/events/***

We hope these sessions complement our popular 'Meet the Experts' webinars, recordings of which you can find in our video library: ***urostomyassociation.org.uk/category/videos/***

200+ CLUB PRIZE DRAW

As we transition to our new lottery, we have pulled our last 200+ Club draws, and winners have been notified. Congratulations to our winners, and a huge thank you to those who have chosen to donate some or all of their winnings back to the UA!

Draw date: **26 Nov 2025** *(last draw)*

1st prize	No 119	**Patricia T**
2nd prize	No 198	**Dennis S**
3rd prize	No 311	**Michael L**
4th prize	No 272	**Anne B**
5th prize	No 29	**Hugh M**

NEWS
FROM OUR BRANCHES

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

"Our branch is continuing to grow, with new members joining us most months."

Cambridge

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

Secretary: Jane Phillips

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

Our branch is continuing to grow, with new members joining us most months.

We are grateful to the excellent speakers who've kindly given their time to join us at our recent meetings. A representative from Co-op Finances gave an informative talk on wills, and a highly experienced physiotherapist shared advice and tips on protecting and strengthening our bodies as we get older.

At the time of writing, we are finalising the details for our Christmas lunch, as well as making plans for next year. We'll be welcoming the CEO of national charity Something to Look Forward To, and we'll also be having a talk from a sleep expert.

We'll be arranging more trips out too, so do please join us if you can.

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 welcomed around 18 people to our October meeting. Thank you to the company reps who joined us, and to Geoff Cummings, a nurse from the Emerald service run by B Braun, who gave a talk on nephrostomies. A nephrostomy is a urinary diversion where a tube is inserted directly into the kidney and attached to a urostomy bag into which it drains. Geoff's talk was very interesting, especially as more nephrostomies are now being performed. They can be permanent or temporary depending on the circumstances of the patient.

Unfortunately, despite several requests for a volunteer to help organise our meetings, no one has come forward. Brian Fretwell has agreed to carry on for another year, in which time we hope to have found someone to step into this role but if not, the branch will sadly have to close.

We hope to hold our next meeting in late January, so please keep an eye out for further details. In the meantime, on behalf of the branch committee thank you for your support in 2025. Wishing you all a very happy Christmas and a prosperous and healthy 2026.

Brian Fretwell

Sheffield & District

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

Branch Secretary: Mary Milner

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

We held our branch AGM and John Topham Lunch in November, welcoming the UA's Chairman Brian Fretwell and his wife Glynis for our celebration of 45 years of the branch. More than 60 members and their guests attended, with several people joining us for the first time. Thank you to the reps from Clinimed, Coloplast and Salts, who kindly attended with products to show us.

At the AGM, Brian presented Julie Varley with a bouquet and gift voucher on behalf of the UA's trustees. Julie has served as UA members' representative for ten years, having represented a number of branches, including Cambridge, Newcastle, Norwich, Sheffield and Yorkshire and Humberside, and has now decided to step down from this role. Brian thanked Julie for her dedication and hard work, as did Branch Chair Martyn Oxley, who presented her with a voucher on behalf of our branch.

After adding his thanks to Julie, Branch and National President Professor Derek Rosario took the chair for the election of officers and committee. Martyn Oxley (chairman) and Mary Milner (secretary) said they were happy to stay in post, and Mary also agreed to continue as acting treasurer until a replacement can be found. With the rest of the current committee happy to continue, the branch was also pleased to elect two new committee members.

Following branch business, Eleanor Milner presented Brian with a cheque for £500 from royalties from her book, '98.4° to 37°, the Memoirs of Eleanor Milner'. We are very grateful to Eleanor for her kindness.

And finally, we were also pleased to introduce Annette Gibson, who works for Coloplast and delivers community stoma care on behalf of Sheffield Teaching Hospitals. It was very interesting to hear about the work she and her colleagues are doing, especially the introduction of community stoma clinics.

We look forward to welcoming everyone back to Tapton Hall in 2026.

Mary Milner

Yorkshire & Humberside

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

Secretary: David Legood

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

It is with great sadness that I have to report that three of our members have passed away.

Wil Andrews died in August after a short illness. He had been Branch Chairman for the past three years and was inspirational in organising Zoom meetings during the pandemic, as well as initiating our 'Urostomeets' at Garforth Golf Club and sharing his journey in the UA's Summer 2025 Journal.

Bill Nimmo was a proud Scotsman and husband of former Branch Secretary Pat Nimmo. He was a valued member of the branch, organising our raffle and raising valuable funds.

Doreen Megson attended all our meetings at Tiger Tiger, but unfortunately, she and her husband Ted were unable to attend branch meetings at the Salvation Army church during 2025. Our thoughts are with Wil, Bill and Doreen's families.

At our AGM, our guest speaker was Dr Sarah Catesby, a clinical psychologist from Harrogate and District Hospital. Sarah's presentation on the impact of health conditions on psychological wellbeing was much appreciated by us all.

> *"Our branch continues to represent the UA at hospital open days."*

Branch Treasurer John Waring gave a summary of our accounts and thanked members who have generously given donations.

Our Branch President Mr Ali then presided over the election of officers, with Bill Bradley being elected as Chairman.

We are grateful to the stoma nurses and company reps who attend our meetings. Our thanks also go to Mr Ali for presiding over our meetings and to the member who kindly bakes cakes for us to enjoy.

Our branch continues to represent the UA at hospital open days, answering questions and encouraging people to attend branch meetings for support and camaraderie.

David Legood

DIARY DATES

Please keep an eye on the events page of the UA website for details of our meetings.

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

Gloucester & District group

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

Secretary: Val Gully

Email: *urostomysupport5000@icloud.com.*

Our October meeting was attended by more than 50 people.

Our first speaker, Annie Troll from Stocare and Ostoform, gave us an overview of the company and showed us various products. She was followed by Continence Advisor Claire Perry from Coloplast. Our third speaker was Shelley Hill, a Volunteer Co-ordinator from Charlie's, a cancer support and therapy centre. Shelley gave us an insight into the free services on offer both in Gloucester, and drop-in centres across the county, for people and their families touched by cancer. We were also joined by Lead Stoma Nurse Catherine Murray, who helped to answer queries as well as gathering spare stoma supplies to donate to the Ukraine.

Our raffle was well supported with a star prize of a £50 voucher donated by Whitminster Nursery, along with other prizes donated by members. Thank you all very much.

If you would like to join us, please don't hesitate to get in touch.

Val Gully

DIARY DATES

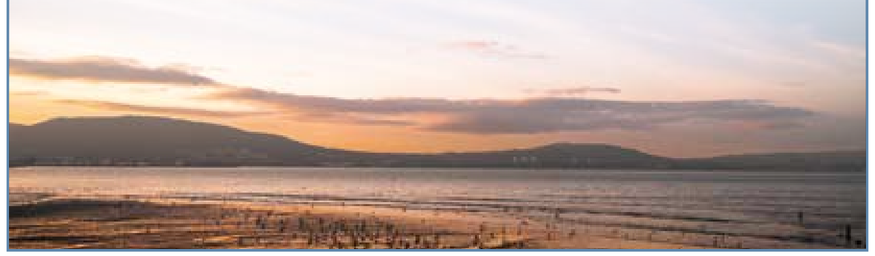
19 February, 10.30am – 12.30pm: group meeting.

Northern Ireland group

We are always delighted to welcome new members. Meeting regularly, we share our experience and swap tips, supporting and encouraging each other while having a really enjoyable social time.

If you'd like to find out more, please contact me via *donna.watson@urostomyassociation.org.uk.*

Donna Watson



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 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.

- **£5 a month** could help ensure our helpline is there for anxious callers.
- **£10 a month** could fund a 'meet the experts' webinar so urostomates can directly speak to those in the know.
- **£50 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 *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.

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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.

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Thank you so much for your kindness.

Scan to donate online or call
01223 910854

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I would like to give a monthly gift of: ☐ **£5** ☐ **£10** ☐ **£20**

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.

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2 Your details

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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:

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Make your gift worth
25% more
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☐ 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.

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