UROSTOMY
ASSOCIATION
Incorporating all types of urinary diversion

journal

Winter 2024 Issue 132

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Urostomate Anna is championing change

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The shocking rise in Ketamine bladder

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Top tips for swimming with a urostomy

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What our survey says

Welcome to our winter Journal

With a new year just around the corner, it's a time of reflecting on the past 12 months as well as looking to the future.

What's particularly encouraging is that - while there's still a long way to go – stomas, and what it means to have one, are being discussed in the mainstream more than at this point last year.

2024 has seen a stoma-related storyline unfold on iconic soap 'Coronation Street', stoma-friendly underwear on the rails in Marks & Spencer, and even a new Lego character with a stoma. Things are moving in the right direction!

Not only are stoma charities, including the UA, working hard to encourage awareness and improve understanding, more ostomates are sharing their stories in print and online. Such openness is doing much to help bust myths and fight stigma.

Thank you to urostomates Anna, Cathy, Roger and Jackie for sharing their stories in this edition of the Journal. They've each faced their own challenges on the road to recovery but are busy embracing life again, united in their determination to bring hope to anyone feeling anxious before or after their op.

Wherever you are on your journey, please remember you are not alone. With the UA, you are part of a friendly, supportive, 'can do' community – all year round!

Warm winter wishes

Paola

Paola Simoneschi
Journal Editor

PS *Do you know about the UA's e-cards? Easy to personalise and send online, they're a great way to show thoughtfulness, save on postage and celebrate special occasions. See page 5 for details.*

We welcome 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 **15 February**.

Thank you.

It's **FREE** to join the UA as well as really straightforward - find out more on page 50.

On the cover

Campaigner Anna has a urostomy and an ileostomy due to severe endometriosis. Turn to page 8 to read her story.

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Journal advertising

Published three times a year (spring, summer and winter), the Journal is the UA's flagship magazine. We welcome advertising – please get in touch via editor@urostomyassociation.org.uk to discuss your requirements.

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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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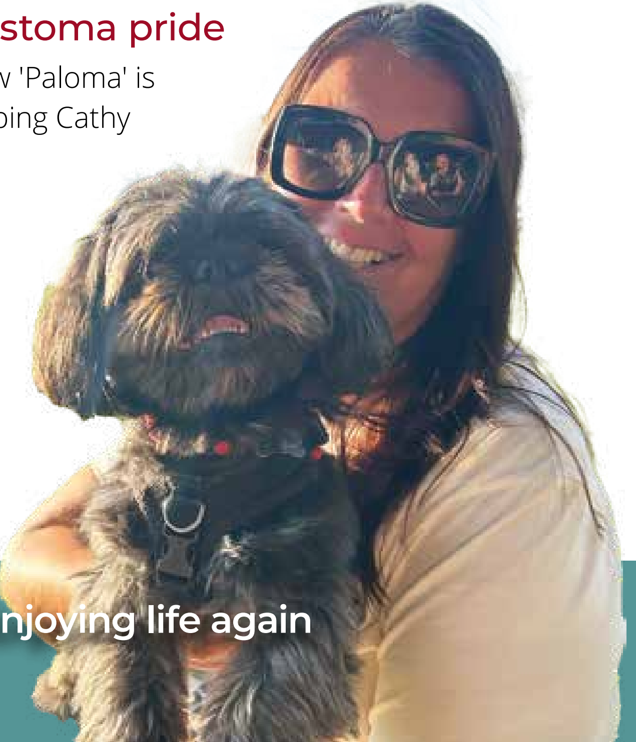

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UA **e-cards:** convenient, eco-conscious and easy to personalise

We all like to show friends, colleagues, customers and loved ones that we care by sending cards for special occasions. But with the cost of stamps, and environmental concerns over the production and disposal of traditional cards, switching to e-cards can be a small yet impactful choice.

By choosing our UA e-cards, you will also help patients find the support and confidence they need to embrace new lives following urinary diversion surgery.

We've partnered with dontsendmeacard.com to offer cards to suit almost every occasion, and they're customisable, so you can add your own personal wishes.

There are corporate versions too, so do take a look and celebrate good times!

- Add a photo, if you wish, alongside your message
- Send multiple cards with one donation
- Track your delivery, so you know your card has been opened

It's easy to pay – just choose your e-card and make a donation using the PayPal link; you don't need a PayPal account to do this. You can pay by debit or credit card, if you prefer.

Find out more on our website: ***urostomyassociation.org.uk/support-our-work/e-cards.***

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, Journal, e-newsletters, webinars, group meetings, social media 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 in person, over the telephone and online. Wherever possible, 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 page 51 of this magazine, or the one on our website: ***https://urostomyassociation.org.uk/join-now/***, and we'll send you our news and information the way you want to receive it.

Show your support for UA

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

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Turning **pain** into **power**

Menstrual health campaigner Anna Cooper lives with two stomas - a urostomy and an ileostomy – due to complications from severe endometriosis, the condition she has battled since her early teens. While Anna's story is not an easy read, it is one she is proud to tell, shining much-needed light on this hidden disease while showing the world that, despite 17 operations, there is life beyond such major surgery.

“Endometriosis ('endo') is a systematic inflammatory condition where cells similar to the lining of the womb occur elsewhere in the body, which can cause chronic pain, rectal bleeding and other debilitating symptoms. Often misdiagnosed, it can sometimes lead to infertility.

I was 14 when I started getting terrible pain and other frightening symptoms. I didn’t know what was happening but needed to be believed by doctors, not told it was simply ‘growing pains’.

In telling my story I hope I’ll help other women and girls avoid the years of gaslighting and invalidation I experienced from parts of the medical profession before finally, I was taken seriously, diagnosed, and able to access the help I needed. It took an ovarian cyst misdiagnosis, and later an emergency appendectomy, to have my symptoms properly investigated. Even then, it wasn’t straightforward because my gynaecologist did not agree with the surgeon who’d spotted endo while taking out my appendix.

Searching for answers

Thankfully, my family was supportive. We knew something was up, and Dad set about finding one of the top endo specialists.

While my consultant was certain I had the condition, he couldn’t be sure how severe it was. This could only be discovered once he operated. It turned out I was riddled with it! Stage 4 widespread endometriosis - so much that it couldn’t all be removed in one go. Two weeks later, I was back for my fourth surgery in less than ten months.

This operation scared me; it was major. I’d just been diagnosed and now I was going to have surgery to save some of my vital organs from permanent damage. In the five-and-a-half-hour operation, they excised the endo from my bladder, ovaries, fallopian tubes, and also from my bowel, where it had grown so deep that they needed to resect part of it.

Finding validation

No-one likes having major surgery, but I felt relief. Finally, my pain was validated. But I was also completely blindsided that, just two weeks from my 18th birthday, I’d been diagnosed with an incurable condition that I was going to have to live with for so many years to come.

On top of this, I was told I would never be able to conceive naturally. I didn’t know it at the time, but they got that wrong. A few years later, just as my now-husband Scott and I were about to start fertility treatment, we found out I was pregnant!

> *“I’m grateful for such a great obstetrician and, when Grace was born, Scott and I were elated. Our world was complete!”*

Now we are three

We thought the universe was finally on our side. I count my blessings every day that I was able to conceive our daughter naturally, but having said that, we weren’t in for an easy ride. I was constantly in and out of hospital due to hyperemesis gravidarum, which causes excessive nausea, vomiting and weight loss during pregnancy.

I was also a high-risk patient due to all my surgeries. I’m grateful for such a great obstetrician and, when Grace was born, Scott and I were elated. Our world was complete!

Fast forward to 2024, and I’m now 31, Grace is eight, and Scott and I have been together for 12 years. The time since Grace was born has been amazing, but tough. The pain of chronic endo can be invisible until you share your story. It is hard longing to do the normal things parents do with their children, and I stayed away from mum and toddler groups because I didn’t want to have to explain why I couldn’t do what they did.

Turning **pain** into **power** continued.

> “I remain grateful to my two stomas for making life better for me and for my family, too.”

My first stoma

For those with severe endo like me, the condition can feel relentless. In 2020, I underwent surgery to have a permanent ileostomy because of the damage the disease and previous operations had done to my large bowel. It was life-changing but once I started healing, I found myself accepting my new body and thanking my stoma for functioning better than my large bowel ever could. This was about me being present for my husband and daughter. For them not to fear every time I was hospitalised with bowel obstructions.

Further surgery

Unfortunately, having my ileostomy was not the end of my surgery story. A year on I had my large colon removed and my stoma revised to create a better ‘spout’, and this time the recovery was much more difficult, testing me both mentally and physically.

The damage caused by endo continued to take its toll and in 2021, I had a radical hysterectomy. I also had major endo excision from my bladder and rectum.

No woman should have to go through this, let alone at such a young age. I felt as if I was less of a woman because I had lost all my reproductive organs. It’s funny how society’s pressures can make you feel that way. I’ve learned that recovery is not linear.

My urostomy surgery was in June 2023. It’s a long story, but because my body expelled catheters and my bladder was failing, it was my only option to avoid kidney failure. I had just turned 30 and was once again undergoing life-changing surgery all because of endo, a disease still not deemed serious.

The majority of urostomates recover well from their surgery, and my experience of contracting life-threatening sepsis is certainly not the norm. It made my journey longer and more complicated, but I remain grateful to my two stomas for making life better for me and for my family, too.

Power from pain

Endo has been a huge negative in my life, so I needed to create something positive from it. Turn pain into power. That’s why I began my Instagram account *@battlewithendo* and am now co-running a charity, the Menstrual Health Project (MHP).

I don’t want anyone to have to endure what I have and feel like they have nowhere to turn. MHP’s vision is a world where menstrual health is no longer stigmatised and severe pain isn't normalised. Our mission is to spark positive change and provide practical support for those with menstrual health concerns and conditions. We give seminars in schools, colleges, universities and workplaces. And we also provide toolkits developed by the patients and medical professionals on our board.

The gender health gap is real, which is obvious when you look at healthcare for women overall. As a society, we need to stop playing down women’s pain and make things better now and for future generations.”

> “The survey outcomes are already proving powerful as we strive to raise awareness.”

To mark September’s Urology Awareness Month, we promoted an online ‘state of the nation’ survey because facts and figures about urinary diversions are few and far between. As a result, patients’ needs are often eclipsed by more common ostomies like colostomies and ileostomies.

Insights Survey update

Samantha sharing information with stoma staff during the international conference held by the Association of Stoma Care Nurses and the World Council of Enterostomal Therapists.

Almost 400 people took part, answering the 40 questions, sharing their experiences before and after surgery, and in the longer term.

The results are rich with data which we’ll be analysing over the coming months. However, a preliminary review reveals a mixed experience—many people reported receiving great quality care surrounding their surgery. For example, 81% said that they felt practically prepared for their surgery.

However, a significant number clearly would have benefited from more support. For example:

- 48% said that they would have liked to receive more information about treatment options
- 38% said that they were not, or could not remember, being referred to a support group, and
- 47% said that they didn’t receive information and support about the possible sexual side effects of their surgery.

The survey outcomes are already proving powerful as we strive to raise awareness. Samantha Sherratt, our Transformation Director, for example, used the early statistics in Glasgow during her presentation to an international audience of stoma staff.

A key outcome of the Insights survey will be a new urinary diversion charter – a clear call to action for politicians and healthcare leaders to ensure better care for all going forward.

As Brian Fretwell, our Chairman, said as he launched the survey, “Our voices need to be heard.”

Thank you to everyone who took part.

Beyond the high: Ketamine's impact on bladder health

An unexpected crisis is unfolding in urology clinics nationwide as more young adults grapple with bladder issues tied to their recreational Ketamine use.

Ketamine has increased in popularity since the rave scene of the 1990s when it earned the party drug nickname. It gives users a quick high, is relatively cheap, and easy to get hold of. It can be injected, snorted, smoked or swallowed, and is a Class B drug.

Users report a 'floating, out-of-body' experience, but the effects are often short-lived as tolerance to the drug quickly develops. This forces users to seek larger and more frequent doses before they can experience the same effects. It also has the reputation of being a 'safe drug' because the side effects aren't widely known.

Ketamine Bladder

The symptoms younger people are presenting with include nausea and vomiting, palpitations, dizziness and gastrointestinal, bladder and liver problems.

The trouble is that these symptoms of recreational drug use are not always recognised by healthcare professionals. They can often be misinterpreted as an infection or interstitial cystitis.

Such patients are frequently treated with numerous courses of antibiotics before being referred to urology specialists. All the while, their continued use of ever larger doses of Ketamine means that, at some point, they cross a threshold and cause themselves significant and irreversible damage. We don't currently know whether it's the duration of use, or dosage, that is causing the problem.

Ketamine is excreted via the bladder, where it sits, and is toxic to the surrounding cells and the muscle wall. This causes it to become fibrosed over time, shrinking the organ down.

Once that's happened, it can't regrow, so that's why we have to do major surgery, because patients just don't have the capacity to hold urine. The bladder simply stops working as a muscle, so they become incontinent.

Life becomes increasingly difficult for patients with Ketamine Bladder, who describe needing to rush to the toilet all the time; as often as every 10 minutes for some. They report feeling that their bladder never feels empty, and they're experiencing pelvic and loin pain, among other symptoms.

Key aspect of management

Many patients presenting with Ketamine Bladder are in their early 20s and have been taking the drug since they were teenagers. If symptoms are spotted early enough, then the extensive damage can often be avoided.

But the most important course of action is to stop taking the drug as quickly as possible to protect the upper tract, kidneys and ureters.

We can't do anything medically if people won't give Ketamine up, so we refer them to the Bristol Drugs Project for help. Once they've stopped, then staff can start offering treatment. If it progresses too far, then all we have to offer is major surgery - cystectomies and urostomies, as well as ureteric implantation if their ureters are affected.

Psychological support

Patients in Bristol are supported by a multidisciplinary team comprising a urologist, nurse, pain specialist, toxicologists and drug support workers.

They are also trying to bring a clinical psychologist on board who can support patients to process what it will be like wearing a bag for the rest of their lives. Such news is distressing for many young patients as they realise that this is going to be life-long. It's not what they're expecting - they didn't know, when they started taking Ketamine so young, that it would affect their bladder.

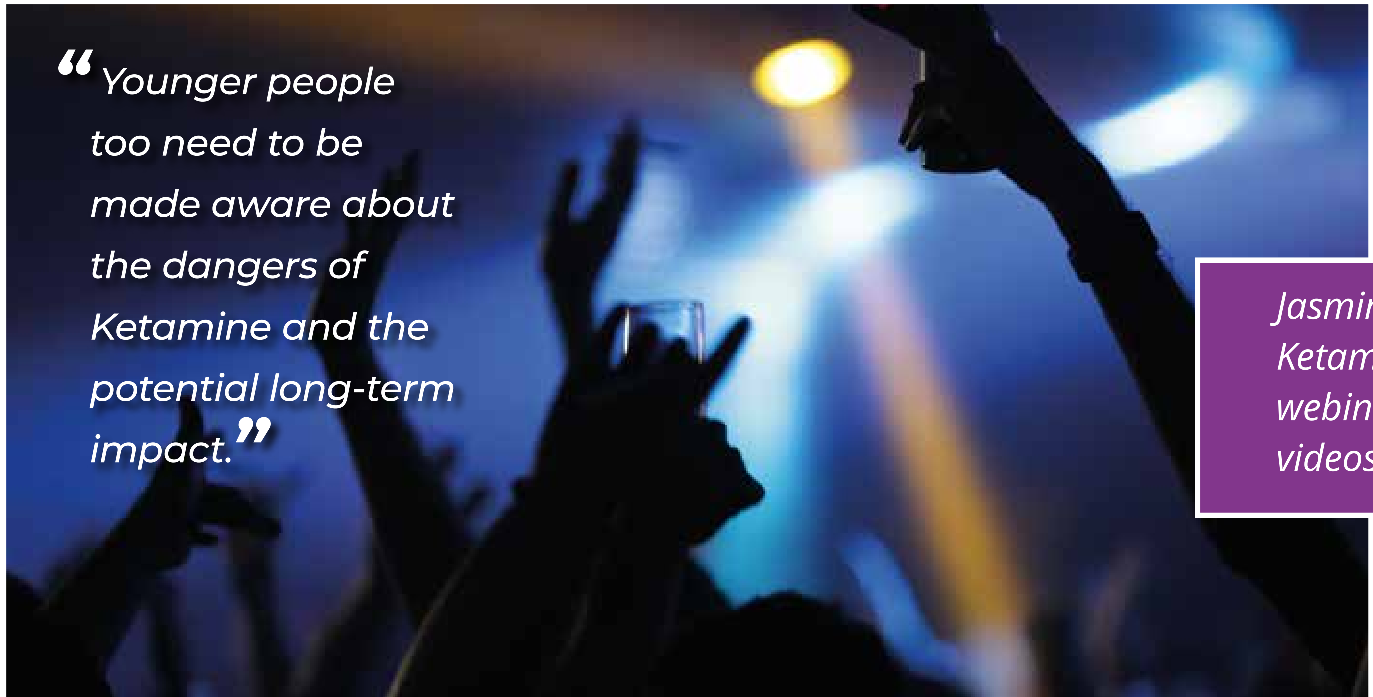
Psychological support is particularly important as younger patients are less likely to want to talk to others; they're just too embarrassed, and they're not sure that life will ever be the same again.

Raising awareness

Raising awareness is high on the Bristol team's agenda. Healthcare professionals need to be more aware that Ketamine Bladder is a problem, and to talk to patients about their drug use in a way which is non-judgemental.

Younger people too need to be made aware about the dangers of Ketamine and the potential long-term impact, just as they grow into adulthood and prepare for the lives ahead of them.

Jasmine King, Urology Specialist Nurse Practitioner with North Bristol NHS Trust.



> *"Younger people too need to be made aware about the dangers of Ketamine and the potential long-term impact."*

Jasmine recently shared valuable insight into Ketamine Bladder at our World Ostomy Day webinar. You can see the recording on the videos page of our website.

What’s **new online**?

World Ostomy Day Insights Webinar

To mark World Ostomy Day on 5 October, we were joined by an array of high-profile speakers from the urology world for our Insights Webinar. The event was designed to explore national trends and emerging themes in urinary diversion care, and what these might mean for urostomates and those involved in their care.

The speakers, all experts in their field, shared their knowledge on subjects ranging from the socio-economic costs of peristomal skin conditions to challenges in the urostomy product supply chain, and The Urology Foundation’s new research strategy. The audience also got the opportunity to discuss what they saw as the three greatest challenges facing urostomates in the next three years.

Jasmine King, Urology Nurse Specialist with North Bristol NHS Trust, gave an eye-opening presentation on Ketamine’s impact on bladder health, and you can read more from her on page 12.

We would like to say a huge thank-you to all the speakers, and to our sponsors - Hollister and Salts - for making this important event such a success.

*Did you **miss the webinar?***

***Good news –** you can watch the recording online at **urostomyassociation.org.uk/videos**, where you can catch up with our ‘Meet the Experts’ webinars too.*

Podcast: preparing for a urostomy

To mark Urology Awareness Month in September, we joined forces with Coloplast Ltd to produce a new podcast, with guests sharing their experiences of preparing for a urostomy, and the early days afterward.

The podcast is part of Coloplast’s ‘Stoma and Continence Conversations’, offering informative and inspiring insights designed to support anyone touched by urological conditions. So, why not grab a cuppa and listen to the recording on our website at *urostomyassociation.org.uk/videos*.

Come and find us on Instagram!

Following us on social media is a great way to keep up with all our latest news and events, and more and more of you have been asking us to launch on Instagram. So, we’ve done just that! You can find us at *Instagram.com/urostomyassn*. Remember, we’re also on *facebook.com/urostomyassn*, *twitter.com/urostomyassn* and *linkedin.com/company/urostomy-association*, so do follow us for bite-sized updates!

Understanding and **managing mucus**

> *“Any irritation or minor injury to your stoma can result in increased mucus production as your body’s natural defence and repair mechanism.”*

We know that mucus is a common concern among urostomates, but what is normal and when might it be time to seek advice from a healthcare professional? Paul Russell-Roberts, OC Manager with Coloplast Professional (pictured above), explains what you need to know.

Mucus is normal and healthy

The production of mucus is normal and healthy. It is part of living with a urostomy. This white, sticky substance can appear as ‘threads’ in the wee inside your bag, or you may notice it on your stoma when changing your bag. However, the overproduction of mucus can be problematic and is a common concern among urostomates, so it is important to understand what’s normal and what might require a trip to your GP or stoma care nurse.

Having supported many urostomates experiencing excess mucus, I hope to provide you with some insight into why it occurs and the steps you can take to manage it.

Causes of urostomy mucus

Your urostomy was formed using a segment of your small bowel, which naturally produces mucus. In its normal function, mucus helps protect the bowel lining and aids the passage of stools. When this piece of bowel is repurposed to create a urostomy, it continues to produce mucus, which can sometimes become problematic.

There are five possible causes of excess mucus:

Dietary irritants

Certain food and drink may irritate your bowel. Since the section of bowel used for your urostomy still behaves as though it is part of your digestive system, it may respond to these irritants by producing more mucus.

It may be helpful to monitor your diet to identify any potential triggers.

Stoma trauma

Any irritation or minor injury to your stoma can result in increased mucus production as your body’s natural defence and repair mechanism. Think back to when you had your stents in when your urostomy was first formed. Can you remember how much mucus there was? One of the reasons is that the stents irritated the bowel.

An over-production of mucus can occur if your stoma appliance is not properly aligned, or was cut too small, causing it to rub against the stoma. Consider when you last checked your cutting template. Your stoma may have changed in size or shape. If you’re experiencing leaks and increased mucus, this is most likely to be the cause.

Don’t hesitate to reach out to your stoma nurse or other support services for assistance with checking your appliance fit.

Urinary tract infection (UTI)

Even a mild urinary infection can trigger more mucus production from your stoma. Be vigilant for signs of infection, such as unusual odours, changes in the colour of your wee, or discomfort. **If you suspect an infection, contact your healthcare provider promptly and have your urine tested.**

Medication side effects

Certain medicines can affect mucus production, though this varies from person to person. If your mucus production fluctuates, it’s less likely to be due to medication, but it is something to be aware of. **Do not alter your medication regime without consulting your healthcare provider first.**

Other factors

Sometimes, mucus overproduction occurs without a clear cause. If this is your situation, you may find that taking a vitamin C supplement helps to reduce the mucus. However, always consult your healthcare provider **before** starting any new supplements.

Managing mucus overproduction

Understanding potential causes of excess mucus will help you take steps to prevent it.

Regularly check the fit of your stoma appliance, monitor your diet, and look out for any signs of urinary infection.

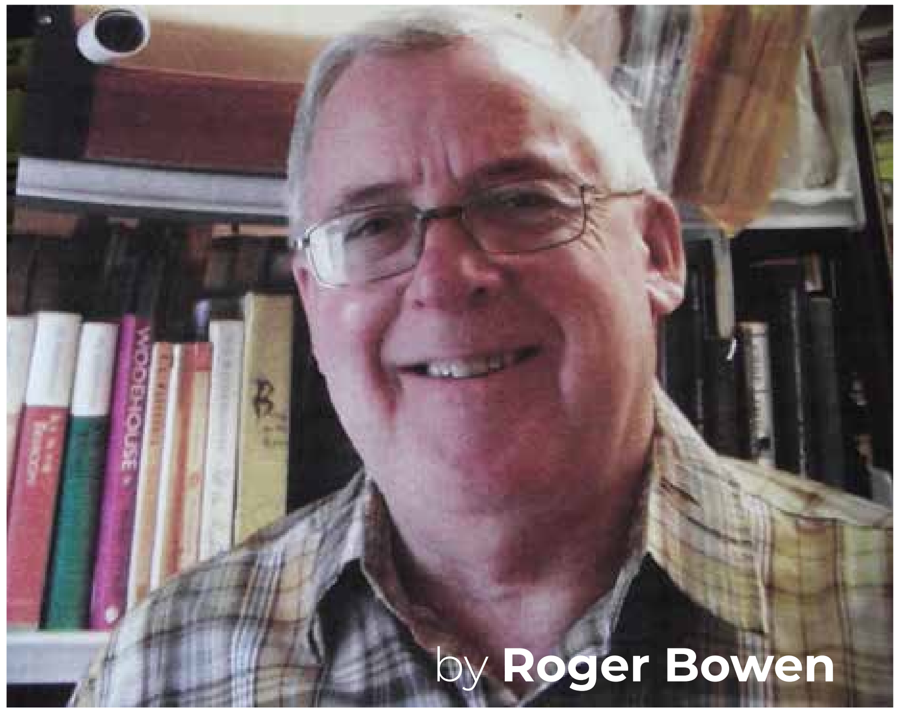
Your stoma care nurse and healthcare team are there for advice and support when you need them, don’t be afraid to get in touch. This applies whether you are concerned about mucus or any another issue relating to life with your urostomy. Getting answers to your questions can help you find greater peace of mind.

> *“Regularly check the fit of your stoma appliance, monitor your diet, and look out for any signs of urinary infection.”*

Paul Russell-Roberts has nearly 25 years’ experience in surgical nursing, becoming a Stoma Care Nurse Specialist in 2011. He is passionate about developing protocols, policies and digital platforms that make a real difference in the lives of ostomates.

The **kindest** cut

Almost 60 years ago I was faced with the proposition of having surgery for a urinary diversion. I was just ten years old, so my parents made the decision for me and I'm glad they did. Having great family support made accepting the changes that an ileal loop conduit demanded much easier than it might otherwise have been. After all, the alternative was continued severe incontinence.



by **Roger Bowen**

I had my operation in 1965 at Newport's Royal Gwent Hospital and was fortunate that it was performed by a surgical genius, David Sturdy.

Some surgeons achieve a rapport with their patients, and this was certainly so in my case. Mr Sturdy talked to me as he would to an adult and explained just what he planned to do for me. Being treated as an intelligent person meant a lot to ten-year-old me and helped me have confidence in the doctors involved in my care.

In the 1960s there was nothing like the information out there for patients today. Now, thanks to magazines like the UA's Journal, urostomates know they are not alone.

In the early days after my operation, I was very self-conscious about my bag and hesitated to use a urinal in case anyone commented on it. It's not usual to strike up conversations in the gents'.

I should not have worried as one day I found myself alongside a man who also sported a bag, which he was happy to talk about. We had a brief joke about the bags while I boasted that I had a bigger one than he had – well, I do have a leg bag!

It's that old joke about when you're young you worry about what others think of you; when you're middle-aged you don't care what they think, and when you get older you realise they were not thinking about you anyway!

In recent times there has been a real change in the willingness of people to discuss stoma issues more openly, and I know stoma charities, including the Urostomy Association, have played a big part in raising awareness and encouraging better understanding. In magazines and on social media, some ostomates appear with their bags visible – sometimes with 'smart' covers. And it was heartwarming to see Radio One DJ and ileostomate Adele Roberts perform on 'Dancing on Ice' with her stoma nurse looking on.

I could not have been more pleased when my GP asked if I could speak to a lady who was facing urostomy surgery. Obviously, my help for her was given as a lay person but this lady was all the more grateful for that.

> *"In the early days after my operation, I was very self-conscious about my bag and hesitated to use a urinal in case anyone commented on it."*

Those of us who have had successful stoma surgery can have a real role in reassuring those new to the stoma world. Sharing from our own experience and passing on tips can help make a difference to anyone who may be feeling anxious.

Other positives are the impressive range of products available to urostomates these days, along with more accessible information on all aspects of living with a urinary diversion. While one-to-one support from a stoma care nurse is invaluable, I know not everyone is fortunate enough to be able to access this easily, which means the Urostomy Association's helpline, website and magazine are all the more needed.

I am now 69 and life is good. My partner Gwen and I have been together for 40 years, and we live in beautiful Blaenavon in South East Wales. We are owned by two cats, and being retired gives me time to enjoy writing articles for magazines. I think it was my former stoma nurse, Lisa Leamon, who first told me about the UA's Journal, and here I am sharing my story with you.

I am grateful to my current specialist, Mr Chris Bates, and his marvellous colleagues at the Royal Gwent Hospital. I'd also like to pass on a few lessons I've learned in my many years of living with a urostomy in the hope that they are helpful to fellow urostomates.

- When out and about, I always carry spare urostomy bags, plus wipes and disposal bags, for those unexpected times when I need to change my bag. I also take a spare pair of underpants.
- I find it easier changing my bag in a disabled toilet rather than an ordinary one. There's more room and often a shelf, which is handy for equipment. For this reason, I carry a RADAR key, which will unlock the majority of disabled toilets in the UK.
- Never be afraid or embarrassed to ask stoma care professionals for their advice. They are trained to help you with your specific needs.
- Keep on reading the Journal as it's full of all sorts of useful information and advice.
- It can take time but for most of us, dealing with a stoma becomes a natural part of life, just like cleaning our teeth.

> *"In the 1960s there was nothing like the information out there for patients today. Now, thanks to magazines like the UA's Journal,* ***people know they are not alone.****"*

Delivery of stoma products:
know your rights

While the delivery of stoma supplies is typically reliable, there's always the possibility that you could encounter challenges in receiving the right product when you need it. If this happens to you, knowing your rights as an ostomate can help you manage a situation that can feel stressful as well as being very inconvenient. That's why I want to let you know about the Code of Ethical Business Practice to which all British Healthcare Trade Association (BHTA) member companies, ie dispensing appliance contractors (DACs), must adhere.

> *"If you need the product urgently, your DAC has a duty to signpost you to another dispenser that has your product in stock"*

The code demonstrates BHTA's commitment to promoting industry-wide best practice and putting patients at the heart of its interactions. It was drawn up to give all dispensing contractors the same guidance as to the rights of ostomates.

You can find the code in full at *www.bhta.com/useful-guidance-documents*, but most important to note is that once your GP (or other prescriber) has issued your prescription for a particular product, that prescription belongs to you as the user of that product. It is, therefore, ***your*** choice which DAC - or pharmacy - you would like your product(s) dispensed from. The code is very clear on this.

There is potential for a conflict of interest to arise in cases where a DAC is owned by a product manufacturer. However, the code makes clear that DACs must not recommend products to patients. It is ***not*** the role of your chosen DAC or pharmacy to suggest alternative products for you to try. Only your GP, stoma nurse, or other prescriber has the right to do this.

If your DAC does not have the product on your prescription, they must let you know this and tell you how long it will take them to get it to you.

If their timing is not acceptable to you, ie if you need the product urgently, your DAC has a duty to signpost you to another dispenser that has your product in stock.

Please remember, it is your right to use the DAC of your choice to supply you with the product(s) on your prescription.

Should you encounter any difficulties, please let the Urostomy Association know. They will pass on this information to the BHTA so that we can take up the issue with the relevant DAC.

The NHS website at *https://www.nhs.uk/service-search/other-health-services/pharmacies/appliancepharmacies* includes a list of all DACs, so if you are unhappy with the dispenser you are using and want to switch to another, you may find it helpful to start by looking there.

***Jonathan Scott**, Chair of the DACs (Dispensing Appliance Contractors) Group, British Healthcare Trades Association (BHTA)*

Stoma care in Scotland

Representing the UA and the Scottish Stoma Forum (SSF), I recently attended a stakeholder meeting on the progress of our campaign to make good-quality stoma care more consistent across Scotland.

Alongside me and fellow SSF members at the meeting with Jenni Minto, Scotland's Minister for Public Health and Women's Health, were Anne Armstrong, the country's Chief Nursing Officer, members of the UK's two other stoma charities, plus NHS Scotland Procurement reps, stoma nurses, and product suppliers.

Shocking statistic

Following an address by the Minister, Anne reported that discussions around the campaign's five calls to action (see right) are ongoing, with further investigation needed before solutions can be proposed.

She promised to report back following the Scottish Executive Nurse Directors' meeting scheduled for 22 November, having highlighted the shocking statistic that – with an estimated 20,000 ostomates living in Scotland – there are just 38 stoma nurses to provide their care. This equates to 526 patients per nurse, with Orkney and some of the other islands having no stoma nurses at all.

Beacon of hope

The situation is very much better for ostomates based in Glasgow, as Elaine Paton from the Greater Glasgow and Clyde Health Board explained. Elaine was instrumental in setting up a local stoma forum that is being held up as a beacon for other health boards to follow.

It was also encouraging to hear from Isla Ramsey of NHS Lothian, who has been working alongside GPs and their communities to identify where improvements in stoma care are needed.

Patient reviews are leading to a more tailored service for them, improving their quality of life. The added benefit is savings to the NHS because ostomates are now more aware of products available and better informed to find what suits them best.

I will continue to keep you updated as the dialogue between the SSF, NHS Scotland and the Minister continues. Please keep an eye out for my update in the next Journal.

Brian Fretwell
Chairman, Urostomy Association

Five calls to action

1. To ensure patients have the choice of the most appropriate product or service to suit their needs.
2. To facilitate and enable equitable patient access to specialist stoma care support, education and advice.
3. To offer people with a stoma an annual review to ensure they have the best quality of life.
4. To put in place educational modules to bring nurses into the profession, ensure robust succession plans are in place and have adequate specialist nurses to support ostomates across Scotland.
5. To ensure health boards collaborate through a national 'once for Scotland approach' and share best practice to deliver the highest quality service.

For more information on the Scottish Stoma Forum, visit *bhta.com/scottish-stoma-forum.*

Intimacy and sexual relationships are important and fulfilling aspects of life that should continue after your stoma operation, but bear in mind that having any type of surgery can affect your sex life. It is an emotional time, which can impact your libido, and it is perfectly normal if you do not experience the same desires as before.

Men's **sexual wellbeing**

After your surgery, you may feel differently about your body, which can affect your self-esteem, and you might have concerns about fertility, sexual intimacy or intercourse, all of which can be difficult to talk about.

> *“You can still have a fulfilling sex life after your operation; don’t be afraid to make changes to help keep your sex life satisfying, taking into account your new circumstances.”*

Remember to be kind to yourself. Expect to have good days and bad days, both emotionally and physically, in the weeks prior to and following surgery. Listen to how your body is recovering and take time to get to know it again. Take the journey at your own speed.

It is a good idea to have a baseline meeting with a healthcare professional who is qualified to discuss sexual wellbeing with you and, if you have a partner, maybe take them along too. This will give you the opportunity to talk openly in a confidential space in a way you may have never done before, which can help relieve your anxiety.

Talking things over

> *“A drop in libido is not unusual and is usually temporary. Stay affectionate in the meantime with other forms of intimacy that may not be sexual, such as massage, hugs and cuddles.”*

If you are in a new relationship, it is natural to feel anxious about when to tell your partner about your urostomy. Ultimately, only you will know when the time feels right so trust your own judgement. If you care for each other, then you will probably find that telling will not make any difference to your feelings.

Even if you have been with your partner a long time, speaking to them about how your surgery has affected you can feel daunting. So, just as you hopefully involved your partner in discussions about your surgery, you could talk through any sexual challenges you may be facing. Good communication, along with mutual trust and understanding, will be vital for you both.

You can still have a fulfilling sex life after your operation; don’t be afraid to make changes to help keep your sex life satisfying, taking into account your new circumstances. If you and your partner struggle to talk about it together, you may want to ask your stoma nurse for a therapist referral.

Psychosexual therapists are specially trained to help people talk and overcome difficulties in their sexual lives and relationships. They can act as a facilitator to help you and your partner talk things through.

Sex drive

After your surgery and during follow-on treatment, you may find that you are losing interest in the sexual side of your relationship or masturbating. This may be due to soreness from your surgery, or to changes in how you are feeling; this is completely understandable as you have been through a lot. If you or your partner are worried that intimate moments might damage your stoma, then rest assured, your stoma should not come to harm.

A drop in libido is not unusual and is usually temporary. Stay affectionate in the meantime with other forms of intimacy that may not be sexual, such as massage, hugs and cuddles.

Erectile dysfunction

Some men have problems with erections before their surgery, while others have problems afterward. Some go on to achieve an erection naturally, but for others it can be more difficult. It may take up to two years before you can be certain whether erectile dysfunction is permanent and whether your erectile function will come back fully. Other aspects of sexual wellbeing that can be affected include the ability to orgasm or ejaculate.

The main cause of erection problems following pelvic surgery is damage to the nerves that carry signals from the brain to the penis. There are several treatments you can try, and it is best to consider all the possibilities, together with the recommendations from your nurse or doctor.

Men who have had both their bladder and prostate glands removed will never be able to ejaculate, but many do achieve orgasms.

If you are having a problem with your erection, speak with your GP or the stoma nurse at your hospital clinic. They should be able to outline pathways for treatment, including possible referral to other specialists. Remember, erections are only part of the sexual wellbeing pathway and people can adapt to have a fulfilling sex life in many ways.

It is important to emphasise that it is by no means certain that problems will automatically follow urinary diversion surgery.

Treatment options for erection problems

Treatment options can include vacuum pumps, penile implants, creams, pessaries, tablets and psychosexual therapy. Talk through which options might be right for you. Here is more information on just two of those – medication and mechanical aids.

Medication

The drug most people will have heard of is Sildenafil, better known by its trade name 'Viagra'. This and other similar drugs (Tadalafil, Vardenafil and Avanafil) may improve your erections but your nerves need to be intact for them to be effective. Research shows that in most circumstances they are safe, but they do have side effects. The most common of these are headaches and indigestion.

Don't take Sildenafil if you are taking drugs for angina containing nitrates, as the combination can result in a severe and potentially fatal drop in blood pressure. Do discuss this with your GP, as they can advise on the best drug to suit you personally.

Other treatments include penile injections into the base of the penis (Viridal Duo, Caverject Dual Chamber and Invicorp), small waxy pellets (MUSE) inserted into the urethra, or a cream – Vitaros - which is applied at the opening of the glans (head) of the penis. Penile injections sound daunting but are extremely effective.

Mechanical devices

Vacuum constriction devices (VCD) comprise a cylinder which you place over your penis, and you create a vacuum with a pump. This causes your penis to become enlarged as blood is sucked into the shaft and you then place a tight specially designed constriction band around the base to trap blood within your penis to keep it firm. The ring should not be left on for more than 30 minutes.

Mechanical devices may be used alone or in combination with drug treatments. Using one does require some practice and can be helpful in maintaining penile length even if a constriction ring is not used.

Another option is that your penis can be splinted internally, by inserting a penile implant. This can be done by inserting two cylinders, which can be partially inflated and deflated from an internal reservoir, or fixed as malleable rods which you bend to support the erection into position.

This sort of surgery is usually considered as a treatment of last resort, if other options have been unsuccessful. Such surgery should certainly be very carefully considered and discussed. If you had a pre-existing erectile dysfunction prior to your urinary diversion, this could be a suitable option earlier in your recovery pathway.

The most important message is to gather as much information as you wish, discuss the options and enjoy this aspect of your life in a way which is closest to your desires and best suits your circumstances and relationship(s).

> *"Some people find greater closeness with their partner as they reinvent their sex lives, while others agree to let this side of their relationship go."*

Fertility

A urinary diversion can cause problems with sperm manufacture in your testes, or there may be a problem with the transport system, carrying sperm from your testes during ejaculation.

If your surgery was performed for a non-malignant condition, your bladder and reproductive organs may not have been removed, so you may need to consider contraceptives if you're not looking to have children.

If you do want children, tell your stoma nurse before surgery and ahead of any treatment, as you may wish to consider semen banking, when your semen is frozen and stored for use later.

Chemotherapy, radiotherapy, surgery or a combination of these can cause problems with fertility and may not be reversible.

If you wish to start a family, both you and your partner will need an assessment, probably co-ordinated by a specialist.

For details about this and fertility treatment options, visit the website of your local fertility centre. The Human Fertilisation and Embryology Authority also has helpful information – please see below for their website link.

Looking forward

Being worried about your sex life following surgery is understandable. You may well recover over time without extra help, or you may want to be referred for additional support. Either way, there is no wrong or right path, and no set timescale to follow. Progress in your own time.

Some people find greater closeness with their partner as they reinvent their sex lives, while others agree to let this side of their relationship go. But if you do need support, then please ask for it, and develop a plan that is right for you.

Masturbation is also helpful during recovery, when the time is right for you, and you never know what life has in store!

We hope this article helps as you explore what sexual well being will mean to you going forward.

> *"It is important to emphasise that it is by no means certain that problems will automatically follow urinary diversion surgery."*

Further information and support

College of Sexual and Relationship Therapists: *www.cosrt.org.uk*

Relate: *relate.org.uk/what-we-do/counselling-services*

Human Fertility and Embryology Authority: *hfea.gov.uk*

The Mental Health Foundation: *mentalhealth.org.uk*

Coming up:
*In our **Spring Journal** we'll be covering women's sexual well-being, from body image and orgasms to fertility and menopause.*

Help for hernias

My name is Tammy Temple. I've been nursing for over 15 years, and a specialist stoma nurse for the past five. I work in Nottinghamshire, and my patients include those with urological stomas. I support them from six months post-surgery onwards, and it's a role I am extremely passionate about.

The best part is helping patients live their best life and finding out what this means for them. It's not only about their clinical concerns, such as leakage, soreness and hernia prevention, but also supporting them in getting back to normal, from returning to exercise to socialising and travel. Giving patients confidence helps them have the best quality of life.

You're probably familiar with the term 'hernia', which is when an internal part of the body pushes through a weakness in the muscle or surrounding wall, causing swelling or a bulge. Urostomates - and people with other types of ostomy - are prone to what is known as a 'parastomal' hernia because it appears under, or around, their stoma. These hernias rarely cause major complications but can sometimes interfere with stoma function and the security of your appliance. So, it's important to know how to minimise your risk, and when to seek advice from your stoma nurse.

What causes a parastomal hernia?

It's usually a combination of muscle weakness and strain around the area of your stoma. Following your urostomy surgery, your abdominal wall will have become weakened and is, therefore, more vulnerable than it was before.

A hernia can occur weeks, months, or years after stoma surgery, and the risk of developing one increases with age. Other factors include surgical technique, muscle weakness, and multiple abdominal operations. Being overweight, straining, and even coughing can also increase your likelihood of developing a parastomal hernia.

What to look out for

Parastomal hernias tend to develop slowly, and don't always cause symptoms or stoma management problems. However, signs include:

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

If you are experiencing symptoms, speak to your stoma nurse. While parastomal hernias don't usually require an operation, they don't go away by themselves and can get worse over time. In rare cases, a hernia can cause twisting in the bowel, which usually requires surgery.

Avoiding hernias

After your surgery, it's important to avoid lifting anything heavier than 2.2 kg (5 lbs) for up to six weeks. Use a trolley to help move heavier items, or get someone to help you.

Your nurse will advise you on the most appropriate exercises for you to do, both before and after your surgery. See below for more about exercise.

Eat a healthy, balanced diet and manage your weight so that you stay within an appropriate range.

If your stoma nurse feels you require some additional abdominal support, they will discuss this with you and provide the appropriate garment to meet your needs.

About exercise

Getting regular exercise can be incredibly beneficial, but get advice from your nurse before embarking on a new regime. No matter what exercise you're doing, start slowly and gradually build up your stamina.

- Walking and running are fantastic for building fitness. Take things at your own pace and start slowly over shorter distances.
- It's highly likely you will need to start rebuilding strength in your core and abdominal wall after stoma surgery. Sit-ups may be impractical for ostomates, so try pelvic tilts, hip lifts and knee rolls, which can bring the same results more safely.
- Yoga, tai chi and pilates are perfect for building core strength without any heavy lifting.
- Swimming puts little strain on your stoma and has both strength and cardio benefits.

Getting treatment

Many people who develop a parastomal hernia don't have any complications. Others find that while their hernia may restrict them from doing certain things, they can still enjoy life.

Gentle exercise, eating a nutritious diet, a good stoma product system, and a hernia support belt or garment can help you manage your hernia.

As well as providing advice, your stoma nurse can arrange for a support garment to be tailor-made to fit you and provide the support your hernia needs. If your hernia means your usual type of urostomy bag no longer works for you, your nurse will help you find a more suitable one.

It is possible to have repair surgery, depending on your symptoms and their effect on your quality of life, but this will need to be assessed by your surgeon.

I hope this article has been helpful and reassuring. **Always make sure you communicate with your stoma nurse as they are there to offer their professional advice.**

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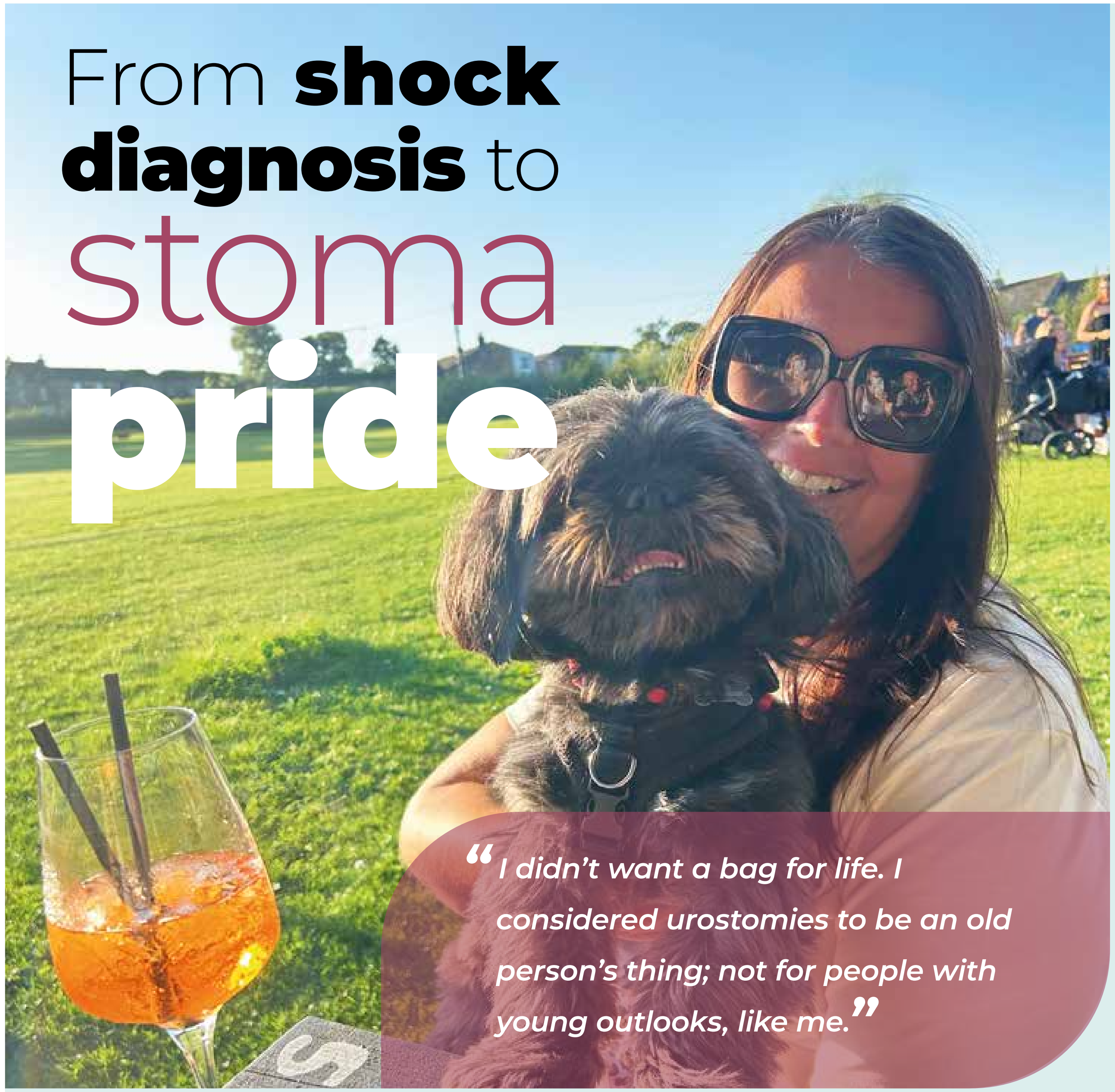
For all articles, visit *www.hollister.co.uk/en-gb/ostomycare/ostomylearningcenter*

For any information on Hollister products, please get in touch on **0800 521 377**.

We serve people living with an ostomy and those who care for them. We are committed to helping empower those who use our products with the independence to maintain a rewarding, dignified life. View our comprehensive portfolio of ostomy care products, and access helpful educational resources here. *(http://www.hollister.co.uk/ostomycare)*

From **shock diagnosis** to stoma **pride**



> “I didn’t want a bag for life. I considered urostomies to be an old person’s thing; not for people with young outlooks, like me.”

Cathy Varley thought that 2024 was going to be her year. But a shock diagnosis of bladder cancer threw her into turmoil. In this interview, conducted just four months after her surgery, Cathy describes how she has not only come to terms with her urostomy, but has grown to be proud of it!

“2024 was supposed to be an exciting year for me. I was turning 50 in the February, and I was embracing it! I’d got weekends away with my girlfriends, holidays, and a big party planned. I’d also had a trip to Florida booked to watch my 17-year-old daughter Greta compete in a huge cheer-leading competition; her ultimate dream come true. I’d never ever missed a competition since she started cheerleading at six years old, and I wasn’t about to miss her being on the world’s stage.

My diagnosis, which I received in the week of my birthday, came as a massive shock; I hadn’t seen it coming. I was being treated for UTIs and the menopause, so I just assumed all my cancer symptoms related to those.

Considering my treatment options

My first instinct, on hearing the news, was to start Googling; looking at what my possible prognosis might be and what my treatment options were. Initially, I was quite positive because what I’d been reading seemed to imply that bladder cancer was quite treatable and, if I’d got one of the lower grade ones, then I could have a quick procedure and a bit of chemotherapy. I thought ‘I can live with that’.

I went for initial surgery in March to determine the grade but, as I was in recovery, the surgeon said, “I’m sorry but we haven’t been able to take the tumour out. It looks muscle invasive. You need to prepare yourself for possibly having your bladder removed". I was just lying there thinking "I’m not having my bladder removed, absolutely not, no way!"

So, I started researching bladder cancer treatments and bladder preservation and that’s when I went to see Professor Rosario, who was going to be leading on my case. I went into the appointment with loads of questions based on the research I’d done. He told me the results of my biopsy and that all the options I’d researched weren’t suitable for me as my cancer was high grade.

I was hysterical. I was absolutely begging him not to remove my bladder. I’m a 50-year-old woman, and I still wanted to wear bikinis. I didn’t want a bag for life. I considered urostomies to be an old person’s thing; not for people with young outlooks, like me.

Professor Rosario also said that going to watch my daughter compete in America wasn’t an option, which was an absolutely devastating blow. I’d already cancelled all my birthday celebrations and the family holiday. Everything just felt horrendous.

An anxious wait

From diagnosis to surgery was a long time; I didn’t have my surgery until July. The amount of waiting, for scans and assessments was really challenging.

Professor Rosario was amazing. He wanted me to have an urgent MRI scan because there were uncertainties about the type of cancer I had due to contradictions in the histology and my presentation. He was concerned that there may be a primary cancer somewhere else.

> “My anxiety calmed down once I was happy with the decision I’d made, and I knew what route I was going down.”

All this was like a punch to the gut. I went to my GP because I was so overwhelmed by the diagnosis and was struggling to process the information I was given. I just couldn’t stop crying and my anxiety was so high. I recognised my reaction as a trauma response and felt I needed some help to calm my anxiety and process my thoughts.

I was prescribed anti-anxiety medication and this really helped and gave me the processing time and space that I desperately needed.

A change of heart

I thought long and hard, and spoke to my amazing network of friends and family about the cancer, and suddenly my outlook started to change.

I'd originally thought I had a small tumour in my bladder, but then I was faced with the fact that the cancer might be somewhere else too. It was high grade and the chance of it spreading was high! I decided that I wanted the surgery; I wanted it all out.

My anxiety calmed down once I was happy with the decision I'd made, and I knew what route I was going down.

I had all the scans and thankfully the cancer wasn't anywhere else; it was contained in my bladder. I explored having a neobladder, but decided it wasn't for me, I was slowly starting to feel so much more positive about the prospect of a urostomy bag as I researched other people who had them.

Finding inspiration

I scoured social media for other women with urostomies and I found lots of young gorgeous women with ostomies, wearing normal clothes, swimsuits and bikinis. A couple of them had young children, and their lives were just carrying on, travelling, partying and living life to the full. That was the turning point for me. Finding those stories of real women inspired me, and made me realise that urostomies weren't just for older people.

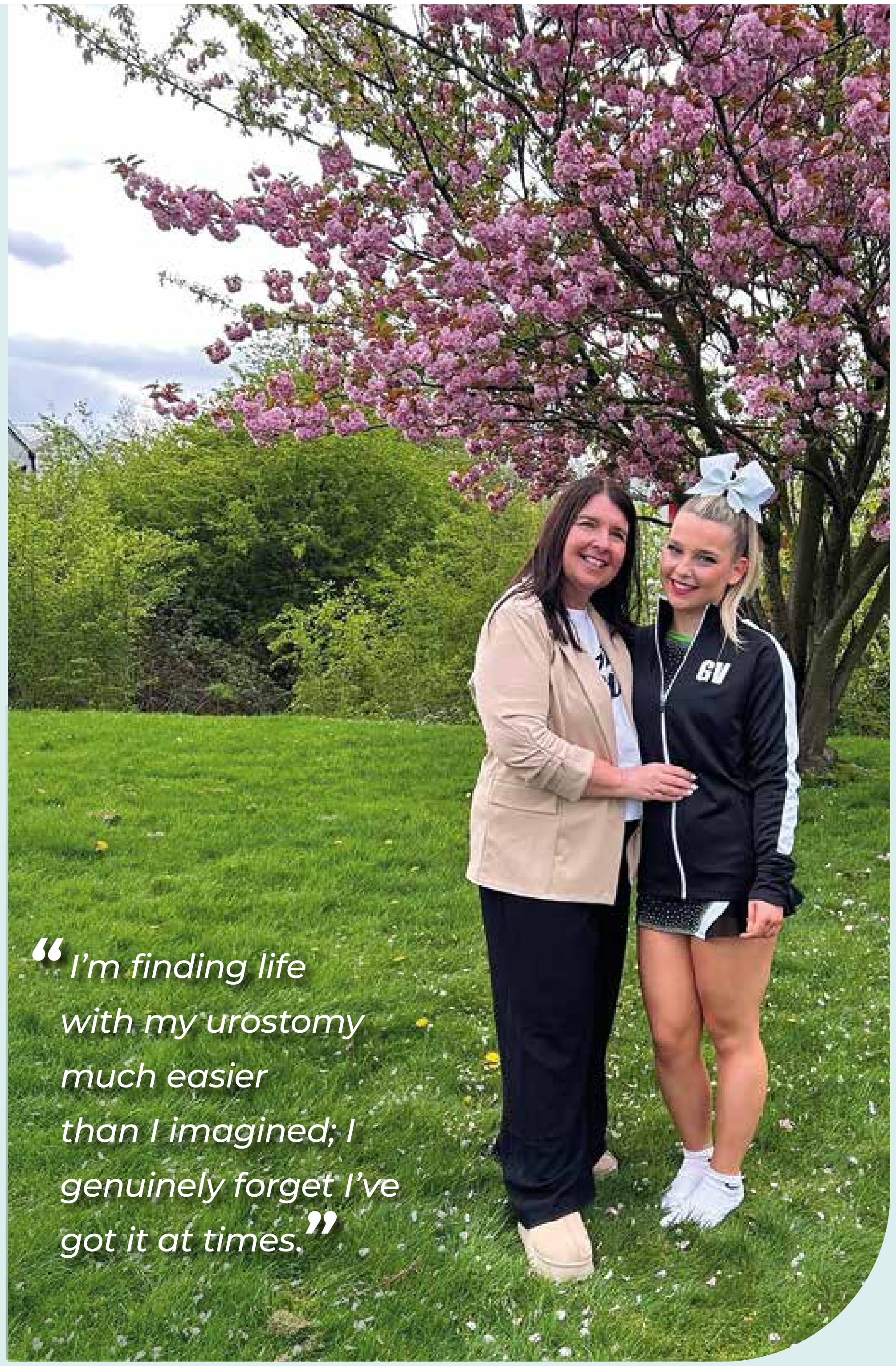
Then I spoke to my kids about it and that was another turning point. When I said I was going to have to wear a bag, they couldn't see the problem. They told me they followed loads of people on TikTok and Instagram who had bags. They were so laid back and cool about it, like it really wasn't an issue to them, and this was incredibly reassuring.

Preparing for surgery

Meeting with my stoma nurse was another key point for me; she was just amazing. With hindsight, I wish I'd had that meeting earlier, when I was still in denial, and I needed to educate myself. At the time, I didn't really understand what a stoma was; I didn't even know what one would look like!

My nurse gave me a little rubber stoma that I could try out, and samples of urostomy bags which I could stick onto my body to see how they felt and looked. I tried them out at home with my kids and my mum. I practised changing it, and trying on different outfits, and even filled a bag with water to see how it felt. My stoma nurse gave me so much valuable information about the surgery and life with a stoma. Finding out the reality was just brilliant. I asked her so many questions and she filled me with so much confidence.

Suddenly I was feeling so much more confident about having a urostomy bag. It was the beginning of my new life. It was such a massive shift from where I mentally was at the outset, when I was so traumatised that I couldn't think straight. I was still absolutely terrified about the enormity of the radical cystectomy surgery I was about to have though.



> "I'm finding life with my urostomy much easier than I imagined; I genuinely forget I've got it at times."

In the end, I had the surgery in July, and it lasted eight hours. They performed a hysterectomy, I had a stoma formed, and they operated on my bowel.

My life now

Throughout the recovery from my surgery, I'd say that the stoma and the urostomy bag have been the easiest bit of the whole process. I had to be more careful about my wounds, and my bowel was very painful. But I've had no discomfort at all with my stoma.

I'm finding life with my urostomy much easier than I imagined; I genuinely forget I've got it at times. I haven't found any major issues so far. I experienced a rash with the adhesive with one bag, which was upsetting but, with the support of my stoma nurse we overcame that quite quickly. I've had two night-time leaks, but I'm now more aware of checking the connections on the night bags.

I genuinely thought I'd be laid up for months, and not being able to do anything. But I went to a wedding two and half weeks after my surgery. It did wear me out, I have to admit, but I was so proud that I went. Take every day, one day at a time; some days you can do things, and other days you can't.

It isn't all plain sailing. I'm having immunotherapy every four weeks, and those sessions wipe me out, and I feel poorly for a week afterward. But the immunotherapy will hopefully stop or slow the recurrence of my cancer, or reduce the risk of it returning somewhere else.

I am back doing everything I did before, and I'm going back to work on a phased return. So far, I haven't come across any situations where I've thought 'I can't do that because of my bag'.

I feel that I have a good relationship with my stoma, and I call her Paloma. I'm really proud of it!"

You can hear Cathy share her story on the Urology Awareness Month podcast, which is in the videos section of our website.

Help provide
hope appeal

Help provide hope - Appeal update

> “Thanks to your kindness, we've been able to design and print a brand new information pack, containing a new 'Need to have a urinary stoma?' leaflet.”

Being told that you will never wee normally again is terrifying. Most people have never heard of a urinary diversion, and simply cannot imagine going through life without a function bladder.

That’s why we were so pleased when Andy North helped us to launch our **Help provide hope** appeal earlier in the year. As readers may recall, Andy is a helpline volunteer, and knows from his own experience the importance of trustworthy information and support when you’ve just received a life-changing diagnosis.

> *“After their initial consultations, we know that people are often worried… they need time, information and support to help them imagine what their future holds. That’s what the Urostomy Association and its volunteers are here to help with, and why they need your support.”*

The response to the appeal to date has been wonderful. Almost 150 of you have made a donation so far, raising over £5,600. And we’re particularly grateful to the Cambridge branch of the UA for donating £1,000.

Thanks to your kindness we’ve been able to design and print a brand new information pack, containing a new ‘Need to have a urinary stoma?’ leaflet describing the services and support patients can expect from the Urostomy Association.

This goes alongside our updated and redesigned ‘What is a urostomy?’ and ‘Understanding issues that may arise with a urostomy’ leaflets. And, of course, each pack contains a copy of the Journal, which is always packed with insightful information, alongside inspirational stories from readers.

We are constantly asked by stoma staff for information for their patients, and we send out over 900 packs every year.

The Help provide hope appeal is also helping to fund our helpline, volunteer training, and webinars, and there’s so much more in the pipeline. All of this is only possible thanks to donors like you. Thank you.

A donation of £25 to the Help provide hope appeal could provide essential information and support to twenty worried patients.

But patients need more than information packs. We know that the best way they can overcome their fears and prepare for their new lives is to ask lots of questions – from their stoma nurses, and from those in the know. That’s where the Urostomy Association’s helpdesk, trained one-to-one support volunteers, webinars, events, private Facebook group and brilliant website are so useful. They can help prepare patients for life with a stoma and reassure them that help is out there.

A donation of £50 to the Help provide hope appeal could help fund a webinar where patients can ask the experts and hear from urostomates happy to share their own experiences.

And, as we know, questions don’t end with surgery. In fact, for many people, it is only once they’ve had their urinary diversion that they consider how to live life to the full afterward. They want to know, for example, when can they drive again, go on holiday, have sex and take up exercise. And that’s alongside practical everyday queries such as managing night bags, avoiding urinary tract infections and stoma skin care.

A donation of £150 to the Help provide hope appeal could help fund the Urostomy Association’s volunteer programme for six months.

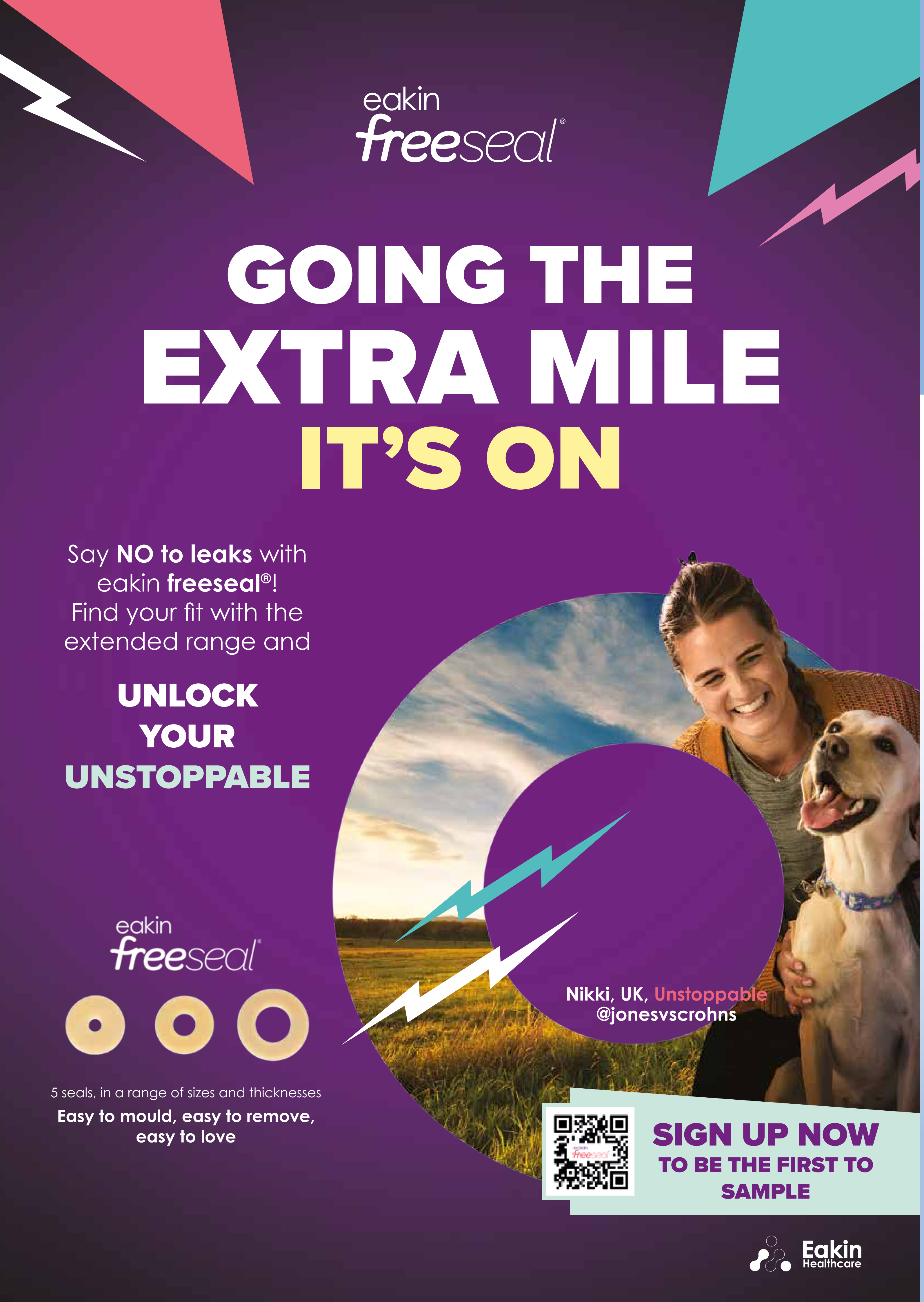
We know that life will be different for everyone undergoing a urinary diversion, and we also know that the majority go on to live active and rewarding lives. In fact, people often describe their surgery as ‘restoring their quality of life’, and some want to ‘give back’ and become a trained volunteers themselves.

Will you support the Help provide hope appeal

by making a donation today, and stand alongside new urostomates as they embark on their new life journeys?

At the Urostomy Association, we understand that people’s finances are tight at the moment, but please know that we work hard to make sure that every penny counts; so whatever you can afford would be much appreciated. Your gift can help with hope at a time when frightened urostomates need it the most.

You can donate by visiting *urostomyassociation.org.uk/helpprovidehope*, scanning this QR code, returning the donation form at the end of this journal, or by calling the office on 01223 910854. Thank you.



Winter fundraising

Did you know that as an independent charity, the Urostomy Association receives no funding from the government? It's the kindness of our volunteers, the generosity of our donors, and the community spirit of those who fundraise for us that keeps us doing what we do for urostomates and their families.

With most of us spending more time indoors during colder weather, winter can be a great time to fundraise for our charity if you have a bit of time and want to help make a difference. Friends and neighbours with cabin fever could be inclined to escape for a few hours to attend your event, or you might find that being at home more motivates you to get outside and take on a sponsored physical challenge.

Whatever your reason for supporting the UA, and whether you pick one of the ideas on this page or come up with something of your own, we can't thank you enough for your support. Have fun!

Host a curry night

With the temperature dropping, why not serve up something hot? Hosting a curry night is a good excuse to enjoy some social time. You don't have to be a qualified chef to follow a simple curry recipe, and asking guests to donate what they'd usually spend on a takeaway raises money along the way.

...or hold a quiz evening instead

If you don't fancy cooking, why not organise a quiz instead and ask each person or team to give a donation to take part? If you don't have room at home, you could invite people to join in online, using Zoom. Virtual quiz nights became popular during lockdown and still attract interest now.

Lose weight, gain pounds

If all those mince pies have added extra pounds you're keen to shed, a sponsored slim can be a great way to lose weight and fundraise at the same time. Once you've set your target weight, ask family, friends and colleagues to sponsor you per pound lost or to make a donation to the UA once you've reached your goal.

New year, new you?

With the start of a new year being a popular time to take on a fresh challenge, how about setting yourself a fitness goal and asking for sponsorship to spur you on? It could be a 'Couch to 5k', a half-marathon, or perhaps swimming a mile or two. Got a habit you want to kick? How about giving up alcohol or chocolate for a month? Ask people to sponsor you for your willpower.

For more information about supporting the UA, and how we use the funds you raise, please visit *www.urostomyassociation.org.uk/category/support-our-work/*

Preparing for your **surgery**

Being told that you need to have your bladder removed and live life with a urinary diversion can feel frightening, and in the run-up to your operation you are bound to have lots of questions. The Urostomy Association is here for you, however you may be feeling, and we are here for your family too.

There's our helpline you can call, and we have lots of information, tips and resources on our website, where you'll also find inspirational, real-life stories from urostomates who are embracing life again.

If you'd like to speak to someone who knows from their own experience what it is like going through surgery and adapting to life weeing differently, we'll link you up with one of our trained 'buddies' for a chat over the phone, in person or online. Wherever possible, this will be someone who has the same type of urinary diversion that you are about to have.

You'll find our contact details at the end of this article.

Thinking ahead

As the day of your op draws closer, there'll be lots to think about, from what to pack for your hospital stay to arranging a lift home after you've been discharged. We've put together some practical tips to help make life a little easier at what can feel like a stressful time.

> *"... we'll link you up with one of our trained 'buddies' for a chat over the phone, in person or online."*

Top tips before your surgery

- Think what you'd like to eat when you return home from hospital. Then do your food shop, prepare some meals and pop them in your freezer.
- Set up a comfortable space at home for rest and relaxation. Make sure you'll have everything you need close to hand while you recuperate.
- Arrange transport to and from hospital.
- Remember to get prescriptions or over-the-counter supplies in advance.

- Let family and friends know you'll need their help and delegate household tasks for the first few weeks.
- Arrange for help with looking after your children or other loved ones, as well as your pets if need be.

- Arrange with your employer about the need for time off work and when you will talk about returning.
- Read the 'Pre op' information on our website (linked from home page).
- Meditation and mindfulness can be helpful if you're feeling anxious. The Royal College of Anaesthetists' website – *https://www.rcoa.ac.uk/patients* – has some resources you might find helpful.

What to pack for your hospital stay

- Nightclothes, dressing gown and slippers
- Underwear and socks
- Comfortable day clothes
- A hand towel
- Toiletries, such as toothpaste, soap, deodorant and shaving products
- Hairbrush or comb
- Sanitary products
- Books and magazines
- Chargers for your phone and tablet
- Headphones to listen to music or films on your devices
- Glasses and contact lenses
- Eye mask and earplugs, if you find these help you sleep

No-one knows what to pack better than someone who has already been through surgery for a urinary diversion. Gill Thomas, a member of our Cambridge branch, said: “The best advice given to me was to have a long phone charger, as the power supply is likely to be a long way from the bed. And you will need a few toiletries, including something to freshen your face. I wore a hospital gown, so didn’t need a nightdress.

“It’s a good idea to wear into hospital something that’s loose and comfortable, as you’ll need those to go home in. Your abdomen will feel very different when you go home from when you went in.”

Thank you for your tips, Gill!

What to have for **when you return home**

- The urostomy supplies you need. Your stoma nurse will advise you on how to get your prescription filled
- A mattress protector (see the Directory of suppliers on our website)
- Good lighting in the bathroom for bag changes

- A list of all the phone numbers you might need, for your stoma or district nurse, for example.

Get in touch

UA helpline: 01223 910854
Email: info@urostomyassociation.org.uk
www.urostomyassociation.org.uk

Swimming with a urostomy

Summer may be a distant memory, but enjoying time in the water doesn't have to be! Swimming is a fantastic way to stay fit and it's not off limits just because you live with a bag. Your pouching system is water resistant and designed not to leak with the proper seal, and water will not harm or enter your stoma.

Most people are advised to wait until six weeks after their stoma surgery before swimming again, but do check with your stoma nurse before starting. To prevent infection, it is important that any wounds are dry and intact before swimming.

Our top tips will help you feel as confident as possible in the sea or the pool.

Preparing for your swim

- Check your bag for any signs of wear and tear and replace it if necessary.
- Rest assured that your bag is unlikely to come loose in the water. It's easy to prove this to yourself by lying in a full bathtub for a while to test and ensure that the seal stays snug and leak-free.
- Empty your bag before you go swimming. An empty bag is flatter and therefore more discreet under your swimsuit. It may also prevent interrupting your swim and reduce the chance of a leak.
- Swimming with a urostomy should feel good, whatever you choose to wear in the water. See 'swimwear options' (right).
- It's natural to worry that others will stare, but the truth is that most people will not even notice the colour of your swimsuit, let alone what is underneath it.
- If you're concerned about changing in front of people, try to find a swimming pool that has private changing rooms. Alternatively, you could use the disabled facilities. These often include a toilet as well as providing a larger space for changing, or you can change at home and wear clothes over your swimsuit.
- When you get out of the water your stoma bag is going to be really wet, but it should maintain its seal. Towel dry it or change it if you can.

Swimwear options

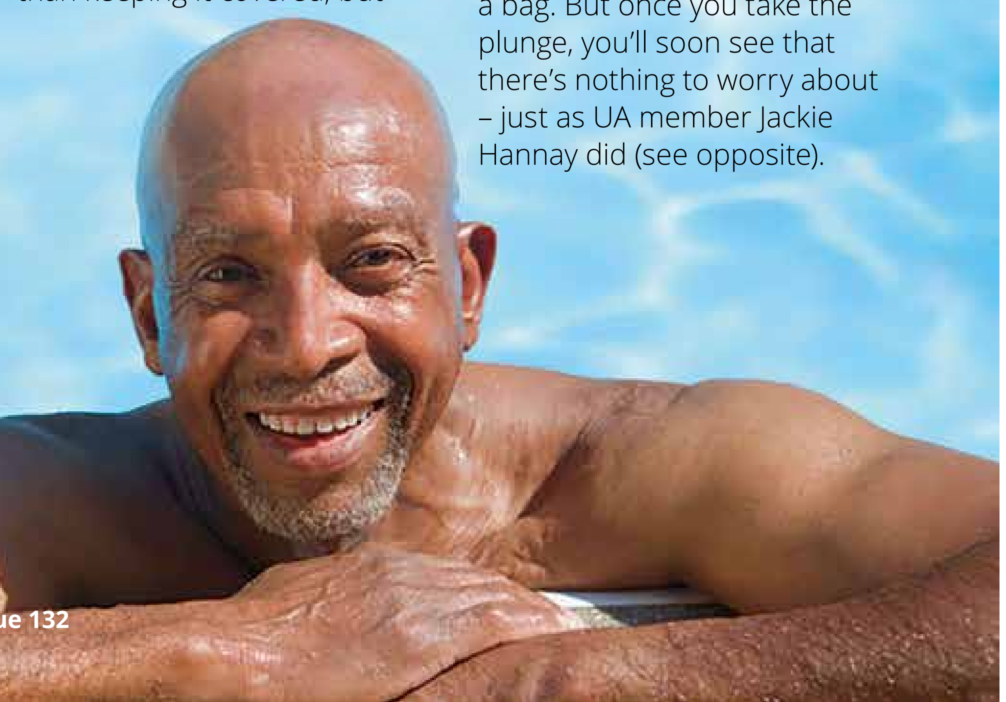
Some urostomates are happy letting their bag show rather than keeping it covered, but it's a case of what makes you feel most at ease.

For women seeking discretion, there are swimsuits and tankinis with high-waisted shorts. Opting for a swimsuit with a pattern rather than a plain colour might also help, as the patterns can divert attention and prevent the outline of the bag from being noticeable. Some women choose to wear a sarong over their swimsuit.

An option for men is to wear Lycra cycling shorts underneath swimming trunks. They come up a bit higher and secure the bag tightly.

There are companies that supply swimwear specially designed for ostomates. See our 'Directory of suppliers' leaflet, search 'ostomy swimwear' online or talk to your stoma nurse, who will be able to advise you.

It may feel strange the first time you go swimming with a bag. But once you take the plunge, you'll soon see that there's nothing to worry about – just as UA member Jackie Hannay did (see opposite).



> *"Swimming felt just like before my operation, with the same freedom of movement in the water."*

Taking the plunge

Urostomate Jackie Hannay, 64, is passionate about swimming. Having survived bladder cancer, she found herself longing to get back in the water, but first, she had to overcome her fear and embarrassment of swimming with a urostomy.

Jackie, who lives in Lewes, Sussex, said: "Once I started feeling more confident about traveling with a stoma, I was desperate to swim but I had concerns. I was worried I couldn't swim as I had before, and that if others saw my stoma, it would cause embarrassment for them as well as myself.

"I found myself putting up barriers. What would happen if the bag got detached, or became too heavy? How would I empty it? How would I get changed after swimming? And what would happen if I was kicked by another swimmer? But once I'd taken my first swim in the local baths, all my concerns became more manageable.

"Swimming felt just like before my operation, with the same freedom of movement in the water. No-one seemed to notice my stoma, and my bag stayed firmly in place. I find swimming first thing in the morning best as the bag fills more slowly, and I always use the facilities before getting into the water. I have never been kicked, although I am careful to make sure there is adequate room when passing other swimmers.

"My confidence has grown, and I now swim two or three times a week. I resumed my SwimTrek holidays, and this year completed my dream one in the Maldives. When I experienced a leak, one of the other swimmers - a doctor - provided me with additional tape that successfully secured my bag during long swims and overnight.

"For long swims I wear a shorty wetsuit with a front zip, which supports my stoma and is easy to remove when required. I empty my bag at various points when we stop on rocks or in other bays, and the support boats have facilities.

"The future feels bright. I run, walk and cycle, but most of all I love my morning swims in the Pells Pool in Lewes, appreciating the crystal-clear crispness of the water and the early morning smiles of fellow swimmers.

There and back, I cycle past the birds and the ducks and am ever grateful for the experience."

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 expert' 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: ***www.urostomyassociation.org.uk.***

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

NEWS FROM OUR BRANCHES

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

Cambridge

Venue: Cambridge Cancer Help Centre, Scotsdales Garden Centre,120 Cambridge Rd, Shelford, CB22 5JT

Branch Secretary:
Jane Phillips

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

We had a fantastic turnout at our November meeting. Bobby from Dansac was a little taken aback by how many people were there, but I hope those who needed it got some good advice from his talk. It was good to see UA's Transformation Director Samantha too, and she showed us the information packs that the branch has helped to fund for new urostomates. Our prize draw takings were a whopping £84, so the branch benefited by £42 and the owner of the winning ticket took home the same.

The main topic of discussion aside from above was the Christmas Lunch that Margaret and Elaine have been busy organising - Margaret has sent a message on the WhatsApp group, and I will send a separate email to those not in the group to save duplicating everything. We are all looking forward to what is always an enjoyable event.

The next monthly meeting will be the Branch AGM (see Dairy dates, below). Suffice to say that once the AGM is finished, there will be plenty of time for our usual social chatting.

Finally, many of you will know David Farr - he and his partner, Rowena, have been active members of the Cambridge Branch for around seven years but he has now made a complete move to Cumbria. He has asked me to pass on his goodbyes and says that if he is ever in Cambridge on the day of a meeting he will pop in to see us.

Looking forward to seeing you all soon.

Jane Phillips

DIARY DATES

***Tuesday 3 December AGM** and **Christmas lunch**. We hope to have a physiotherapist as our guest speaker in February. Please get in touch for details.*

Lothian & Fife

Established at the request of member Anne Haston some nine years ago, our Lothian & Fife branch flourished, with good attendance at our meetings at the Western General Hospital. Now though, with the hospital having made changes to its facilities-for-hire policy, and parking charges rising, the venue is no longer a viable place for us to meet. The alternative venue we found has proved very expensive, and the last time we contacted members, we received just four replies to attend.

It is with regret, therefore, that we have now closed the branch. I know that this may come as a disappointment to some of you, but I hope that you will choose to remain a valued part of our wider UA community. You will continue to receive the Journal and our regular e-updates, as well as invitations to our online events, including our popular, expert-led webinars.

A special thank-you to Rhona McLaughlin, our Branch Secretary from the start, whose kindness and hard work have been so appreciated. I also want to thank branch members for all your support over the years, and if you have any stoma-related queries or concerns, please don't hesitate to get in touch via the Association's helpline: 01223 910854.

Brian Fretwell
Chairman
Urostomy Association

Newcastle

Venue: The Freeman Hospital, Newcastle-upon-Tyne

Branch Secretary:
Eileen Spraggon

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

We held our AGM on 21 September. Our Chair Ann Collins welcomed everyone, and we then heard from guest speaker Nikki Baker of Eakin Healthcare.

Nikki explained that Eakin now has a range of product companies – including Pelican and Respond – under its umbrella. As well as sharing news about product innovation, Nikki also told us the story behind the Eakin seal, which was developed 50 years ago and named after the man who created it for his daughter after identifying her need for a product that improved adhesion.

The UA's Chairman Brian Fretwell gave his update about what is happening nationally, and told us about the growing number of resources available on the Association's website, from leaflets to webinars.

Moving on to branch business, Ann stated that committee members were standing down due to ill health and other reasons. Both Ann and Branch President, Professor Harding, stressed the importance of the continuation of the branch, with several members sharing their own experiences of how much it meant to them having face-to-face contact with other urostomates, especially during difficult times.

Brian offered to take up the role of Branch Chair if needed and explained that the duties of Treasurer could be assigned to the UA's head office.

In recognition of their sterling service as volunteers, Ann Collins and Ivy Blakey were awarded honorary membership of the UA. They were each presented with a framed certificate and a bouquet of flowers.

I was delighted to receive a bouquet presented to me in recognition of my dedication and service to the branch, having set it up over 50 years ago.

Eileen Spraggon

Sheffield & District

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

Branch Secretary:
Mary Milner

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

At our summer meeting, we welcomed 44 members and guests. We were especially pleased to welcome Samantha Sherratt, the UA's Transformation Director, alongside new people attending for the first time. Several appliance and delivery companies had stands, and our members were able to have a chat with their representatives. We are always grateful to the reps for coming along to support our meetings, especially on a Saturday afternoon. Our raffle raised £106 and the craft stall £69 for branch funds.

Following our business meeting, Samantha gave her presentation, briefly outlining her career within the charitable and health sectors and then giving an interesting insight into the running of the UA, plus latest developments and plans for the future.

On behalf of our members, our Chairman Martyn Oxley thanked Samantha for coming to our meeting and giving such an informative and helpful presentation. Eleanor Milner then presented Samantha with a cheque for £250 for

UA funds. The sum was from royalties from sales of Eleanor's book, '98.4° - 37°C, the Memoirs of Eleanor Milner', which in part outlines her daughter's journey of urostomy surgery in the 1970s.

After refreshments and a selection of delicious cakes, our meeting closed with the drawing of our raffle.

We held our annual John Topham Lunch on 2 November, and it was lovely to see so many faces, both new and familiar. Following lunch, we held our branch AGM and election of officers and committee for the coming year. I think we all appreciated the opportunity to meet up, and we are looking forward to our meetings in 2025 after the winter break.

Mary Milner

Yorkshire & Humberside

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

Branch Secretary: David Legood

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

To attract more members, we held a social gathering at Garforth Golf Club in Leeds in July. It was successful, with more than 30 people attending, some of whom were members we had never met face to face. After a brief introduction from our Chairman Wil Andrews, we talked among ourselves, chatted with stoma care nurses, and spoke to company reps to get advice and find out about their products.

Special thanks to branch and Garforth Golf Club member Neil Robinson, and the Golf Club Manager. We are also very grateful to Lou from Dansac, who sponsored our refreshments, Karen from Coloplast, and last but not least, the stoma nurses from both Leeds Teaching Hospitals NHS Trust and Mid Yorkshire Teaching NHS Trust.

At our AGM in August, voting took place to ratify the appointment of our Branch Officers and our Committee, which resulted in Wil officially taking up the position of Chairman. For those who don't know him, Wil is pictured - along with his wife Sue - on the front cover of the UA's Summer Journal.

Wil explained that one of his key objectives is to improve the two-way relationship between our branch and the stoma nurses at our regional hospitals. As a result, three of our members will be giving a presentation about travelling abroad with a urostomy at the Patient Wellbeing Day organised by the Mid Yorkshire Teaching NHS Trust.

Representatives from our branch have attended open days at Scarborough, Leeds, Preston, Huddersfield and York Hospitals, raising our profile and boosting our member numbers.

> *"Following the success of our 'Urostomeet' gathering at Garforth Golf Club, we will be holding a second."*

Following the success of our 'Urostomeet' gathering at Garforth Golf Club, we will be holding a second – please see 'Dairy dates' (below). Our thanks to the Golf Club for hosting our event and to Dansac, Hollister and Fittleworth for sponsoring guest speaker Gill Castle, the first ostomate to swim the Channel. We are also grateful to Coloplast for kindly sponsoring the refreshments. Do come along if you can. There will be an opportunity to speak to the stoma nurses and company reps joining us, and we'll have some mince pies too!

David Legood

DIARY DATES

***Tuesday 10 December, 1.30 - 3.30 pm**, social gathering at Garforth Golf Club, Leeds.*

Gloucester & District news

Our October meeting coincided with the Covid/flu vaccination session held at the same venue, Churchdown Community Centre, so it was certainly 'game on' to find a parking space, but thankfully we had a good turnout.

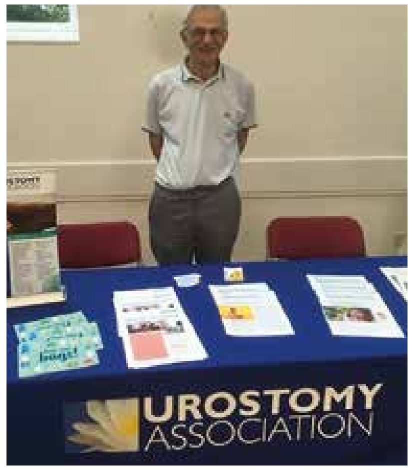
We were joined by the UA's Transformation Director Samantha Sherratt, who brought us up to date with national news and developments. Two representatives from Hollister joined us too, displaying their products and explaining new initiatives.

If you are interested in finding out more about our group, please contact me via ***urostomysupport5000@icloud.com.***

Val Gully

London & Surrey news

Our most recent gathering was a social lunch in late September. Numbers included both new urostomates and those with many years' experience, which enabled us to have a wide-ranging discussion useful for both new and old hands.



We are planning a visit to the Royal Surrey Hospital, Guildford, to see a surgical robot of the sort now routinely used for urostomy operations. Further information about this guided tour will be sent to our members when arrangements have been finalised. In the meantime, anyone wanting information on other local UA matters is welcome to email me via brianglicksman@gmail.com or to contact me by telephone on 020 8642 1899.

Earlier in September, I represented the UA at a stoma event at Frimley Park Hospital. I made contact with four new urostomates, two of whom joined us for our lunch the following week.

I wish all Journal readers a happy and healthy Christmas and New Year.

Brian Glicksman

Northern Ireland news

The Northern Ireland Support Group continues to grow, both in terms of participants and volunteers. Our regular meetings enable urostomates to share their experiences and exchange useful advice. But foremost, they are immensely enjoyable social occasions where conversation ranges far and wide and where new friends are made. Our most recent get-together attracted 23 people and ran well beyond the allotted time.

We are extremely grateful to the many organisations who provide us with meeting venues, some free of charge and some at very little cost, and to all those who help or sponsor us in other ways. One charity that has been particularly welcoming is Macmillan Cancer Support, which regularly lets us use its space at Belfast City Hospital for our meet-ups.

If you'd like to find out more about our group, please get in touch with me via *donna.watson@urostomyassociation.org.uk*. Meanwhile, the UA continues to be represented by a volunteer on the Northern Ireland Consumer Council's Accessibility Forum, giving us a voice on issues such as special assistance for passengers with disabilities or reduced mobility who use Northern Ireland's airports.

Donna Watson

The **importance** of making your will and **keeping it up to date**

willPOWER

Many of us put off making a will. In fact, it's estimated that only four in ten adults in the UK have made theirs. But putting a will in place is important for many reasons, and doesn't have to be time-consuming, complicated or expensive.

Having an official record of your wishes for after you die is the only way of ensuring your family – including any dependents – are provided for the way you want them to be after you've gone. If you die without a will, a court will appoint administrators to deal with the distribution of everything you own, which may not match up with your wishes.

Making your will also saves the people you love time, stress and paperwork when it matters most. It is one of the kindest things you can do for them, and knowing you've done what you need to for their future can bring you peace of mind.

Leaving a will is important because you can:

- ensure your family and friends are looked after financially
- reduce the complexity of administering your estate
- make sure arrangements for your funeral, and other wishes, will be respected
- leave a gift to charity, reducing the inheritance tax your family pays
- name an executor, someone you trust, to deal with your affairs
- ensure sentimental items can be distributed according to your wishes

Remember to keep your will up to date

It's crucial to revise your will whenever your personal circumstances change. For example, if you get married or divorced, have children, purchase a property or start a business, or if your partner dies.

Never write on your will, as that would invalidate it. If you are making major changes, you might need to write a new will. If you're making minor additions, you can use a separate document, called a codicil, which must be signed and witnessed in the presence of two independent witnesses. You should store your codicil with your will.

Making or updating your will needn't be complicated

You don't have to spend lots of time and money to make your will. The handy downloadable Gifts in Wills pack on our website has all the jargon-free information you need to get started.

What's more, with our trusted partner Octopus Legacy you can create your will free of charge – just use the code UROSTOMYFREE to qualify.

Octopus Legacy specialises in making these arrangements as straightforward and stress-free as possible, providing their service face-to-face, online or over the telephone.

Your gift of kindness for anxious urostomates

Creating or updating your will is also a time when you can choose to make a gift, big or small, to a charity close to your heart. For the Urostomy Association, it is gifts in wills that help us plan for the future, so that we can continue reassuring and supporting anxious urostomates for many years to come.

Once you've made provision for the family and friends who mean so much to you, we hope you might kindly consider leaving a legacy gift to our charity. In doing so, you'll make a lasting impact on the lives of people who might otherwise struggle without the trusted support we provide for them for as long as they need it.

Each gift we receive helps us do more for those who need us, listening when they need to talk, providing them with helpful resources and training more volunteers to give vital one-to-one support.

Thank you for keeping the Urostomy Association and all those who need us close to your heart.

UROSTOMY
ASSOCIATION
Incorporating all types of urinary diversion

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

To join the Urostomy Association, simply complete the form opposite and post it to us or go online:

www.urostomyassociation.org.uk/join-now.

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

Join the UROSTOMY ASSOCIATION

SIDE 2 OF 2

How did you hear about us?

☐ Nurse/GP/Other healthcare professional ☐ Advert ☐ Open day ☐ Facebook

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

How to receive our news

As part of our community, you'll receive our popular magazine, The Journal, three times a year and, if you leave us your email address, we'll email you our monthly e-updates. Choosing to receive our communications by email saves our small charity money, as well as being kinder to the planet. Please tick the relevant boxes below to indicate how you want to be contacted.

☐ Journal by post ☐ Journal by email ☐ e-newsletter

We'll also post you updates every now and again on our news, events, fundraising and campaigns.

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, group meetings, social media and fact sheets. Thanks to donors, we can also increase awareness across healthcare and the general public, and influence urostomy policy and practice. Will you make a donation today? Simply visit *www.urostomyassociation.org.uk/shop/donate.*

Thank you!

Scan to donate
online or call
01223 910854

Please post your completed form to:
Urostomy Association, Office 205, No 9 Journey Campus,
Castle Park, Cambridge, CB3 0AX.

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

200+ CLUB PRIZE DRAW

Be in it to win it and support the UA too!

*Right: **Carolyn Swash** and **Maddie White** from the Association of Stoma Care Nurses (ASCN) draw the winning numbers at the international conference held jointly by the ASCN and The World Council of Enterostomal Therapists in September*

Latest WINNERS

Draw date: **1 October 2024**

1st prize	**£250**	No 115	**David S**
2nd prize	**£150**	No 275	**Carole C**
3rd prize	**£100**	No 260	**Anthony S**
4th prize	**£75**	No 66	**Leslie B**
5th prize	**£50**	No 144	**Robert D**

Did you know that together, 200+ Club prize draw subscribers raise more than £3,000 a year to help the Urostomy Association continue its trusted support for people living with a urinary diversion? That's incredible!

By playing, you can do great things! With your support we can bring support and reassurance for people considering a urinary diversion, as well as those living life to the full post surgery.

We hope you will take great pride in the important difference your support will make.

Water SURE

Do you know about the WaterSure scheme?

WaterSure helps some people with their water bills. To be eligible, you – or someone in your household – must be in receipt of benefits and need to use a lot of water for medical reasons. You also need to be on a water meter or be waiting to have one installed.

Your bill will be capped so you will not pay any more than the average metered bill for the area your water company covers.

For details, get in touch with your water company.

Priority services register

If you have a urostomy, it's worth talking to your water company about getting on the 'priority services register'. This means that if your water is cut off (if there is a leak, for example) you'll receive bottled water, rather than you having to fetch it.

UROSTOMY ASSOCIATION Merchandise

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

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

Lanyard £2.50 ***Badge £1.75***

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

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

Official Radar key £3.50

All prices include p&p within the UK

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

Please send me:

☐ ***Sunflower lanyard*** *Quantity* ________

☐ ***Sunflower badge*** *Quantity* ________

☐ ***Radar key*** *Quantity* ________

Title: First name: Last name:

Address:

Postcode:

Email: Tel:

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

UROSTOMY ASSOCIATION

SIDE 1 OF 2

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

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

Thank you for your kindness.

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

1 Your donation

I would like to give a single gift of: ☐ **£20** ☐ **£50** ☐ **£150**

OR other amount £

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

☐ I would like to donate by debit/credit card

Card no: *(Maestro only)*

Expiry date CVV number* *Maestro issue no:*

Signature: Date:

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

2 Your details

Title: First name: Last name:

Address:

Postcode:

Email: Tel:

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

☐ Email ☐ Phone ☐ SMS

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

3 Increase your gift with Gift Aid

Signature: Date:

☐ I am a UK tax payer

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

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

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

Registered with FUNDRAISING REGULATOR

Please return this form to:

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

Thank you!

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

UROSTOMY
ASSOCIATION

SIDE 2 OF 2

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

Thank you so much for your kindness.

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

1 Your donation

I would like to give a monthly gift of: ☐ **£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.

Card no: *(Maestro only)*

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐

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

Signature: Date:

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

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