

journal

WALKING BACK TO BEING ME

GARY'S STORY OF MORE
HOPE AND BETTER HEALTH,
ON AND OFF THE PITCH

SEE PAGE 12



Welcome to the Winter Journal



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Paola Simoneschi
Editor

Contributions to the Journal are always welcome. Please send your letters, stories and articles for the spring edition to editor@urostomyassociation.org.uk by **15 February 2024**. Your contributions should be submitted as Word documents and any related images as jpegs, please.

If you do not have access to a computer, please get in touch by post:

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Chipping Campden,
GL55 6UG.

I've really enjoyed editing this winter edition of the Journal, in which we welcome UA's recently appointed Transformation Director Samantha Sherratt, who joined as our charity's new leader on 6 November. Read about Samantha, and what it is about our community that has so captured her interest and enthusiasm, on page 8.

On page 20 we reflect on how far the Association has come during 21 years' service given by Hazel Pixley, first as National Secretary and then as CEO, and what has been achieved. Our article includes messages of thanks and good wishes to Hazel as she leaves UA to embark on her next chapter. I would like to add my own personal thanks to Hazel for being super to work alongside and for the faith she has shown in me.

It takes courage to share your story, but this can do so much to dispel myths and reassure people facing surgery or adjusting to their 'new normal'. Thank you to Gary Layzell for being so open about his experience (page 12) to help bring hope to anyone who might be struggling. And for introducing us to the power and joys of walking football!

Thank you to Christine Houghton, too, for sharing her 'travelogue' (page 30) transporting us to sunnier climes and showing that, with the right advice and support, holidaying abroad needn't feel daunting with a urostomy or other type of urinary diversion.

UA is all about being stronger together, whether that's uniting as one voice to lobby for positive changes to make life better for urostomates, swapping information and tips, or supporting each other through difficult times. **Wherever you are on your journey, please remember you are not alone.** The Urostomy Association is here to help you every step of the way and we are just a phone call or a click away.

Warm winter wishes

Paola Simoneschi
Editor

PS Don't forget it is free of charge to join the Association – please see page 48 for details.

We want to hear your stories – please keep them coming!

Issue 129 _____ Winter Edition



A very big thank you to everyone who has contributed to this edition of the Journal

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UA Journal

The UA Journal is published three times a year. The views expressed by contributors are not necessarily those of the editor or the Urostomy Association. Great care has been taken to ensure accuracy but the UA does not accept responsibility for errors or omissions.

Photo credits

Thank you to members who have contributed photographs for this edition. All other images throughout the magazine are courtesy of Pexels.

Disclaimer

Any product displayed, described, demonstrated or distributed by samples, either by our officers or members at meetings or any product recommended by a member of UA does not constitute an endorsement of the product or services by the Urostomy Association.



FREE Recorded Journal available

A recorded version of this Journal is available **free of charge** for the partially sighted and blind. Those members who have a problem holding the Journal may also benefit from this service.

For details please contact National Office.

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 It's free of charge and we'd love to welcome you!

We are the national charity providing information and support for people with – or about to have – a urostomy or other form of urinary diversion.

Together with our members and other supporters, we are a welcoming community for everyone who needs us before, during and after surgery, helping them live their best lives. We are here for their families and carers, too.

Our community

Joining the Association is free of charge, making our services accessible to everyone who needs them, regardless of their financial circumstances. As a small charity we can only do this thanks to the support we receive through donations, fundraising and corporate sponsorship.

Our joining form is on page 49 together with information about how to make a donation if you can afford to do so. If you'd prefer to join the Association via our website, please go to www.urostomyassociation.org.uk/join-now. We look forward to welcoming you!

One-to-one support

Our members are at the heart of everything we do. Among them are our volunteers who draw on their own lived experience, kindly giving some of their time to support people who, whether newly diagnosed or further along in their journey, are in need of a listening ear and reassurance that can help them return to a normal way of living as smoothly as possible.

This is what our peer-to-peer scheme is all about, linking up those looking for encouragement and support with our volunteers who understand what they are going through and the challenges they face because they have been there themselves. Our trained peer support volunteers are invaluable, providing support over the telephone and sometimes in person, too, including during hospital visits.

Board of Trustees (National Executive Committee)

The Association is administered by a Board of Trustees (National Executive Committee), who are volunteers. The board meets at least four times a year.

Local branches

We have a small number of local branches around the country, where some of our members get together socially. Sometimes, guest speakers are invited, covering both medical and non-medical topics of interest. See page 38 for branch details.

Find out more

On our website at www.urostomyassociation.org.uk you'll find information to help you at every stage, from diagnosis and surgery to adapting to life as normal. It's also where you can find out more about fundraising and volunteering as well as keep up to date with our latest news and events.

The Association can be reached by calling **01386 430140** or sending an email to info@urostomyassociation.org.uk

ALL MEMBERS OF THE NEC,
APART FROM THE CEO, ARE
VOLUNTEERS AND UNPAID

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Stomas in Parliament

Our Chair of Trustees Brian Fretwell has been clocking up more miles on behalf of our community of people, who – like him - live with a urostomy.

In early October Brian, who is a member of the Scottish Stoma Forum, travelled to Edinburgh to join others walking up local landmark Arthur's Seat to highlight five calls to action to improve stoma care services in Scotland. The same day, Brian attended the Scottish Parliament debate at which Sir Edward Mountain, MSP for Highlands and Islands, reiterated the five calls. Leading the debate, Sir Edward drew on his own experience of having a temporary stoma (now reversed) to advocate for the estimated 20,000 people in Scotland living with a stoma.

Brian said: "After the debate, I attended a reception for more than 100 people, where stoma patients and members of the

Scottish Stoma Forum mingled with nurses and representatives of stoma product manufacturers and delivery companies. Many useful conversations were had and contacts made."

Alongside Brian to hear the speeches from Edward Mountain MSP, Kevin Hodges of the Scottish Stoma Forum, First Minister Humza Yousaf and stoma patients was Secretary of UA's Lothian and Fife branch, Rhona McLaughlin. Brian said: "All five calls to action were noted by Scottish Members of Parliament, who have agreed to address and promote them – a fantastic step forward that will help bring positive change for everyone in Scotland who is living with a stoma."

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.

The Scottish Parliament Building at Holyrood

Evolution, not revolution

Following our rigorous recruitment process to find the person who will lead the Urostomy Association into its exciting next chapter, we are delighted to announce the appointment of Samantha Sherratt.

Samantha, who lives in Cambridge, took up her new role on 6 November. She brings with her a wealth of experience from a long career spent predominantly in the voluntary sector, during which time she has held senior management positions in small charities as well as in much larger organisations. Most recently, Samantha has been Interim CEO of Raise, West Hertfordshire Hospitals Charity, where she worked with trustees to devise and implement a new transformation programme, putting in place the foundations needed for Raise's growth.

Previous employers also include education charity Red Balloon, where Samantha was Director of Fundraising and Communications, and Addenbrooke's Charitable Trust, where – as Head of Supporter Engagement – she oversaw its individual giving programme, managing a team that, in her last year, secured £2.7million to support innovation in patient care across Cambridge University Hospitals NHS Foundation Trust.

Brian Fretwell, UA's Chair of Trustees, said: "During our recruitment process, which included using an agency specialising in senior-level appointments in the charity sector, Samantha shone out amongst a very strong field. Not only does she have the charity leadership and transformation experience the Association needs to take us forward, she has very clear empathy for those we support. Her passion for driving forward

positive change that helps improve people's quality of life comes across very strongly, as does her business acumen.

"My fellow trustees and I are looking forward to working with Samantha, building on what the Association has already achieved with Hazel Pixley as CEO so that our organisation, and the community we support, go from strength to strength."

Samantha said: "I'm delighted to have joined UA, working closely with the Board to lead the charity towards its exciting vision.

"When I read the job advertisement the role felt very 'me', and in doing further research I was struck by the solid history of the Association and its obvious warmth and care for its members. Similarly, members are clearly very supportive of each other. While I do not have lived experience of a urinary diversion, having a family history of bowel conditions means I know how important it is to find a source of support that speaks your language without embarrassment.

"Thanks to Hazel and the Board's obvious dedication and hard work, UA has strong foundations. I am very much looking forward to getting to know members to find out more about what matters most to them, their families and the professionals who support them."



A message from our Chair of Trustees Brian Fretwell, and National President Professor Derek Rosario

By the time this Journal is published, Samantha will be a couple of weeks into her full-time role, discovering more about us and all our stakeholders, most importantly our members and their families, as well as our wider community

of healthcare professionals, stoma product companies and fellow charities. This will inform her work with the Board, continuing the transformation of the Association so that it has the profile and resilience needed to succeed in this tough economic climate and thrive as the 'go to' national charity for people with a urostomy or other type of urinary diversion.

With member numbers declining and a continuing financial deficit year on year, transformation is essential to keep the Association moving forward. This said, we recognise that times of change can feel unsettling and we acknowledge the concerns some of you have expressed, including in relation to the services UA provides.



That's why we are re-stating here the Board's firm commitment to continuing these services so that everyone in need of information, support and reassurance can access it free of charge regardless of their financial circumstances.

It's important to say that what we are talking about is evolution, not revolution. In fact, we plan to both increase and enhance what UA offers. We will do this by growing our charity's network of trained volunteers who kindly give their time and skills to support people online, over the telephone and in person, and by further embracing technology to offer webinars, videos and 'ask the expert' sessions.

Providing a first-class service remains our top priority, and in Samantha, we are confident we have a Transformation Director with a strong record of managing organisational change as well as generating income to support key projects.

"Samantha shone out amongst a very strong field. Not only does she have the charity leadership and transformation experience the Association needs to take us forward, she has very clear empathy for those we support."

We are looking forward to her input, and she will receive our full support to achieve what needs to be done to make our charity more visible, accessible and sustainable for the long term.

Through UA Voices, members and friends have the opportunity for greater influence on the way the Association is run and the services we deliver. There is still time to apply to join our UA Voices group, so please don't miss this opportunity. You can find further details on our website at www.urostomyassociation.org.uk/ua-voices-have-your-say. Alternatively, please call the Association on 01386 430140. The deadline for applications is 31 January 2024.

Next steps

Once Samantha has settled into her role as Transformation Director, we'll be holding a webinar giving you the opportunity to meet her, hear more about our plans and ask any questions. Please keep an eye out for our next newsletter for details.

In the meantime, thank you for your continued support. It's this that enables us to be the trusted friend people need as they contemplate surgery and adjust to life afterwards, as well as continuing our lobbying for high-quality, joined-up care for people with a urinary diversion, wherever they live in the UK.

We have much work to do to ensure the Association fulfils its exciting potential, and with your ongoing support we remain confident of getting there.

"I am very much looking forward to getting to know members to find out more about what matters most to them, their families and the professionals who support them."



“With coverage on the BBC and Channel 4, as well as in many print publications, the campaign is gaining in profile and momentum”

Telling Westminster: Boys need Bins

In early September, UA's Chair of Trustees Brian Fretwell was at Westminster, representing our community at an event hosted by Prostate Cancer UK (PCUK) to tell MPs that Boys need Bins.



According to a recent PCUK survey, 95 per cent of men with continence issues experience anxiety because they might not be able to dispose of their incontinence pads or stoma products hygienically in an appropriate sanitary bin in a cubicle, when they go out. Worryingly too, around half of these men stated that they now reduce the amount of time they spend out of the house due to incontinence.

We've proudly joined forces with fellow charities and other organisations, including the British Toilet Association, to support the Boys need Bins campaign to help make things better for men and boys affected. At the Westminster event, sponsored by Stuart Andrew, MP for Pudsey, Horsforth and Aireborough, MPs heard firsthand from

men who shared candidly about how they're impacted.

Conversations were sparked and the campaign report was launched, highlighting three key areas where change needs to happen:

- Creating new legislation for the specific provision of at least one sanitary bin in male toilets.
- A national conversation about incontinence, pads, stoma bags and catheters, and how they impact men.
- Recognition by medical/healthcare professionals of the mental health and emotional support needs for men, as well as practical advice about managing incontinence.

Along with all our Boys need Bins partners, we won't stop lobbying until

“Along with all our Boys need Bins partners, we won't stop lobbying until these aims are met.”

these aims are met. Watch this space for further news. In the meantime, you can find more information about the campaign at www.prostatecanceruk.org/get-involved/campaigning/incontinence.

Thank you for your support!

ASCN 2023

Further developing the Association's relationship with health professionals involved in the care of people living with a urinary diversion is key for our charity, so that GPs, nurses and others are not only aware of our existence but feel confident referring their patients to us for ongoing support.



UA's Chair of Trustees Brian Fretwell (left) with ASCN Chair Andrew Bird.

In October, we were at the **Association of Stoma Care Nurses (ASCN) Annual Conference** in Brighton with our exhibition stand and literature, alongside other patient support organisations and stoma product suppliers and delivery companies, meeting stoma care nurses – familiar faces and plenty of new ones, too.

With more than 300 nurses in attendance, it was a very busy few days' networking for UA representatives Brian Fretwell, our Chair of Trustees, and Sharon Fillingham, UA's Nurse Advisor. Unfortunately, due to a wrist injury preventing her from travelling, CEO Hazel Pixley was unable to attend this year.

Between lectures and workshops, nurses visited our stand, gathering information about our services and contributing suggestions and ideas for ways we can work even more collaboratively with them for the benefit of patients.

There were rave reviews – including from ACSN Chair Andrew Bird - for our unique book, 'Bags, bags, bags', which helps adults explain their urostomy to young children. While some nurses had already received their copies from us, others were seeing it for the first time. Many also requested UA's information leaflets and gave their contact details for us to add to our growing database.

Over the course of the event, Brian also took the opportunity of talking with company representatives, renewing contacts and making new ones. He said: "The annual ASCN conference is a highlight in UA's calendar, giving us a fantastic opportunity to raise our profile with stoma care nurses, companies and fellow charities and to have conversations that help keep moving UA forward so that we continue to meet the needs of our community.

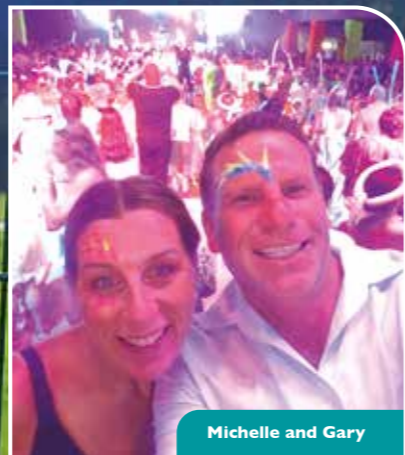
"Thank you to ASCN for providing our charity's exhibition space free of

charge. We are already looking forward to next year's conference in Glasgow, a joint event with the World Council of Enterostomal Therapists, a global leader in specialist ostomy, wound and continence care."

“The annual ASCN conference is a highlight in UA's calendar, giving us a fantastic opportunity to raise our profile with stoma care nurses, companies and fellow charities”

WALKING BACK TO BEING ME

Life was going so well. I was enjoying my work as a trainer/consultant supporting local authorities to deliver revenues and benefits services. I was big into my fitness and taking on whatever adrenaline-inducing challenge I could find. Travel was finally on the agenda as I had the time and money to be able to do that. Things were looking good, and I'd even started a new relationship with a beautiful lady, Michelle, who I'd met through work.



As always seemed to be the case with me, though, there was something not quite right that would spoil things. Michelle thought it odd how many times a day I went to the toilet, and despite telling her it was normal for me, I had noticed I was going a bit more often. It was only when one of my mates said, "If you go for a drink with Gaz, you might as well go on your own" it made me realise I needed to take action.

I'd put off going to the doctor longer than I should, thinking things would get back to normal, but it was the opposite. The GP diagnosed me with an enlarged prostate and prescribed medication that it turned out didn't work for me for reasons which later became obvious.

As 20 trips to the loo a day became 30, I went back and was given a new prescription, which I was told could take up to six months to become effective. I waited. By now I was losing weight, couldn't sleep for more than half an hour at a time and was reduced to tears with the pain at least twice a day.

Expected but unwelcome news

Covid was in full swing at this point, but I was desperate so pushed for another appointment. This was when my doctor was finally persuaded to send me for a cystoscopy (a procedure to look inside the bladder using a thin camera called a cystoscope). However, despite the screen flashing up images I'd feared from 'Dr Google', the nurse was unsure and wanted to see me again in a month's time.

It was on this next occasion it all started to become real. Just two weeks before Christmas 2020, I had the expected but unwelcome news... aggressive Stage 3 bladder cancer.

Despite the seriousness of the situation, I was in denial about what

“Just two weeks before Christmas 2020, I had the expected but unwelcome news... aggressive Stage 3 bladder cancer.”

it could mean. Plus, I felt frustrated at what I went through to get a diagnosis. I had all the classic symptoms but did not fit the profile - surely that type of thinking has to change?

The choice was stark: life-changing operation or chemo treatment with a 20 to 30 per cent chance of survival. With those odds and four children to think of, there was no option but to choose surgery. At that point though, I didn't take enough time to really prepare myself or get proper understanding of all the implications. Instead, I carried on as if nothing was happening.

I closed down to everyone, not wanting to be reliant on anyone as I'd lived independently for the past ten years and had people relying on me. I ended up isolating myself with my own thoughts and demons. I failed to do the things I'd spent a lifetime saying, and it had a devastating effect on my mental health. Looking back, I blame it on a mixture of the sleep deprivation and the desire to try to protect others from the pain and hurt I was feeling.

Surgical success, but mental isolation

The day of my operation came, 16th March 2021, in the midst of lockdown. Just four days before my 50th birthday I was given the gift of Little Sid the Stoma! I woke up from the operation in pain and with a dark sense of fear about the future.

The operation was hailed a success, and I was mobile again fairly quickly.

My initial physical recovery was going well and I'd even started a new job as an Exchequer Services Manager for a council in Derbyshire which provided a mix of home and office working. Mentally though, I was still blocking things and everyone else out. In the state I was in, I couldn't be 'me' and until I was that person again, I didn't feel worthy. Michelle was amazing, taking care of me to help with my physical rehabilitation, but inside I was screaming in pain. I told no-one, and the mental isolation I created for myself back then still haunts me.

Existing, not living

Six months on from my op, I hit a wall - my fitness levels were not increasing and I was so tired I needed a nap a couple of times a day. It felt like I would never be the person I was before, physically or mentally. My focus was just not there and my thoughts were not being processed rationally. I began to exist rather than live.

There was something else, too. The pump I was given for erectile dysfunction due to nerve damage wasn't

“In the state I was in, I couldn't be 'me' and until I was that person again, I didn't feel worthy.”

WALKING BACK TO BEING ME CONT.

working for me. I tried the pills, but no joy there either. Then came prescribed injections, but I'm in the 5 per cent of people who have an adverse reaction so find myself in the 'last chance saloon' of needing a pump fitted. I'm awaiting that operation, but it comes with no guarantee.

Michelle and I separated, and though we still have a great friendship, it is no substitute for a loving, intimate relationship. I'm scared that I'll never be able to find that again with my current physical condition. "Who will want that?" is what I keep asking myself. The thought of not finding that special someone just to walk and hold hands with feels out of reach because of my physical condition – a scary thought for a 52-year-old. Even though I am happy focussing on the main parts of my life, I can't help my mind wandering off into the future, a future that I don't want to spend alone.

Breaking the cycle

I needed something to help me break out of the cycle I was imposing on myself, and when – by chance – I spotted an ad for walking football, a spark was lit. Competitive sport,

especially football, has been part of my life since I was seven.

Meeting Elvis, who runs the walking football for the Nottingham Forest Community Trust, led to my first session with just four other players. I persevered – and a switch was flicked! Finally, I had a outlet and time in the week where things where not affected by the aftershocks of cancer. Playing was fun and good for me physically without being too intense.

Now, two to three times a week, I play sessions of mixed ability. While some on the pitch have reasonable fitness and power, others are older and simply want an hour's exercise. With both men and women and mixed abilities, it's by far the most inclusive sport I've been involved in.

Eight months on from joining the team, I've represented Nottingham Forest in a number of charity games raising thousands of pounds and played against other premier league representative sides, including Chelsea, Arsenal and Crystal Palace. I've achieved more in a few months of walking football than I did in 30-odd years of playing traditional football and so happy I got involved.



Gary with his England walking football teammates

“Finally, I had a outlet and time in the week where things where not affected by the aftershocks of cancer.”



Forest vs Chelsea

Three lions

Even better than playing with Forest, I was asked to play for an England representative side for heart attack and cancer survivors. At 52, I became an England International! I couldn't have been prouder to put on a shirt with the three lions emblazoned across my chest. A couple of days later, I was invited to talk about the sport on Notts TV, and in November I will be playing for England again against the Australian national team. Not quite Harry Kane levels but it

has been a great experience!

I highly recommend this fun sport to anyone looking for a lift mentally or physically. Not only does it benefit your mind, it's a great way to get the bulk of your 10,000 steps a day. It's helped me find the way back to the 'old' me, and even though I have a long way to go and need to open up more, walking football has set me on such a positive path.

With renewed vigour for travel, I've got a trip to the Norwegian fjords already planned and am not long back

from a holiday in Cape Verde with Michelle, where we went all out on the Ibiza revisited party night.

I think I have been to my darkest place that the cancer could have taken me, and it's now time to say finally say goodbye to my bladder and everything else I lost with it. Who would have thought walking and kicking a ball could be the catalyst for a positive shift in mental health?

Gary Layzell

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1 Understanding Urostomies report (n=178) EA-004979-RP

CHIEF EXECUTIVE'S **REPORT**



This is a very difficult report to write, as it is my last one as your Chief Executive Officer, before the existing National Office relocates* at the end of year. Please indulge me, therefore, as I take a look back at what has been achieved during my 21 years in office, initially as National Secretary before a title change to CEO a few years ago.

It all started when my predecessor, Angela Cooke, decided to retire. The role of National Secretary was advertised within the membership, and my husband Miles and I decided that I should apply. The recruitment process seemed to take forever, including a trip to London to give a presentation (no Powerpoint back then!).

On moving day, it became clear there was far more equipment/paperwork than we had been shown, and the whole the downstairs of our home was soon full of 'stuff', including at least 20 manual typewriters, a fax machine and a telephone answering machine (remember those?), plus a machine which we never did find out the purpose of. First call of the day was to our National Treasurer to ask permission to dispose of a lot of surplus and take on a storage unit, which we still have to this day.

As I was already a UA trustee, I had a good knowledge of the workings of the Association and knew some of the members, which really helped in the first few months. The first job was to create a database from the 2,000+ pieces of membership information. That database was still in use until the beginning of this year, when we moved over to a new one, so I must have done a reasonable job!

Moving with the times

During my time in office society has, of course, changed an awful lot, and the Association has worked hard to try to keep up with those changes, including becoming a company limited by guarantee, registering with the Office for Scottish Charity Regulation, the Fundraising Regulator, the Data Commissioner's Office and others. There is far more 'red tape' than there was when I joined. We also now have a bigger emphasis on safeguarding.

“As I was already a UA trustee, I had a good knowledge of the workings of the Association and knew some of the members, which really helped in the first few months.”

Once I got going, I started getting out and about. I have lost count of the number of visits I have made to branches over the years, along with meetings with manufacturers/ suppliers of our products, visits to Parliament, stoma care nurse conferences and all sorts of other representation. The National Secretary of the Ileostomy Association and I used to joke that our meetings were always held at airports and train stations, usually over breakfast or dinner – I remember once us still sitting talking to stoma care nurses at 2am.

The Annual Conference and Annual General Meeting took up a whole weekend, and a year to organise. They were great fun, with everybody on the dance floor on Saturday night. It was amazing watching past President Cliff Moisey and his wife Ruth network a whole room in a very short time. Unfortunately, as prices rose, numbers dropped and these events were making too much of a loss for us to continue.

At the beginning, I also had many visits to other countries in Europe, including Denmark, France and

CHIEF EXECUTIVE'S **REPORT** CONT.

Switzerland among others, sometimes to attend the European Ostomy Association conferences, and others at the invitation of companies.

Our celebrity golf days, hosted by Dennis Waterman, were great fundraisers, but also good fun too. Would the celebrities turn up, or would Don Haines need to telephone and get them out of bed?! Would I know who was a celebrity and who wasn't? Would the weather be kind? Again, most people had no idea how hard Don (as a volunteer) worked to organise these events – thanks, Don! I was seen out and about, and photographed, with Don for the Journal, so much that members thought we were married. I even started a talk at Shropshire Branch with the statement "I am not married to this man (photo of Don) but am married to this one (photograph of Miles)."

Supporting members

However, the main focus of the job for me has always been our members and potential members. When somebody telephones the office in a state of great anxiety at what is happening to them, there is nothing more satisfying than being able to reassure them that there is a 'normal' life out there to be had. When they realise they are talking to somebody who has a urostomy, but is working full time, travelling and continuing their hobbies, it is sometimes a real revelation. Our volunteers are also very important in this role, as I can put the person in touch with somebody with a similar story to them, so thank you all!

As National Office is based in our house, when we moved, so did you. Luckily, we have not moved around



much, and each time you have gained a larger office. In the last move, we didn't just move around our Uttoxeter estate, but instead to Gloucestershire as Miles changed employers. That move was a logistical nightmare, with house, office, storage unit and a pony all needing a new home, plus a new part-time colleague to find. But we got there in the end, with UA settled into the new top-floor office, and Dave, who lives literally just down the road, walking to work each day.

Then Covid hit, and things changed again. I continued to work, but Dave was not allowed into the house. At first he was furloughed, but when we were able to have part-furlough, he took his computer and some of the work home, although it wasn't ideal. Our meetings all went online (and most have stayed that way). Some branches embraced this, but others sadly closed and did not re-open. We now had to look at new ways of delivering our services and UA's Project 50+ was born, with Carmel joining us to project manage the new strategy, Rachel leading our fundraising, and Paola heading up communications, including the Journal.

“However, the main focus of the job for me has always been our members and potential members.”

To conclude

As I leave, I would like to thank everybody who has supported me over the last 20 years – all of our volunteers, colleagues past and present and my ever-patient husband, who has often been in the office late at night or at weekends trying to fix some technical issue, or spent his Christmas redecorating the office.

Also, colleagues in other charities, many of whom will remain friends I am sure, and the contacts made in the manufacturer/supplier companies.

I wish the Association every continuing success as Transformation Director Samantha Sherratt and other new colleagues take up their roles.

With best wishes to all our members/friends. I am sure that Dave/I will speak with some of you before we leave.

Hazel Pixley
Chief Executive Officer

**We will let you know the new National Office contact details as soon as we can, but the helpline and emails will be forwarded on, so please continue to use these.*

Best wishes to Dave

A familiar voice at the end of the UA telephone, Dave Page (below) has been our hardworking Administrative Officer since joining our charity in this part-time role in October 2018.

As he prepares to take retirement this December, we want to say a big thank-you to Dave for everything he has done to help keep the office running smoothly, working alongside CEO Hazel Pixley.

Said Hazel: "When Dave joined, I had been single handed for a while, so there was a large backlog of work, which he got stuck into immediately. He has taken a huge amount of work off my shoulders, and tackles whatever is given for us to do, including all of the mailings for AGMs, Journals, newsletters and so on.

"Dave has been an integral part of the National Office set up, and I couldn't have managed without him, particularly over the last year, when he has held the fort while I have been dealing with family bereavements. As he lives just down the road, and we pass his house when we go for a walk, I am sure my husband Miles and I will be keeping in touch with him and his wife Karen.

"Thank you, Dave, for your help and support. We all wish you a long and happy retirement."



Dave Page, UA's Admin Officer.



Gill rises to Channel challenge

Wow! We're in awe of ostomate Gill Castle, who in September became the first person with a stoma to swim the English Channel solo.

Forty-three-year-old Gill has a colostomy rather than a urostomy, having experienced complications during the birth of her son, in 2011. Following months of training, she took on the epic challenge of swimming the Channel from Dover to France, completing it in 14 hours.

Gill, who lives in Alnwick, Northumberland, said: "It was a big risk to do this swim with my stoma, but I did it to prove that anything is possible after ostomy surgery. I am proud to raise awareness of living an active life as an ostomate, and if I can swim the Channel then others need not worry about going to their local pool with their stoma bag. Where there are no secrets, there is no shame!"

Along the way, this brave and determined lady has raised a whopping £17,000 for Chameleon Buddies, the charity she founded to advocate for those struggling with lifechanging injuries following childbirth, in the UK and also in Kenya.

Congratulations to Gill on her fantastic achievement, which - with lots of media coverage, including on the BBC - has done much to raise awareness that living with a stoma does not need to hold you back from the activities you enjoy.

With our long-serving Chief Executive Hazel Pixley's time as leader of the Association coming to an end, former UA trustee Don Haines reflects on how far our charity has come with Hazel at the helm. Thank you to Don for writing this piece – and, of course, thank you so much to Hazel for all her dedication and hard work with and for our members throughout the years. You have done us proud!



“As well as representing the Association nationally and working closely with companies on initiatives to benefit patients, Hazel has always gone out of her way to help people through the various stages of their stoma journey, from pre-op to post surgery and sometimes for many years after their initial hospital visit. “On behalf of UA’s Board, I would like to thank Hazel for her dedication and all she has accomplished, and the sensitive way she has approached her role. I wish her well in the future and I hope she will continue to be involved with the Association in some way going forward.”

Brian Fretwell
Chair of Trustees

A BIG THANK-YOU FROM US ALL

“At the end of December, we’ll be saying farewell to CEO Hazel Pixley, who for the past 20-plus years has been responsible for upholding the ideals established in 1972 by our founder, Val Kings MBE. Val discovered that there was no UK national organisation in existence solely dedicated to the support of anyone with a urostomy, and she set about founding the charity that was to become the Urostomy Association. Fifty-one years later, UA remains the only such national organisation, anywhere in the world. “In 1992, Hazel took on the role of National Secretary of UA, having previously served as our Female Young Persons Adviser (husband Miles was the male equivalent), and she immediately set about building

upon the foundations laid by her predecessor, Angela Cooke. Over the past two decades, in an increasingly digital world, Hazel has been influential in helping UA confront the new challenges of the modern age, and has worked hard to ensure the Association has adapted accordingly. She has also ensured that our charity has complied with some increasingly complex legal requirements, not the least of which has been the need for UA and its branches to comply with the demands of data protection legislation. “The fundamental reason for UA’s existence is the facility for anyone with concerns about their urostomy, or other urinary diversion, to speak to someone who has the same condition, before or after surgery, to

obtain reassurance and confidence for their journey. Anyone calling our National Office for help with any aspect of their diversion will have found themselves talking to Hazel, who, if necessary, would then arrange for one of our volunteers to talk to, or even visit them. However, even this important function is just the tip of the iceberg, because Hazel has a myriad of other roles, in addition to the more obvious day-to-day administrative responsibilities. “Other regular tasks have included organising UA’s national annual general meetings, training volunteers, producing newsletters and writing faulty appliance reports, to name just a few. Integral to all of Hazel’s work over many years has been forging and maintaining important links with

the major UK manufacturers and suppliers of urostomy appliances, who have been supportive in so many ways, not least by regularly advertising in our magazine, thereby covering its production costs. “Equally important has been Hazel’s close involvement with the Association of Stoma Care Nurses, the British Association of Urology Nurses, and the British Healthcare Trades Association. Other work has included participation in lengthy government consultations, in England and separately in Scotland, where numerous efforts have been made to cut the costs to the NHS of providing appliances and ancillaries free of charge to all ostomates. “The very real threat to the choice of appliances available to

our members has been averted on more than one occasion, solely due to Hazel’s representations on behalf of UA. Another important part of Hazel’s job is working with a paid bookkeeper to ensure UA’s accounts are always in good order. Support of the Branches has always been vital, but many of them have closed due to lack of volunteers for the key roles, despite every effort by Hazel to keep them viable, and each closure has added to National Office workload. “All this and more has been successfully accomplished by Hazel with diligence and with an unrivalled professionalism, not to mention a high degree of patience on the part of both her and Miles, concerning the inevitable domestic disruptions

caused by running a charity from a home office. That same dedication was in evidence when the couple had to relocate when Miles was offered a new job – finding a new house that was big enough to accommodate the Urostomy Association national office was a priority. This dedication to duty has often made it difficult for Hazel to find time to get to her beloved fell pony Yorkie. “We owe Hazel an enormous debt of gratitude, and we will miss her, both on a personal and professional level. Good luck and best wishes to you Hazel, in whatever you decide to do next.” Don Haines
Honorary Lifetime Member

My name is Jose Caeiro and I have been a nurse since 2003, with a background mainly in urology. I live in Cambridge with my wife and two daughters. I joined Addenbrookes Hospital in 2014, where I became a Urology Nurse Specialist and Stoma Care Nurse. In 2022, I became a community Stoma Nurse in Cambridgeshire, working for Hollister.

While a Urology Specialist Nurse at Addenbrookes Hospital, I had the pleasure of working with the Cambridge Branch of the Urostomy Association (UA). I referred pre-operative patients to the organisation in order to put them in contact with established urostomy patients and provide them with the opportunity to getting to know the charity and its services for members.

Where possible, I have participated in the monthly meeting with members of the Cambridgeshire Branch, to provide support and guidance to members.

As leakage is a common concern for urostomates, I hope the following three simple steps will be helpful.



3 simple steps to preventing leakage

1 Find the right fit: The first step is to make sure you have a skin barrier that is the right size and fits well around your stoma. A flat skin barrier might seem like a good idea because it is likely the type of skin barrier on the pouching system you were using when you were discharged from hospital after surgery. However, if your skin barrier is leaking and/or your stoma is in a skin fold or crease, it can be more difficult to get the skin barrier to fit to the skin to help prevent leaks. You might need to consider a convex skin barrier – please see the information about convexity (below). Consult your Stoma Care Nurse about the possible use of a skin barrier with convexity, so that the right type is used in your situation.

Another thing to consider is that your stoma can change in size and shape over time, especially in the first six to eight weeks after surgery. Weight loss or gain can also impact the appearance of your stoma. It's ideal to measure your stoma every time you change your skin barrier to ensure the correct size, so that it fits properly and protects your skin from stoma fluid. The skin barrier should fit close to the stoma, without touching it and without any skin showing.



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2 Achieve a secure seal: The second step is to ensure a good seal around your stoma. Leakage not only occurs when stoma output seeps out from under the edge of the skin barrier, but also when output gets stuck between the skin and skin barrier instead of going into the pouch - this is known as 'seepage'. To help prevent this, it's important to look at where your stoma is located on your abdomen and how far it protrudes from your skin. If your stoma is level with your skin, located in a skin crease or fold, or is still healing after surgery, you may need to use a convex skin barrier to help prevent leakage. There are different formulations of convex skin barriers to suit your skin type and stoma output.

Convex skin barriers may apply downward pressure on the skin surrounding the stoma to help the stoma protrude more and make it easier for output to go into the pouch. When using a convex skin barrier, you should first try it without a barrier ring. The closer the skin barrier convexity is to the base of the stoma, the better the seal it will create. If a good seal is still not achieved, you can try incorporating a barrier ring.

3 Remember that less is more: The final step is to keep your ostomy skincare routine as simple as possible. Some ostomates believe that using baby wipes or applying lotion on the skin around the stoma will help protect it. However, these products may contain oils that can prevent the skin barrier from achieving a good seal. It is important to follow the instructions for use. For most people with stomas, water is sufficient for cleaning healthy skin. If soap is needed, select a mild bar soap with no added oils, moisturisers, or fragrances. Remember to rinse it off completely.

In addition, keep in mind that sometimes skin preparation agents and wipes can be mistaken for adhesives because they leave a tacky or sticky residue on the skin. However, these products are designed to create a film that will prevent the skin from stripping, caused by changing the skin barrier frequently. While useful in certain situations, skin prepping agents can interfere with how the skin barrier adheres, which may cause leaks.

Skin barrier paste can also be mistaken for an adhesive. While the paste is designed to fill uneven skin surfaces near the stoma and improve the fit of the skin barrier, too much paste can prevent a good seal. It may be a better idea to use a barrier ring to fill skin creases and folds.

If you have tried these steps, but are still experiencing ostomy leaks, be sure to reach out to your Stoma Care Nurse.

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Taking an interest

If your world sometimes feels humdrum, or all work and no play, hobbies help add colour and variety.

Then there are the health benefits - studies show that people who frequently engage in hobbies they love tend to live longer. From giving your brain a boost to expanding your social circle, there are so many reasons to keep doing the hobbies you love, or perhaps try something new.

In need of inspiration? Read on! Even if these suggestions aren't very 'you', they could provide food for thought.



Birdwatching

Birdwatching spiked during the pandemic, when many people were looking for a safe, outdoor hobby. If you're seeking an interest where you can spend time quietly, without distractions, you could find it a very meditative activity.

Then there's the option to involve family and friends, since birdwatching can be enjoyed by all ages and abilities. Not only can you discuss what you see in your garden, but you can also compare notes with others who are taking part.

The RSPB's Big Garden Birdwatch provides a vital snapshot of how the UK's garden birds are faring, taken over one weekend. Find out all you need to know, including how to take part, at www.rspb.org.uk/whats-happening/big-garden-birdwatch.

Upholstery

Got a piece of furniture that's looking a bit tired? By learning to upholster you can breathe new life into it. Or if something doesn't quite go with the decor in your room, upholstery can give it a brand new look. You can also snap up bargains that are a bit of an eyesore and transform them into stylish and unique pieces.

With a bit of patience and practice, anyone can learn how to upholster. You don't even need to be especially crafty or have any experience with DIY. Once you've learned the basics, you can start practising on more complex pieces, but it's always best to start small. Trying to tackle a full armchair or sofa on your first attempt probably isn't the best idea. Instead, beginning with smaller, more straightforward pieces can help you to gradually work your way up to more ambitious projects.

To find an upholstery teacher near you, visit www.findacraft.co.uk/product-category/upholstery.

Nordic walking

One of the fastest-growing forms of physical activity, Nordic walking (using a pair of specially designed lightweight poles for extra support) is a full-body exercise that was originally a summer training regime for cross-country skiers. It's easy on the joints and suitable for all ages and fitness levels.

There are different classes available, including gentle walks for anyone with health concerns. There are also workout walks for those looking to improve their fitness, lose weight, or tone their body. By using the poles, you are taking the weight off your knees and lower body joints, all while soaking up the scenery and getting plenty of fresh air.

Find out more at www.nordicwalking.co.uk.

Gardening

Getting some soil under your nails can boost both mental and physical health. It can be hugely satisfying, too. Imagine biting into a sweet cherry tomato ripened in your garden, or arranging some beautiful, scented home-grown flowers in a vase.

Don't think your fingers are green enough? These days, there are so many online tutorials – including on YouTube. Get started on something straightforward, such as planting cress or sunflower seeds, and see where it takes you.

If you're really keen, you could rent an allotment from your local council, or join a local gardening club. Community gardening is a great way to combine your new favourite activity with a chance to get out and meet new people - the Royal Horticultural Society (RHS) website has a handy tool to help you find a group near you: www.rhs.org.uk/get-involved/community-gardening/find-a-group.

Taking classes

It's never too late to build on your knowledge and skills. Classes are available online as well as in person,

providing a deeper dive into just about any subject, from languages and art history to upholstery, photography and car maintenance. While it may feel challenging, particularly at the beginning, it's important to take a compassionate approach. You don't have to do it perfectly; just be open and receptive.

Not only does learning a new skill get us out of a rut, it can widen our social circle too. Visiting www.findcourses.co.uk is a good place to start.

Car booting

Car boot sales are an easy way to make some extra cash from all you want to declutter from your home. Whether it's those jeans that no longer fit, crockery you inherited but don't want to keep or piles of books gathering dust, if you don't mind getting up early at the weekend and spending a few hours in a field or car park, chances are you'll return home with less of everything - except cash!

And if buying up booty is more your style, car boot sales are fun to visit and a fantastic source of super-affordable clothes, toys, bric-a-brac and more. It's true what they say, one person's 'tat' is another's treasure, and if you're a

collector, you might just find the piece that's been eluding you and perhaps even pay less for it than you would online.

To find your nearest boot sale, visit www.carbootjunction.com.

Mastering music

Just like language, music exercises the parts of the brain responsible for memory, reasoning, and planning – and learning how to play an instrument as an adult can boost your brain in powerful ways.

It's long been thought that because learning to play an instrument strengthens connections between the two hemispheres of the brain, young people who practise music become better at both linear maths (such as algorithms and equation solving) and problem-solving. Recent studies say that taking up a musical instrument as an adult can return the same benefits.

Other research shows that learning how to play a musical instrument can improve memory and increase cognitive function. A five-year study of 469 older adults found that playing musical instruments was linked to a reduced risk of dementia.

Visit www.musicteachers.co.uk/music/learn-instrument-as-an-adult to find out more.

Over to you

Has taking up a hobby helped you? We'd love to hear what it is, how you got involved and the benefits you get from it. Please get in touch at editor@urostomyassociationjournal.org.uk or send your letter to the address on page X.



Kirsten

WHEN A STOMA BAG FITS RIGHT
IT FITS EVERY SIDE OF LIFE



Take the Ostomy Check and check your stoma health



We understand over time that the size of your stoma, your body shape and lifestyle can all change. That's why it's so important you regularly check your stoma care routine and stoma health. As well as ensuring that you are still on the best product solution to **fit your body shape**, you will feel **secure** and **confident** in your everyday life.

Why not take the **Ostomy Check** today to help you identify common issues such as sore skin, or problems with adhesion and leakage. We'll then review your answers and a member of our dedicated Coloplast Clinical Services team will contact you.

Which best describes the area around your stoma?

Please tick in circles where appropriate

Regular
The stoma opening is above or level with the skin surface

Inwards
The stoma opening is below skin surface or requires some support due to challenges on dipped areas

Outwards
The stoma opening is on curved body shape or outward area (e.g. a diagnosed hernia)

Do you have any adhesion issues?

Ensuring your product sticks securely to your body helps you feel secure. You can tick one or more issues.

None

Insufficient adhesion when applying

Adhesive dissolves during wear

Adhesive edges roll

Do you have any skin irritation issues?

Your skin around your stoma should look like the rest of your stomach. If not, you can tick one or more issues.

None

At the outer edge of the baseplate

Under the baseplate

Around the stoma

Do you have any pouch issues?

It is important that your pouch works for you and that you feel confident wearing it. You can tick one or more issues.

None

Leakage

Odour

Ballooning or pancaking

For two-piece product users only

It is important your two-piece works for you. Tick on any coupling issues you might have. You can tick one or more issues.

None

Coupling difficult to close or open

Pouch falls off

Leakage at coupling

By completing this coupon, one of our Clinical Services team will contact you to discuss your answers. Simply post back by sending to **FREEPOST COLOPLAST** (no further postal address details or stamp required) and we'll be in touch.

First name: _____

Email: _____

Signature:

Surname: _____

Telephone No.: _____

Date of Stoma Surgery: _____

By providing your personal and sensitive data, you are consenting to Coloplast Limited that we may process and store your data for the purposes to fulfil your sample request, to keep you informed about it and follow-up via phone, text, email, or post, and to improve our products and services. We may refer you to healthcare professionals if needed. We may share your data with our sub-vendors when necessary to fulfil the request and transfer data securely outside the EU to support our business operations. You may withdraw consent at any time without ramifications, by writing to privacyrequests@coloplast.com or calling us at 0800 132 787. For more information, please visit our privacy policy for consent at www.coloplast.co.uk/about-us/Landing-pages/privacy-notice/

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Sleep well to boost immunity

With colds, flus and other respiratory illnesses more common in winter months, it's more important than ever we do what we can to make sure our immune systems are functioning at their best.

As well as eating healthily and keeping as active as possible, getting enough good-quality sleep is also key. Easier said than done if you're someone who finds it difficult to drop off or stay asleep for the optimum seven to eight hours per night recommended for adults.

If you're struggling with sleep, or rather lack of it, our top tips could help you get there – without counting sheep!

And relax...

Around half the UK population suffers from stress-induced sleep problems. If you're one of those struggling, it's important to give yourself time to unwind before you go to bed, whether that's by taking a warm (not hot) bath, losing yourself in a book, or listening to soothing music. Head still buzzing? Keeping a notebook handy and jotting down everything you want to get done the following day can help ease anxiety before you close your eyes for the night.

Routine, routine, routine

Just as a familiar routine helps babies

and children fall asleep at bedtime, adults respond well to a sleep routine too. Going to bed and getting up at a regular time allows your body to programme itself to naturally fall asleep and wake up at certain times. You can still be flexible, of course, but following a familiar pattern most of the time is likely to yield results.

Turn off technology

Ban your mobile phone, computer and TV from your bedroom, and avoid looking at them for an hour before bed. These devices emit blue light, which suppresses the sleep hormone melatonin.

Create a restful environment

A clutter-free space, tranquil colours, and smells such as lavender and geranium help create a soothing setting that encourages quality sleep. Make sure your bed provides the correct support, comfort and space, and ensure your room is the right temperature – between 16 °C and 18 °C (60°F to 65°F) is optimum.

Stop watching the clock

Fretting about getting enough sleep can itself inhibit sleep. If you can't stop checking the clock, try turning it around or putting it on the other side of the room so it's not so easy to watch time ticking away.

Experts recommend getting out of bed if you have spent 20 minutes trying to fall asleep. Instead of tossing and turning, it can be better to get up, do something relaxing in a quiet and

dim setting such as reading a book – without using your phone or other electronic devices – and then try to go back to bed once you start feeling drowsy. This approach is advised because it is important to associate your bed with sleep. Staying in bed while struggling to sleep can do the exact opposite, linking your bed with a feeling of restlessness.

Eating right

Eating healthily improves sleep generally, but some foods are particularly beneficial, such as milk, chicken, turkey and pumpkin seeds. They contain the chemicals tryptophan and serotonin, which are vital for the production of melatonin, the hormone that promotes sleep.

To avoid broken nights, steer clear of spicy food, alcohol and large meals in the hours before bedtime. For many, drinking coffee or other caffeinated drinks in the afternoon can affect sleep, so consider caffeine-free alternatives instead.

Darkness matters

Before clocks, people would wake up when the sun rose and go to sleep when it got dark. Similarly, turning the lights down can make you feel drowsy. If you don't have a dimmer switch, inexpensive lamps with a dimmer are a good option.

If 'standard' curtains don't cut it for you when it comes to blocking out light from outside, try installing blackout blinds, adding an extra lining to your curtains or wearing an eye mask.

Stay active during the day

Physical activity is great for sleep, as well as for your health generally, of course. Some people find, though, that vigorous exercise less than two hours before bedtime makes it more difficult getting to sleep. If you don't find this a problem, then there's probably no need to change, but it's something to bear in mind.



Find out more

For advice on all things sleep, visit www.thesleepcharity.org.uk, and for guidance on the best bed for you, try www.bedadvice.co.uk.



Liquid assets

Is there anything better than a piping hot mug or bowl of soup to warm you up on a cold winter's day? These three delicious, nutritious recipes are a great source of hydration, too, which is all the more important if you are living with a urinary diversion.

Leek and butter bean soup with crispy kale and bacon

The butter beans in this recipe give this dairy-free soup a creamy texture and the starchy liquid from the can helps to thicken it into a comforting lunch or supper.

- Ingredients**
- 4 tsp olive oil
 - 500g sliced leeks
 - 4 thyme sprigs, leaves picked
 - 2 x 400g cans butter beans
 - 500ml vegetable bouillon stock
 - 2 tsp wholegrain mustard
 - ½ small pack flat-leaf parsley
 - 3 rashers streaky bacon
 - 40g chopped kale (stalks removed)

Method

Heat 1 tbsp oil in a large saucepan over a low heat. Add the leeks, thyme and seasoning. Cover and cook for 15 mins until softened, adding a splash of water if the leeks start to stick. Add the butter beans with the water from the cans, the stock and mustard. Bring to the boil and simmer for 3-4 minutes until hot. Blend the soup in a food processor or with a stick blender, stir through the parsley and season.

Fry the bacon in a large, non-stick pan over a medium heat. Cook for 3-4 mins until crispy, then set aside to cool. Add the remaining 1 tsp oil to the pan, plus the kale. Cook for 2 mins, stirring until the kale is wilted and crisping at the edges. Cut the bacon into small pieces, then stir into the kale mixture.

Reheat the soup, adding a splash of water if it is too thick. Serve sprinkled with the bacon and kale mixture.



Broccoli and pea soup

Vibrant and packed with vitamins and minerals, this broccoli and pea soup hits the spot!

- Ingredients**
- 1 tbsp rapeseed oil
 - 1 finely chopped onion
 - 1 large, crushed garlic clove
 - 400g broccoli, chopped into small florets
 - 300g frozen peas
 - 200g chard, chopped
 - 1l low-salt veg stock
 - ½ small bunch of basil, chopped
 - small bunch of dill, chopped
 - 1 lemon, zested and juiced
 - 2 tbsp pumpkin seeds, toasted

Method

Heat the oil in a large saucepan. Add the onion and fry for 8 mins until soft and translucent. Add the garlic and cook for 1 more minute. Add the broccoli, peas and chard, then pour over the stock and bring the mixture to the boil. Reduce the heat to a simmer, cover and cook for 25 mins.

Stir through the herbs, lemon zest and juice, then blitz the soup with a stick blender until smooth. Delicious served with toasted pumpkin seeds scattered on the top.

Mushroom soup

Mushrooms contain nutrients to support a healthy immune system. This simple recipe is made without milk or cream. The mix of butter and flour thickens chicken stock to create a velvety soup without being too heavy.

- Ingredients**
- 3 tbsps unsalted butter
 - 2 minced garlic cloves
 - 1 finely chopped shallot
 - 4 ounces chopped crimini mushrooms
 - 4 ounces chopped white button mushrooms
 - 2 tbsps all-purpose flour
 - 3 cups chicken stock
 - Large pinch teaspoon fine sea salt
 - Large pinch ground black pepper
 - Sliced sautéed mushrooms and chopped parsley for garnish, optional

Method

Melt 2 tablespoons of the butter in a large over medium-high heat. Add the garlic and shallot, cook for 1 minute, until softened. Add the mushrooms and cook until tender and browned. Transfer all the contents of the pot to a bowl.

Add the remaining 1 tablespoon of butter to the pot. Once melted, sprinkle in the flour and whisk it into a paste. Reduce heat to medium. Add the stock bit by bit, whisking out clumps as you go.

Increase the heat back to medium-high and allow the soup to simmer for 3 minutes. Add the mushrooms back to the pot and continue to cook for 2 more minutes. The stock will thicken slightly, becoming creamy.

Cook for 3 to 4 minutes, then ladle into bowls. Garnish with mushrooms and parsley.



Have stoma, will travel

It takes time to gradually adapt to life with a urostomy, and gaining confidence with travel – at home or abroad – is part of the process. Whether your mode of transport is plane, train, car or boat, it can feel daunting, but as UA member Christine Houghton found, with encouragement and support, the world really can be your oyster.

"We bought an old Mercedes convertible five years ago with the intention of doing an annual road trip. The first one took us through the French and Italian Alps. Then Covid happened and the world came to a standstill. In the midst of the lockdowns, I was diagnosed with bladder cancer and had surgery in February 2021. The trips were mothballed. But, this summer, my husband and I completed a three-week,

2000-mile tour through Portugal and Spain in a car that is now 20 years old. We travelled on alternate days either side of a week in a villa on the Algarve and visited several UNESCO World Heritage sites along the way. "The Santander ferry departed on a bright sunny day; we were disheartened to dock in Spain in misty grey drizzle. However, once over the mountains, we found glorious sunshine and clear blue

sky. And, for the next three weeks, we never saw a single drop of rain. "Our first stop was just north of Salamanca in a converted 11th-century fortress surrounded by its own vineyard.

I was diagnosed with bladder cancer and had surgery in February 2021. The trips were mothballed. But, this summer, my husband and I completed a three-week, 2000-mile tour through Portugal and Spain in a car that is now 20 years old.

"The approach is across a bridge that at one time would have traversed the moat, but which now contains a swimming pool. Past reception, there is a cool and airy courtyard with access to the rooms. We ate at the hotel on both nights and had very good food at a really reasonable price. It helps the budget when the wine is produced by the property!

"The following day we ventured into Salamanca itself - the city is full of history and well worth a visit: from the beautiful Plaza Mayor to the house of shells and the two cathedrals (the newer one includes a carving of an astronaut around the door!).

"After visiting the historic town of Almeida (its 17th-century defences are laid out in the shape of a 12-pointed

star), we continued our journey through an alien landscape – huge, grey, granite-like mound-shaped boulders, stacked precariously as far as the horizon.

"Two nights in a hotel in Belmonte gave us panoramic views across the valley. In a former convent, the original chapel is now a very comfortable lounge, while the well-proportioned rooms are housed in a modern extension. There is also a good pool and a restaurant serving food and wine from the region.

"Our Mercedes came into its own on a tour of the Serra da Estrela mountains - twisting, winding roads through fragrant pine forests. The 60-mile round trip takes in pretty towns and villages and Portugal's highest point, Torre, at 1993m above sea level.

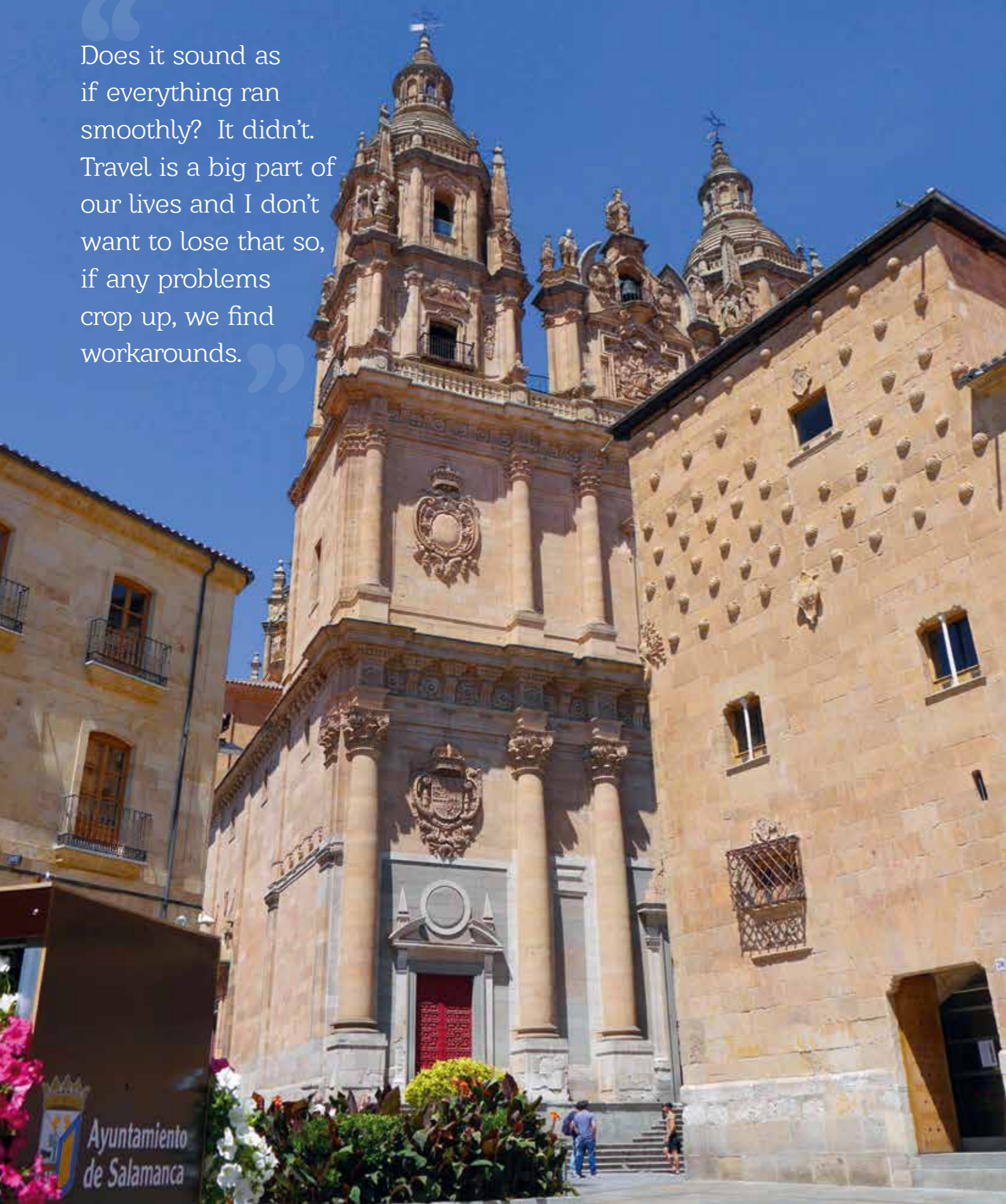
"Our third stop was Evora. The hotel here was modern and stylish with a big pool and a peacock strutting his stuff in the garden! Once again, there was a good selection of local food and wine on the menu. Historic Evora has a Roman temple thought to date from the 1st century, and the church of Sao Francisco that contains a chapel lined with human bones.

"As we dropped down towards Lagos we saw our first glimpses of the Atlantic Ocean. Our accommodation for the next week was a villa in a peaceful location a few miles outside of town, but also close enough for its array of shops, boutiques, restaurants and bars. Most of the week was spent chilling by the pool.



Have stoma, will travel cont.

Does it sound as if everything ran smoothly? It didn't. Travel is a big part of our lives and I don't want to lose that so, if any problems crop up, we find workarounds.



“

“I’ve been quite apprehensive about life with a stoma but with the help, support and understanding of my husband, family and friends, plus confidence and positivity, I CAN carry on enjoying life. And so can you!”

”

“We knew that the drive from Lagos to Granada was going to be a long one. It took us about six hours with the temperature hitting 44 degrees! But what a pretty drive - for mile after mile the central reservation is planted with pink and white oleander bushes. Frequent stops were essential to rehydrate, stretch out and to use the facilities (which I found, throughout the trip, to be very clean).

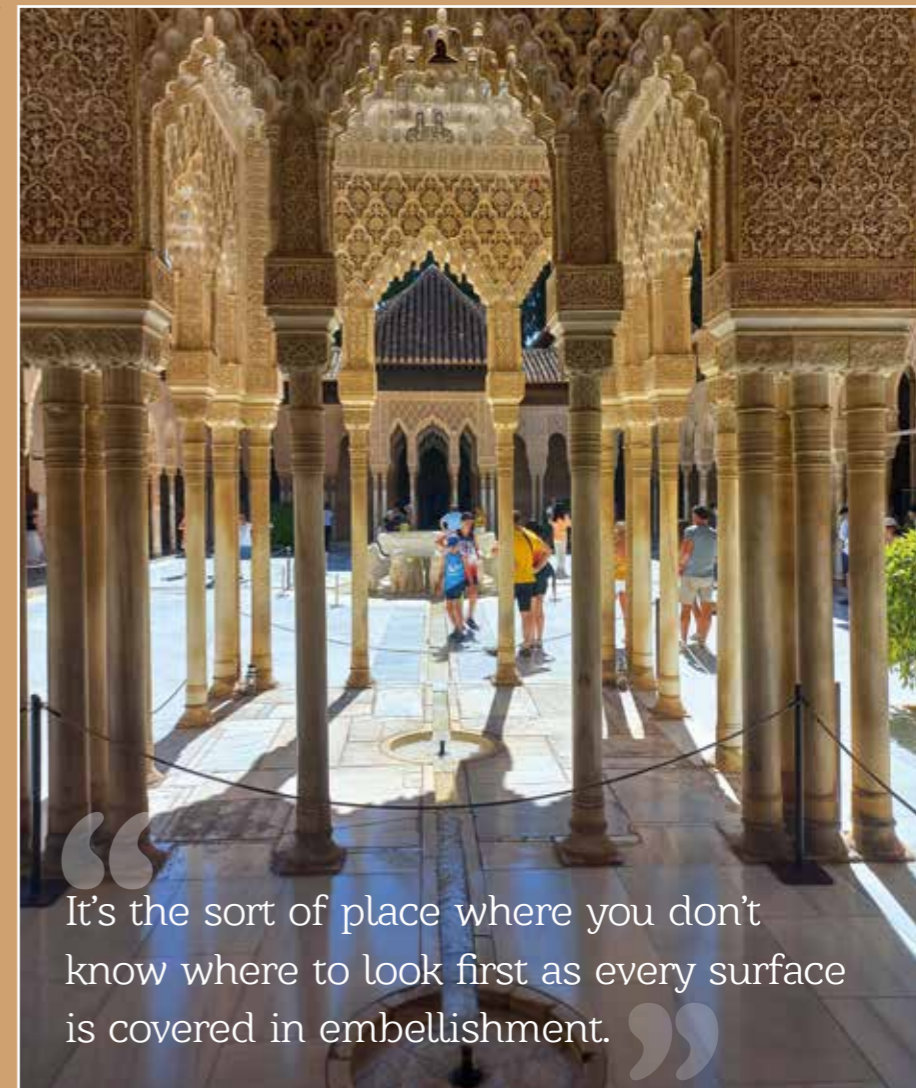
“For our visit to the Alhambra Palace and the old part of Granada, we left the car in the shade of the trees at our farmhouse hotel and used taxis instead. The Palace is stunning - beautifully laid out gardens, shady areas under trees and in courtyards, and cooling water features at every turn. There are impressively intricate stone carvings that have been done entirely by hand. It's the sort of place where you don't know where to look first as every surface is covered in embellishment.

“As we headed north it got cooler - if you can call 39 degrees cooler! The scenery was wonderful - olive trees cover both mountains and plains as far as you can see. Next stop, Toledo, where we had a pleasant walk of 6.5 miles that took us about five hours.

“After negotiating the outskirts of Madrid on the motorway network, we used back roads along a lovely route through a national park, forests and authentic towns and villages all the way to our next stop at Carrion de los Condes. The hotel is in a former monastery set around peaceful cloisters. The church altar is adorned in gold from floor to ceiling and parts of the floor have been excavated to reveal the original 11th-century paving.

“It was then just a short hop back to Santander for our ferry back to Plymouth.

“Does it sound as if everything ran smoothly? It didn't. Travel is a big part



“It's the sort of place where you don't know where to look first as every surface is covered in embellishment.”

of our lives and I don't want to lose that so, if any problems crop up, we find workarounds. Southern Europe was in the grip of a heatwave, which presented issues with my usual barrier spray not drying and bags not sticking. Instead, I used a powder on my skin and a hairdryer on its cool setting. Heeding advice from my stoma nurse (“Take three times the number of bags/supplies you would normally need”), I knew I had enough bags to last the duration.

“Another concern was access to toilets. Why worry? There are toilets everywhere - cafes, bars, shops, supermarkets, petrol stations. A

foreign language is no barrier either - Google Translate is a godsend! In the countryside, I can nip behind a tree. No trees? Stop in a safe place, angle the car and the doors as a shield, sit on the seat away from the roadside and empty out on the ground or into a wide-necked, screw-top bottle. If a car goes by, all they see is a car in a lay-by with the doors open.

“I’ve been quite apprehensive about life with a stoma but with the help, support and understanding of my husband, family and friends, plus confidence and positivity, I CAN carry on enjoying life. And so can you!”



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200+ CLUB NEWS

Just £2 Per Month



'May I please join the 200+ Club?'

Message from the Administrator, Toni Haines

Can Buddy and I appeal to all UA members who are not yet part of the 200+ Club to join us in helping to raise much needed funds for the charity? Support this great cause and you could be one of our 200 Club winners!

Just £2 per month

With some members no longer with us, please - if you can afford just £2 per month, per number - join us and give yourself a chance of winning some cash prizes.

We are able to donate well over £3,000 per year to the Association and we now have five cash prizes, five times a year, so 25 chances a year to win!

If you can afford just £2 per month, please get in touch with me, Toni Haines, on 07510 123400 or email me at: toni.haines@urostomyassociation.org.uk.

Each number costs £24 per year, payable either by Standing Order for £2 per month or £24 per year, OR by cheque OR online OR by credit/debit card by telephone call to National Office.

Results of the 2nd draw of 2023

1st prize of £250 No 10 Judy Crook

2nd prize of £150 No 120 Eddie Cooper
(Eddie kindly gave £50 back to UA)

3rd prize of £100 No 5 John Spencer

4th prize of £75 No 110 Carol and Edward Lloyd

5th prize of £50 No 65 Roland Peach

The total raised for National Funds during the past year was £3,100

BE IN IT TO WIN IT NEXT TIME AND MAKE YOUR EXTRA CONTRIBUTION TO UA FUNDS

WOULD YOU LIKE TO JOIN THE 200+ CLUB?

Organiser Toni Haines would love to hear from you, 'You may not be able to run a marathon or climb a mountain, but anyone can raise money for UA by joining the 200+ Club. Each number costs just £2 per month or £24 per year. Call me on 01952 400971 or 07860 554536, or email me at toni.haines@urostomyassociation.org.uk

Where there's a will...

When it comes to making a will, it is easy to keep putting it off, as though having one in place will somehow hasten your death. But having an official record of your wishes is important for making the here and now more peaceful for you as well as the people close to your heart.

Creating your will is an act of kindness for your loved ones because when you die, it can help make a distressing time for them that little bit easier. A will also avoids everything you own being shared out in a standard way defined by law, which might not be what you want. Of course, having a will is especially important if you have children or other relatives who depend on you financially, or if you want to leave something to people outside your immediate family.

If you own a business, it's vital to think about who should inherit the company or shares after you pass away. Effective will writing can help ensure this happens as you intend and can

prevent your business interests from passing to someone unsuitable or not equipped to handle it.

Not sure where to start with writing your will?

With the right support, making your will needn't be complicated, time consuming or expensive. The Urostomy Association has partnered with highly trusted UK company Guardian Angel to offer you the opportunity to create your will free of charge, in a straightforward way, using their expertise to guide you.

As well as making provision for their nearest and dearest, many people choose to remember the charitable causes that matter to them. Remembering the Urostomy Association in your will is a meaningful way of making lasting impact for people in need of support to help them adapt to life with a urinary diversion and live with more confidence.

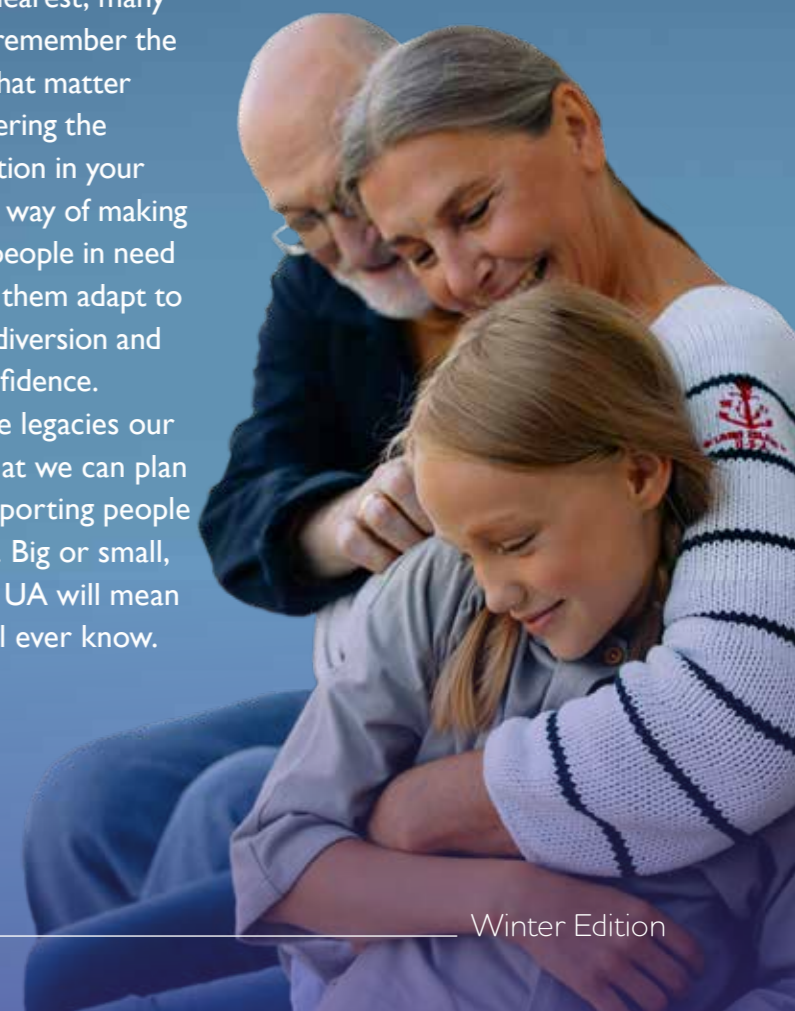
It's thanks to the legacies our charity receives that we can plan for the future, supporting people for years to come. Big or small, your legacy gift to UA will mean more than you will ever know.

Free offer code

To find out more about the opportunity to create your will free of charge using Guardian Angel's expertise, start by visiting www.guardianangel.network/bow/start/welcome.

The code you'll need to qualify for the free offer is UROSTOMYFREE.

If you decide to remember the Association in your will, thank you so much. Please know how much your generosity is appreciated and the difference you will make to those whose lives you touch.



News from the branches

Do you know about the Association's local branches? We have six across the country: Cambridge; Lothian and Fife; Newcastle; Sheffield; Shropshire, Wales and the Marches, and Yorkshire and Humberside, all open to anyone living with a urinary diversion, or preparing to, as well as their family members and carers. We also have a support group for London and Surrey as well as one in Northern Ireland.

Meetings and socials are an opportunity to gather with those who understand from their own experience how you might be feeling. They're somewhere you can enjoy a friendly chat in a relaxed setting, swapping information and tips or simply listening if you prefer.

Our branches often have guest speakers, as well as outings and fundraising events. Our round-up of branch news gives you a flavour of what's going on, and if you'd like to join a group near you, please email the Branch Secretary, or contact the Association on 01386 430140



Cambridge

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

Branch Secretary: Jane Phillips

Email: secretary.cambridge@urostomyassociation.org.uk

We've had another busy summer in the branch: talks from Salts and Coloplast and a stoma nurse giving private consultations.

Socially, we had a lovely afternoon tea in the beautiful and historic town of St Ives in September – 40 members and their guests attended, making it a very enjoyable day. The weather was excellent and as it was market day, many members had a walk around the stalls before we met up.

The branch continues to grow – at each monthly meeting we welcome new faces and we have a wealth of advice and experience in living with a urostomy, together with friendly people and a very comfortable venue for the meetings. We have speakers throughout the year, and hold a cash prize draw at each meeting, as well as having social events arranged by the committee.

Please come along to meet us, or contact me at the email address above for more details.

Diary dates: We meet every first Tuesday of the month between 10.30am and 12.30pm. Our branch AGM is on 5th December, and our Christmas lunch is on 7th December.

Jane Phillips

Newcastle

Venue for next meeting: Education Centre, Freeman Hospital, Newcastle upon Tyne

Branch Secretary:

Eileen Spraggon

Email: secretary.newcastle@urostomyassociation.org.uk

When you are reading this edition of the Journal, let's hope the weather is better than now in September! The majority of us have had more than our fair share of rain.

This year has been a special one for the Newcastle Branch as we celebrated our 50th anniversary. (It does not seem that long since I started a stoma support group and then joined UA at their second branch, in 1973!).

We had a wonderful afternoon at Newcastle City Golf Club. All members were invited and also

previous Presidents. Mr Hassan and his wife attended, but unfortunately Philip and Angela Powell had another firm appointment. Mr Ramsden was on holiday and of course we missed the late Professor Rob Pickard. Philip Powell also did a wonderful job as National President for quite some time. We are so fortunate to have Professor Chris Harding as our current President, who attended with his wife Ella. It was also good to see Don Haines, past UA Journal Editor, and Julie Varley, one of UA's member representatives.

A committee member had compiled a questionnaire to ask members if they would prefer meeting up nearer their home. The replies will be studied and hopefully we'll fulfil some wishes next year. The Newcastle branch covers Northumberland, Tyne and Wear, Cleveland, parts of North Yorkshire and North Cumbria.

We held our branch AGM in the newly refurbished Education Centre at

the Freeman Hospital. Six companies attended for members to view their ranges of urostomy pouches and accessories. Also on show was the stoma model our branch purchased for the Urology Unit at the Freeman Hospital, for patient and staff education. Stoma Nurse Keighley Brownlee-Moore explained the differences in stoma types, reasons for formation, and the care of stoma patients.

Brian Fretwell, UA's National Chair, gave an interesting talk on the proposed changes to the Association and an explanation of why they are necessary. We then had a raffle of prizes contributed by our generous members and company representatives before the meeting came to a close.

Diary dates: Our spring meeting is on 23rd March 2024

Eileen Spraggon

Lothian and Fife

Venue: Carrington Suite, Inverleith Building, Crewe Road South, Edinburgh EH4 2LF

Secretary: Rhona McLaughlin

Email: secretary.lothian@urostomyassociation.org.uk

I am sorry it has been a long time since we have met but as most of our branch members are aware, we had difficulty in securing a room, at a reasonable price, for our meetings.

The Carrington Room at what was the SHSC building (now known as the Inverleith Building) was only to be used for NHS staff meetings. However, Brian Fretwell and I met with the accommodation organisers at the



Western General Hospital and we have managed to get approval to use the room going forward. The availability for the period up to Christmas 2023 was very sparse but we have secured a date of Thursday 16th November for our meeting. We will be holding a raffle, and we would appreciate any items you wish to donate. Tickets will be available to purchase on the day of the meeting. We are fully aware of the parking

requirements of members and unfortunately this will be issue at the Western General Hospital. There is good public transport to the hospital though, so hopefully lack of parking should not be a major problem, and there is off-street parking near the Inverleith Building.

Those of you without access to a computer can contact me at 79 Balcarres Street, Edinburgh E10 5LT.

We look forward to seeing you!

Diary date: Branch meeting on 16th November, 1 – 3.30pm. (Tea and coffee between 1 and 2pm, equipment suppliers from 1.15 – 2.15pm, main meeting 2.15 – 3.30pm)

Rhona McLaughlin

News from the branches

Sheffield and District

Venue: Tapton Hall, Shore Lane, Sheffield S10 3BU
Secretary: Mary Milner
Email: secretary.sheffield@urostomyassociation.org.uk

We held our branch summer meeting on 1st July, attended by 36 members and guests. We were very pleased to welcome our new Chair, Martyn Oxley, as he formally chaired his first branch meeting. We were also pleased to welcome a couple of new members attending one of our meetings for the first time.

As usual, we were supported by a number of representatives from



different appliance and delivery companies with their displays of products and services. The raffle raised £72, with our craft stall raising a further £38, all going towards branch funds.

Our guest speaker for the afternoon was well known to us as our committee member, Alan Wade. Wearing another hat, Alan gave a talk entitled 'Treading the Boards', with numerous tales from his experiences of amateur dramatics. He entertained us with stories going back to his childhood nativity plays, with tales we could probably all relate to, and bringing us up to date with his more recent appearances in Gilbert & Sullivan musical theatre.

Our branch AGM on 4th November was preceded by the John Topham Memorial Lunch named after our founding Chair, where we enjoyed a lovely meal with our friends from UA.

Mary Milner

Shropshire, Wales and the Marches

Venue: Bicton Village Hall, Bicton, Shrewsbury
Branch Secretary: Toni Haines
Email: toni.haines@urostomyassociation.org.uk

Our 1st July branch meeting took place at Bicton Village Hall, Shrewsbury. In all honesty, the turnout was disappointing, but on the plus side, the list of apologies was enormous! However, we did go ahead with our AGM, there was a quorum, and all the officers were re-elected. Unfortunately, the Zoom facility at the hall was out of action, so we couldn't enable members to join in online as we usually would. Technology again failed us, when the planned bi-monthly branch Zoom meeting didn't take place in August because the wi-fi signal on the canal boat belonging to my husband Don and me proved to be non-existent! We had hoped to have a meeting in



North Wales in late September or early October. However, health problems for yours truly also made that impossible.

At our October meeting, we discussed all the changes being made to UA, and heard about the Association's plans. Alex Browning from Dansac/Hollister joined us to give a talk on the company, which was very interesting.

Diary dates: We'll be having three branch Christmas lunches - one in Bridgend at the Best Western Heronston Hotel on 29th November, one in North Wales, returning to the

Faenol Fawr Hotel, Bodelwyddan, on 6th December, and one returning to the Corbet Arms, Shrewsbury, on 13th December. All the lunches are subsidised by the branch for each member and their partner. The two lunches held last year were enormously successful, with everyone enjoying the ambiance as well as the food. I am sure the same will be true this year, too. Please email for details (see address above).

Toni Haines

Yorkshire and Humberside

Venue: Salvation Army Church, Hunslet Hall Road, Hunslet, Leeds, LS11 6QB
Secretary: David Legood
Email: secretary.yorkshire@urostomyassociation.org.uk

We held our branch AGM on 19th August, when officers and committee were all re-elected. A large proportion of the meeting was taken up with members discussing aspects of the future of the Association, having received news about the planned change in leadership and admin arrangements.

Twenty-four members and their guests from the West Yorkshire area enjoyed afternoon tea at Tingley Garden Centre in August. We hope to hold similar events for members in



Humberside and North Yorkshire.

Branch members have represented the Association at open days at Leeds, Huddersfield and York hospitals, with the Huddersfield open day being very busy.

On a personal note, I would like to thank both Hazel Pixley and Dave Page

for all the help and assistance they have given me over the last few years.

Diary date: The Pinderfields Hospital open day at Normanton Golf Club will be held on 29th November, where the branch committee will be in attendance.

David Legood

London and Surrey news

Although Urostomy Association branches in London and Surrey have been wound up, activities for members have recommenced, starting with a summer lunch party at my house in July. The intention was to have lunch in the garden but, unfortunately, the weather was not kind and we had to retreat indoors. Nevertheless, with over a dozen people present, an enjoyable and sociable time was had. Attendees included both longstanding members of the Association and people who had only recently acquired a stoma. The group agreed to meet again and one couple volunteered to host a lunch at their house in January.

The group also agreed that a more formal meeting and felt a presentation on a subject of interest would be welcome. This has now been arranged for 2pm on 22nd November, when we will have a joint meeting with the bladder cancer support group at Charing Cross Hospital. Information



will be sent out to all members in London and Surrey but, in the meantime, anyone who would like more details can email me at brianglicksman@gmail.com or phone 020 8642 1899. In September I also gave a talk about UA to the bladder cancer support group at University College Hospital, which seemed well received. In October,

Elizabeth Marshall and I represented UA on a stand at a stoma awareness event organised by Tower Hamlets Council. The photo shows us with some of the Association's literature. Very few people attending the event had urostomies, most seeming to have colostomies.

Brian Glicksman

Fundraising



A message from Rachel Shepherd

By the time you read this, my contract with the Association will have completed and the next fundraising chapter for UA will be just beginning.

My time as the charity's Fundraiser, getting to know and working alongside our fantastic supporters as well as my UA colleagues, has been a remarkable and humbling experience. Over the past 18 months, many of you have supported UA, from signing up as volunteers to donating towards our children's book 'Bags, bags, bags', and from fundraising as part of UA your Way to standing next to me in various toilets, assessing their suitability for urostomates as part of our Safe Spaces pilot project.

My thanks to each and every one of you who supports UA. Your commitment to making a positive difference to people with a urinary diversion has been a constant source of inspiration. Your generosity has brought about real change in the lives of many individuals, and for that I'm very grateful. I remain an ardent supporter of UA and send you all my very best wishes for the future.

Do good as you shop



Don't forget, shopping for Christmas presents or snapping up bargains online in the New Year sales can do good for people with urostomies – and it doesn't have to cost you a single extra penny!

Easyfundraising is the UK's biggest online charity shopping site, partnering with more than 7,000 brands who will donate part of what you spend to a cause of your choice. It won't cost you any extra.

John Lewis, Argos, Marks and Spencer, Tesco and Halfords are just a few of the well-known names participating in the scheme to help charities like ours. To get started, simply sign up at www.easyfundraising.org.uk and choose the Urostomy Association at the checkout. It's such a straightforward, hassle-free way to show your support for people who turn to our charity for information and a listening ear. Thank you for getting onboard!

Safe Spaces update

In the summer Journal, we introduced our Safe Spaces pilot project, explaining its aim of working with venues to help them identify what they can do to help urostomates feel more at ease on a day out.



Having visited two National Trust (NT) properties – Shugborough Hall and Attingham Park – accompanied by UA members who kindly gave their time and feedback, we shared with NT representatives criteria which, if met, could do so much to encourage people with a urinary diversion to feel confident on visits to these national treasures.

Our criteria, which range from providing information about the location of accessible toilets ahead of people's visits to making sure toilet doors reach the ground and including urostomy awareness in training for NT staff and volunteers, have been welcomed by both properties. They are keen to work with UA to roll out improvements more widely, too.

Following our Safe Spaces pilot, the following recommendations have been submitted for consideration by UA's Board of Trustees.

- Creating a document with advice to help venues become more urostomy aware
- Rolling out Safe Spaces nationwide, engaging the wider National Trust, plus English Heritage, the Association of Independent Museums, local authorities, garden centre chains, etc, advocating for greater accessibility, plus improvements to staff and volunteer training
- Developing a map of 'Places we Love' for UA's website (and potentially, an app), showing the venues members rate as safe, comfortable and enjoyable for a day out following stoma surgery.

A big thank-you to our members who took part in our pilot. We really appreciate your support, helping us drive forward more awareness and greater understanding for everyone living with a urinary diversion.

Read all about it



We're delighted many of you with young children in your lives have been downloading our unique resource 'Bags, bags, bags' or placing an order for a printed copy. We hope you're finding it a useful conversation-starter for explaining to youngsters that some people wee differently and there's no embarrassment required!

We're also really encouraged that our professionally illustrated book has been so well received by stoma care nurses keen to make their patients aware of it.

Kindly sponsored by companies Hollister, Coloplast, Dansac, Salts

Healthcare and Fittleworth, 'Bags, bags, bags' is available on our website at www.urostomyassociation.org.uk/bags-bags-bags-childrens-book. You can find it on Kindle, too.



A Bear Named Buttoney

Stoma acceptance as an adult can be difficult for many but how do you manage when it is your child? How do you explain the 'special bag' on your child's tummy is their new way to go to the toilet?

This is the position Jenny Gow (pictured above with her now grown-up daughter Eilidh) found herself in more than 20 years ago. Out of a desperate desire to help her young daughter following stoma formation, a friend came up with a unique idea - an idea so simple yet it has helped thousands of children and their families since: a teddy bear with a 'stoma'.



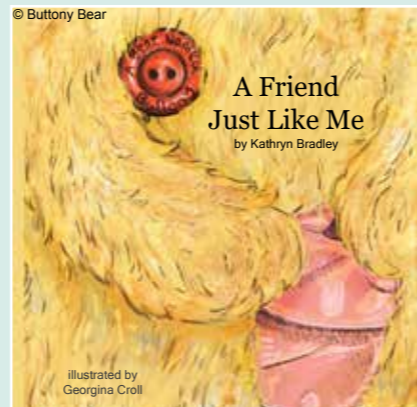
Years later, vowing not to let others go through a similar experience alone, Jenny set up the charity 'A Bear Named Buttoney' with the support of friends. She turned the unique idea into one that could help so many other families avoid some of the distress and difficulty that she, her husband and her young daughter had experienced... and so Buttoney Bear was born.

A simple, yet very effective concept; Buttoney Bear is a teddy bear with a 'button' stoma.

The concept of a button stoma with a small stoma bag attached over the top is one that children can interact with. They can remove or re-attach the bag as many times as they wish to help with understanding and acceptance. Buttoney bear fully conforms to UKCA marking standards.

However, Buttoney is more than just an educational tool. To a young child with a stoma, Buttoney is someone who listens, gives confidence, brings a much-needed smile and is a friend. Most importantly, Buttoney is just like them.

Since 2015, A Bear Named Buttoney has issued more than 5,500 bears to children around the UK. In the past few years, the charity has published a



story book - A Friend Just Like Me - aimed at young children. This beautifully illustrated story book helps young children to understand that they are not alone.

The latest addition to the 'Buttoney' range is an inclusive colouring book. A set of easy-to-colour illustrations, each of which show Buttoney in an everyday setting that a child is familiar with to highlight that a stoma doesn't have to stop them doing the things they enjoy.

For older children, the charity offers a Young Adult pack - a toilet bag with a small sample of non-medical items they can store their dressings and other related items in discreetly within in an educational setting. The idea behind this is to encourage independence.

Founder Jenny said: "At A Bear Named Buttoney, we pride ourselves in supporting such a brave and wonderful community of children and their families. Putting a smile on a young face at a difficult time is one of the most rewarding and priceless things one can do."

To find out more visit
www.buttoneybear.org.uk

Among our community-spirited members are two special ladies who, having contributed so much to the life of the Association over the years, deserve an extra big thank-you from us all.



Hot on the heels of the somewhat Covid-belayed 50th anniversary celebrations of the 1971 foundation of the Urostomy Association came the 50th anniversary of UA's Newcastle-upon-

Tyne Branch. As impressive as this latter landmark is, even more remarkable is the fact that throughout the entire history of this, the oldest remaining UA branch, the driving force has been its remarkable Branch Secretary, Eileen Spraggon (pictured on the right of the photo here).

At a well-attended lunch in the summer, UA's Chair of Trustees Brian Fretwell paid tribute to Eileen's remarkable record of service, and Branch President, Consultant Urological Surgeon Professor Chris Harding, assisted Eileen in cutting the celebration cake. Professor Harding brought the house down when he declared, deadpan, "I'm no good with knives!"

The lunch was also attended by former Branch President, Consultant Urological Surgeon Mr Tahseen Hasan. Eileen was visibly moved when she was presented with a bouquet of flowers by

Elizabeth Walton, who also spoke about her in glowing terms.

Later, Eileen said: "Thank you, Don and other members who have travelled quite a distance for the occasion. We had a wonderful celebration lunch with members and family, stoma nurses past and present, and also representatives from the stoma equipment industry. I was overwhelmed with the beautiful bouquet presented to me.

"Fifty years has only been achieved by the wonderful support that members, their family, friends and other branch officers and committee members have given me. A special thank you to the busy consultant urologists past and present who have given their time to the office of Branch President."

Don Haines

Honorary Lifetime Member

THANKING TWO special ladies



On behalf of our Sheffield and District membership, our committee recently met at The Lighthouse, Eckington, where our Chair presented former Branch Treasurer Anne Turner with a silver salver in recognition of all her work with the Urostomy Association and, in particular, our branch.

Anne, who stepped down from her role at the 40th anniversary celebration

of our branch in November 2022, had been Treasurer from the very first branch meeting in the old boardroom of the Royal Hallamshire Hospital, in 1980.

For many years, working alongside our founding Chair John Topham, Anne played a key role in the running of the branch, having also previously held the post of Fundraising Officer alongside her Treasurer responsibilities. Sadly, John passed away in 2013, but Anne continued as Treasurer, always keeping a steady eye on the finances, and it is a credit to her that our branch has always remained in a good financial position.

In the days when we held our meetings at the hospital, with the support of members Anne would co-ordinate an annual buffet lunch prior to our branch AGM. The table was always beautifully presented and laden with delicious food. She continued doing this

when we relocated meetings to Tapton Hall.

Over the years the Sheffield and District Branch has hosted the National Annual General Meeting on three occasions; once again these successful events, held at the University of Sheffield, were organised by Anne.

Unable to attend our presentation to Anne, our previous Chair Derek Finney, who worked with her for many years, sent a message: "Thank you to Anne for the dedication and unrivalled service over the past 40-plus years. Without her support, the Sheffield and District Branch would not have been as successful as it has been, and her future involvement will be sadly missed."

We would certainly echo his words.

Mary Milner

Secretary, Sheffield Branch

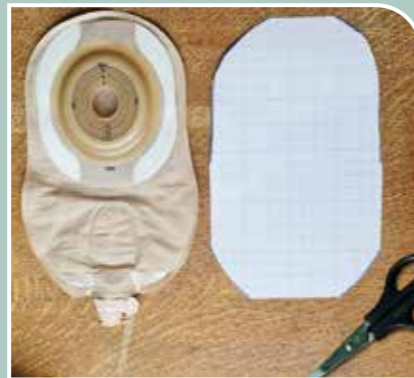
Your letters Winter 2023



The vinyl frontier

I was diagnosed with bladder cancer a few years ago and had to say goodbye to my bladder in May 2021. Swimming had been my main form of exercise, so I immediately started looking for ways to cover up my urostomy bag in the pool or at the beach. I bought several bag covers on Etsy and even had one custom made with a small drawstring which gripped the plastic flange of my Hollister pouch. No problem sunbathing, but all of these covers came loose sooner or later, either when swimming laps, or more quickly, in the sea. One wave and off went my carefully made cover, usually never to be seen again!

A friend suggested some kind of stick-on cover. After doing some research I tried using self-adhesive vinyl film. This is widely available and is used for covering tabletops, and for decorating skateboards, motorbikes



and crash helmets. This turned out to be a great solution. It's cheap - have a look on eBay - and it's easy to cut and shape. It's waterproof and easily lasts the two days that I wear a pouch. I've found I can even unpeel it from a discarded pouch and reuse it on the next! I've worn my disguised urostomy bags at the beach and in public pools with any problems or embarrassment. Give it a try!

Richard Tarry

Hidden solution

Apart from the first few weeks after my operation, I have always worn my leg bag on my thigh. I find this more comfortable to wear than below the knee, with the added advantage that it presents the tap at the right level for emptying into a toilet without the need to stand with one foot on the edge of the bowl. I have had all my

trousers modified to include a full-length zip in the outer seam of the right leg so I can gain access to the bag.

I do a lot of walking, and have noted over time that the upper strap has to be quite tight at the very top of my leg because otherwise the increasing weight as the bag fills can cause it to gradually slip down my thigh. Applying my thoughts of how to overcome this, I have come up with a slightly unusual solution - a ladies' suspender belt! They are available to purchase online, or by visiting - as I did - a well-known supplier of glamorous lingerie.

The button attachments fit perfectly into the suspension holes at the top of the bag, and are firmly retained in place by the clips, plus the length of the suspenders can be adjusted to suit. There are sizes available to suit any waist, and since the belt is hidden under clothing, it can be worn discreetly by either sex.

Eugene Kennedy

Editor:

Many thanks to Richard and Eugene for kindly sharing their tips with fellow urostomates. If you, too, have a suggestion that could help others, please get in touch.

Getting in touch

If you have an email or letter for consideration for this page, we'd love to hear from you. Please get in touch at editor@urostomyassociation.org.uk, or by post at Urostomy Association, 2 Tyne Place, Mickleton, Gloucestershire GL55 6UG.

Your Facebook friend



If you're a Facebook fan, why not follow us on the platform? Our public page is where you'll find our latest news, events and campaigns, and you can leave a comment, ask a question or share our content with others who might be interested.

Urostomy Association public Facebook page: www.facebook.com/profile.php?id=100070965356234

Meanwhile, our private Facebook group - with 1,500 members (and counting!) worldwide - is just for people with a urinary diversion and those who care for them. It's where you can ask questions of people who might be facing similar challenges to your own, swap tips and share as much of your experience as feels comfortable for you. You'll find support and camaraderie in abundance, and some amusing anecdotes, too!

Urostomy Association Private Facebook group: www.facebook.com/groups/158052257866449/





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Help with water bills

Following a query from a member about water bills, we want to let all of you know about the money-saving WaterSure scheme, just in case you're not aware of it.

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.

If you get help through the WaterSure scheme, your water 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 and to check your eligibility, 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'. While this does not give you money off your water bill, it does mean 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.

Being on the register also means you are not affected by hosepipe bans, which is handy if, for instance, you have a parastomal hernia and should not lift heavy watering cans.



Our UA community is welcoming, friendly and inclusive, and if you haven't already, we would love you to join us! It's free of charge and you can be involved as much, or as little, as you choose to be. Like those who've already signed up, you'll find camaraderie and support that can make any difficult times that much easier, plus plenty of resources and tips to help you stay well and get the best out of life. As with the majority of our community, most of our small team have a urinary diversion, so understand from their own experience how you might be feeling. We are also here for family members and carers, recognising that they sometimes need support too.

Every person is unique and that's why our services are designed around you as an individual rather than 'one size fits all'. Whether you access our helpline, resources and one-to-one support on a regular basis or dip in every now and again, what matters is that you receive the understanding, reassurance and information you need, whenever you need it and for however long.

How to join us

Joining the Association is really straightforward. You can do so via our website at www.urostomyassociation.org.uk/join-now, or fill in your details on the form opposite..

We look forward to hearing from you!

Everyone in our community is welcome to access our services and resources:

- Information covering all types of urinary diversion
 - Helpline
 - One-to-one support
- Regular newsletter and magazine
 - Comprehensive website
 - Friendly Facebook group

www.urostomyassociation.org.uk/join-now

As a small, independent charity, we receive no government or NHS funding, which means we rely on donations and fundraising from our kind-hearted community to continue our vital services. Your gift – big or small – to the Association, is an act of compassion for people who are feeling anxious, isolated or overwhelmed before and/or after their lifechanging operation. Thanks to your generosity, we can be the trusted friend they need to help them live with increased confidence, knowing UA is here for them no matter what. To make a donation of whatever you can afford, please visit our website at www.urostomyassociation.org.uk/donate, telephone us on 01386 430140 or send a cheque made payable to 'Urostomy Association' to us at 2 Tyne Place, Mickleton, Chipping Campden, GL55 6UG. Thank you for your support.

APPLICATION FORM – PAGE 1 OF 2

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

Please fill in your details below (and overleaf) and we will be in touch. We won't bombard you with communications and you can opt out at any time.

Personal details			
Title			
First name			
Last name			
Main phone number			
Email address			
Date of birth			
Address line 1			
Address line 2			
Address line 3			
Town/City			
Postcode			
Type of operation			
<input type="checkbox"/>	Ileal conduit/urostomy	<input type="checkbox"/>	Bladder reconstruction/neo-bladder
<input type="checkbox"/>	Continent diversion (eg Mitrofanoff)	<input type="checkbox"/>	Other
<input type="checkbox"/>	Not applicable		
Reason for operation			
Hospital			
How did you hear about the Urostomy Association?			
<input type="checkbox"/>	Nurse/GP/other healthcare professional	<input type="checkbox"/>	Open Day
<input type="checkbox"/>	Google/Bing/etc	<input type="checkbox"/>	Facebook
<input type="checkbox"/>	Advertisement	<input type="checkbox"/>	Other (please specify below)

Form continued overleaf

APPLICATION FORM – PAGE 2 OF 2

When you join our community, you'll receive our popular magazine, the Journal, three times a year. We'll also send you our regular newsletter with details about latest developments, events and campaigns. However, we can only do this with your permission. Please tick the relevant box below

to let us know if you give your consent and if so, how you want us to contact you.
Choosing to receive our communications by email saves our small charity money on printing and postage, as well as being kinder to the planet. If you'd still prefer to hear from us by post, making

a donation of whatever you can afford is greatly appreciated. You can donate at www.urostomyassociation.org.uk/donate, or by sending a cheque, made payable to Urostomy Association, to the address at the foot of this form.

I consent for UA to send me the following communications:			
Newsletter		Magazine	
<input type="checkbox"/>	By email	<input type="checkbox"/>	By email
<input type="checkbox"/>	By post	<input type="checkbox"/>	By post
If you'd also 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 as we do not share your details with third parties.)			
<input type="checkbox"/>	Yes – I give my consent for UA to send me details from stoma product suppliers:		

By submitting this form, you are consenting to the Urostomy Association holding and processing your personal data strictly in accordance with our Privacy Policy at www.urostomyassociation.org.uk/privacy-policy or available upon request.	
Signed	Date

Please post this form to:
Urostomy Association,
2 Tyne Place, Mickleton,
Chipping Campden, GL55 6UG

Contact:
Tel: 01386 430140
Email: info@urostomyassociation.org.uk
Website: www.urostomyassociation.org



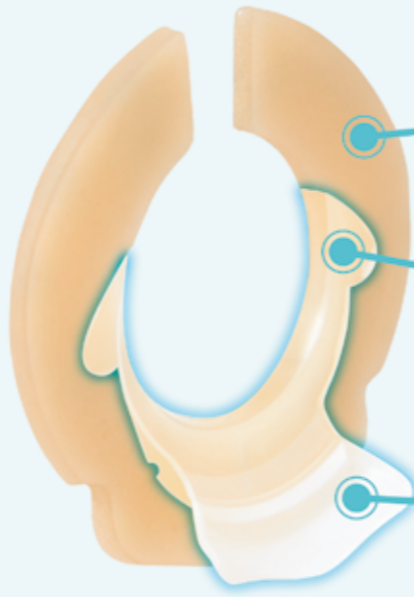
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Sunflower badge	Quantity	
Radar key	Quantity	

Name

Address

Postcode

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Urostomy Association, 2 Tyne Place, Mickleton, Chipping Campden, GL55 6UG

Email: info@urostomyassociation.org.uk