UROSTOMY ASSOCIATION
journal

Issue 128
Summer 2023

DIVERSITY, DIGNITY AND STYLE MEET THE CHANGE-MAKER CHAMPIONING EVERY BODY

SEE PAGE 18

Registered Charity Number: England and Wales 1131072 Scotland SCO47740

Welcome to the Summer Journal

Paola Simoneschi
Acting Editor

We welcome your contributions to the Journal. Please send your letters, stories and articles for the winter edition to: *editor@urostomyassociation.org.uk* by **13 October 2023.**

Your contributions should be submitted as Word documents* and any related photographs sent as jpeg attachments.

Thank you.

**If you'd like to submit a short letter for the magazine but do not have access to a computer, please send it by post to:*

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

We've got another packed edition, full of news, features and tips. I hope you enjoy reading it as much as I've enjoyed putting it together with input from members and other contributors.

People living with a urinary diversion are not one homogenous group, so creating a magazine that's an engaging, useful read for as many as possible is quite a challenge, and this is why I'm always encouraged to hear from you. Whether it's to share your story, highlight a particular issue or pass on tried and tested suggestions that have worked for you, thank you for contributing to the more open conversations that need to happen, raising awareness, creating better understanding and helping more people live with increased confidence.

In this edition, Laura MacKenzie tells her story of how she came to be living with not one bag but two, while trailblazer Victoria Jenkins shares what spurred her into action to create Unhidden, an adaptive clothing brand that's already made waves at London Fashion Week and been featured in 'Vogue'.

There's also latest news from the Association, including the important, positive change that's making our services more accessible and our community more inclusive. Plus, there are tips to help you get the most out of summer, whether you're at home or abroad.

Until next time.

Paola

Paola
Paola Simoneschi
Acting Editor

PS Don't forget it is free of charge to join the Association – please see page 44 for details.

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

A very big thank you to everyone who has contributed to this edition of 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 everyone who contributed photographs for this edition. All photography included in our article 'From Lightbulb Moment to London Fashion Week', as well as the image on our front cover, is by Deb Burrows. Photographs on pages 8, 9, 15, 17, 27, 29 (apart from the picture of Alex Shepherd) and 31 – 37 are courtesy of Pexels; photograph on page 44 is courtesy of Shutterstock.

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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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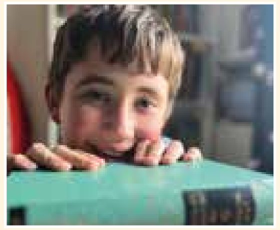

UROSTOMY ASSOCIATION

Registered Charity Number:
England and Wales 1131072 Scotland SCO47740

We are the national charity providing information and support for people with – or are 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 45 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!

Peer-to-peer 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.

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

National Executive Committee

all are Directors and Trustees of the Association

National Office

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www.urostomyassociation.org.uk

Making your voice **heard** in **Parliament**

In April, our Chair of Trustees Brian Fretwell represented the Association and our community at a parliamentary reception organised by the Urology Foundation and the Urology Trade Association and hosted by Chris Green, MP for Bolton West and Atherton.

Bringing together clinicians, industry representatives, patient organisations and policymakers, the event focussed on how best to keep patient choice at the heart of the NHS and medical technology (medtech) reform. Following an introductory speech by Chris Whitehouse, Chair of the Urology Trade Association, David Lawson, Director of the MedTech Directorate of the Department of Health and Social Care, spoke on changes needed to put patients at the centre of decision making about their care, and for closer working with patient organisations like our own.

"This was encouraging as David will be leading the review of Section IX of the Drug Tariff, which includes stoma appliances," said Brian. "I had the chance to talk to him one to one, and he welcomed the opportunity to engage with the Association to discuss the forthcoming review.

"I also met Mary Garthwaite, Chair of the Urology Foundation, which is dedicated to the fight against urology disease, and we had an initial conversation about ways in which our two charities could work together to enhance the services we provide for all who need us."

We are seeking follow-up meetings to continue these important conversations about collaboration – we will keep you informed on progress.

Debate on the future of stoma care

Just a few weeks after the parliamentary reception, the Association was made aware of an upcoming Westminster Hall debate on the future of stoma care. Brian took the opportunity to email leader of the debate, Giles Watling, MP for Clacton, asking him to raise the following three points for consideration:

Choice of equipment – One size does not fit all, and stoma patients need to have the choice of a variety of products from different companies. It is sometimes the case that a urostomate can have serious skin issues from using the particular type of adhesive used by one company and therefore needs the freedom to change suppliers.

Access to a specialist stoma nurse when needed – Ideally, it would be useful for people with a urostomy to have an annual check with a stoma nurse, but in the main, that is not possible currently. Where one person might only need to see a nurse once in ten or more years, another can have constant problems with leakage and would benefit from more regular specialist nursing advice.

Education of GPs – GP surgeries are required to approve prescriptions for stoma supplies but have been known to delete items requested on a cost basis, not realising this will cause suffering for the patient.

We are pleased to tell you that all three points Brian raised were included in the MP's speech.

The full report of the debate, which took place on 17th May, can be found in Hansard at ***www.hansard.parliament.uk*** *(search 'future of stoma care').*

Positive change to help UA thrive

We never want anyone to miss out on the reassurance, information and support the Association provides to help people with a urinary diversion get the most from life. So, we're delighted to share the positive news that UA is now providing its services free of charge for everyone, both our current members (who all have voting rights) as well as people who prefer to join our community as a 'friend' rather than signing up for membership.

When we put to our members the proposal to reduce the Association's annual subscription fee to £0, the overwhelming majority voted in favour of this change, recognising the need for our charity to become more inclusive, which in turn means we're in a stronger position to secure the grants, donations and corporate sponsorship that will increase our resilience for the months and years to come.

Now that it's free of charge to become part of UA's community, everyone who needs us can join, regardless of their financial circumstances. We are also more attractive to people who are seeking information, support and camaraderie but do not find the idea of membership appealing.

As we have been communicating to our members over recent months, reducing UA's annual subscription fee to £0 is something we've given lots of careful consideration. We went ahead with putting this proposal to the vote based on what stoma care nurses were telling us about the fee creating a barrier to their patients joining, and because subscription renewals have been falling for some time. Standing still simply wasn't an option.

Whichever way you voted at our Extraordinary General Meeting in early July, thank you for taking part. It was clear from your queries and feedback just how much you care about the Association and us being here, not just for the short term but for generations to come. Just like us, you want UA to continue being the trusted friend people need when they are facing surgery and recovering afterwards. This is so heartening.

Change can feel unsettling, but it is absolutely necessary for growth, and we are so pleased to have you with us as part of our UA family, which now has the very best chance of thriving.

Your support makes a vital difference

With membership now free of charge, as well the option for people to join the Association as a friend if they prefer, our charity is more inclusive and hence, better placed to secure grants to help fund our services. We are also continuing to build on our strong relationships with corporate sponsors, including stoma product suppliers.

What remains crucial is that we continue to receive support from the caring community of people who use our services, download our resources and receive our newsletter and magazine.

Many of you are choosing to keep your standing orders in place so that the Association receives them as a donation, and some of you are increasing the amount you give. This is much appreciated, as are each of the gifts we receive via our website, over the telephone and by post.

Each time you make a donation of whatever you can afford, or fundraise for our charity, you are doing something really kind for others who need the encouragement, trusted information and unwavering support UA provides. Your generous gestures mean more to these people than you may ever know, ensuring they have a 'safe place' to turn to, whether they are facing surgery, adjusting in during the months afterwards, or encountering challenges further along on their journey.

Thank you so much for your continued support. Together with our members and friends, we will continue making a really positive difference for people living with a urinary diversion, and for their family and carers, too.

Brian Fretwell
Chair of Trustees

Hazel Pixley
Chief Executive

> "Change can feel unsettling, but it is absolutely necessary for growth, and we are so pleased to have you with us as part of our UA family, which now has the very best chance of thriving."

Members and friends

Both our members and people who sign-up to the Association as friends have **access to all our services**, from our **helpline** to the **one-to-one support** we provide and our **resources** covering a wide range of topics. Our **newsletters** and the **Journal** are for **both groups**, too.

We welcome feedback and suggestions from both members and friends, who will have the opportunity to join the UA Voices* group we are developing to give our community more say in how the Association is run and the services we provide. If you are a UA member, you will continue to receive invitations to our charity's Annual General Meetings and remain eligible to vote in the ballots we hold.

**Formerly referred to as Membership Council*

Communi-tea & connections

Afternoon tea isn't just about the nation's favourite brew and delicious treats, yummy though they are. It's an opportunity for social refreshment and connection, encouraging conversations big and small.

It was such a pleasure meeting all of you who joined us for our 50th Anniversary Afternoon Teas at venues up and down the country over the past year. These events, which we'd had to put on hold due the pandemic, felt all the more special because, finally, we were connecting with members in person once again, while you also connected – or reconnected – with each other.

Across 22 Afternoon Teas, 331 of you enjoyed tea and cake while UA's Chair of Trustees Brian Fretwell and Chief Executive Hazel Pixley shared latest news from the Association, answered your questions and listened to your ideas. From your feedback, we know you also appreciated the opportunity to meet representatives from the stoma products companies who attended.

Thank you to everyone who joined us. It was wonderful seeing so many familiar faces as well as meeting newer members. The Afternoon Teas didn't just expand waistlines but UA's understanding of what members and their families find most helpful from the Association, as well as where we can do even more so our charity continues to have a really positive impact on their lives. We are very grateful to our big-hearted gold sponsors, Hollister and Salts Healthcare, for making these special events possible, and indeed to all the exhibitors who took part.

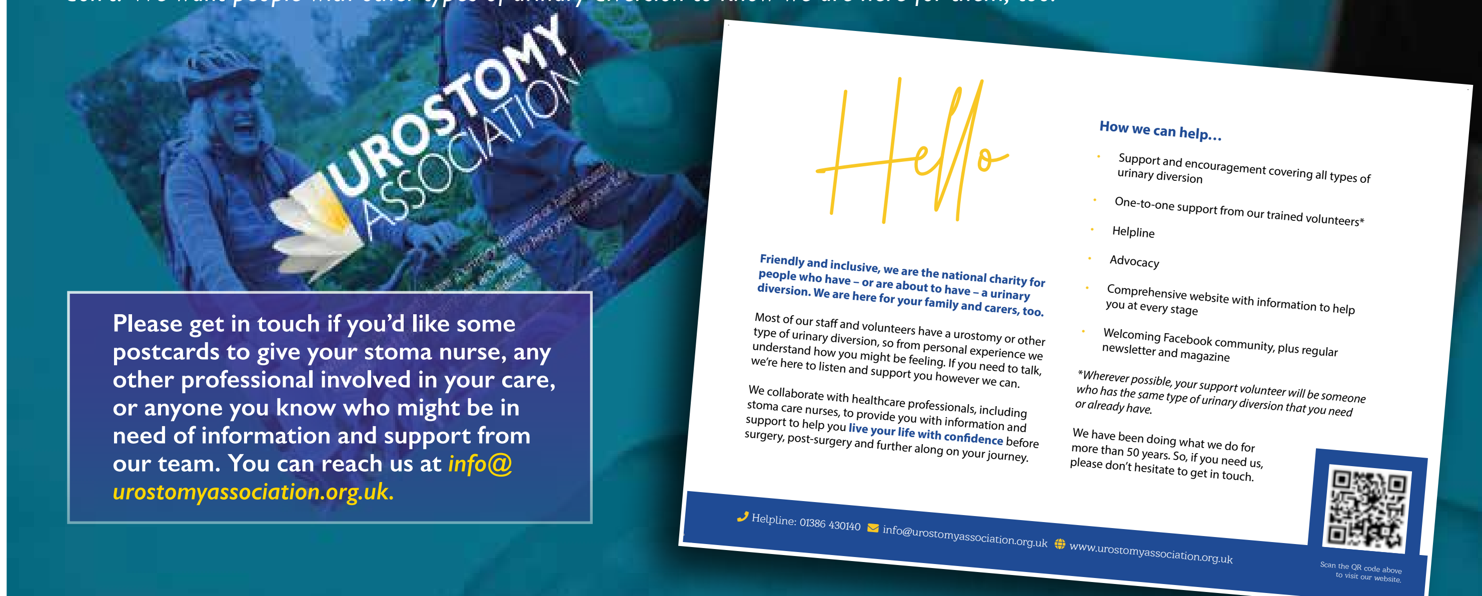
Fun facts

- **170 litres of tea and coffee drunk**
- **625 scones devoured**
- **6 litres of cream consumed**

Simple signposting

At UA, we strive to help everyone who needs us, no matter where they are on their journey, but first and foremost we need them to be aware of our charity and make it really easy for them to find us. That's why we created our eye-catching, handy postcards for stoma nurses to give to anyone who could benefit from the services the Association provides.

"Not all stomas are the same, and the postcard is a reminder to nurses that we are the national charity specifically for people with a urostomy, whose needs will be different to those with an ileostomy or colostomy," said UA's Chief Executive Hazel Pixley. *"It's vital that urostomates and their families receive information and support tailored to them. It's potentially harmful if they don't! We want people with other types of urinary diversion to know we are here for them, too."*



Friendly and inclusive, we are the national charity for people who have – or are about to have – a urinary diversion. We are here for your family and carers, too.

Most of our staff and volunteers have a urostomy or other type of urinary diversion, so from personal experience we understand how you might be feeling. If you need to talk, we're here to listen and support you however we can.

We collaborate with healthcare professionals, including stoma care nurses, to provide you with information and support to help you **live your life with confidence** before surgery, post-surgery and further along on your journey.

How we can help...

- Support and encouragement covering all types of urinary diversion
- One-to-one support from our trained volunteers*
- Helpline
- Advocacy
- Comprehensive website with information to help you at every stage
- Welcoming Facebook community, plus regular newsletter and magazine

**Wherever possible, your support volunteer will be someone who has the same type of urinary diversion that you need or already have.*

We have been doing what we do for more than 50 years. So, if you need us, please don't hesitate to get in touch.

Helpline: 01386 430140 info@urostomyassociation.org.uk www.urostomyassociation.org.uk

Scan the QR code above to visit our website.

Please get in touch if you'd like some postcards to give your stoma nurse, any other professional involved in your care, or anyone you know who might be in need of information and support from our team. You can reach us at *info@urostomyassociation.org.uk*.

Laura's story...

Two bags for life

My name is Laura. I'm 47 years old and live in Wemyss Bay on the west coast of Scotland. When I saw on the Association's Facebook page the reminder that in telling our own individual stories we can help create more understanding, encourage feelings of hope and take away the stigma surrounding stomas, it was the prompt I needed to share my story with you.

Everyone's bladder cancer story is unique and mine is certainly unusual. My diagnosis was Stage 4 invasive squamous cell carcinoma, a rare form of bladder cancer. My specialist doctor advised me that it accounts for less than five percent of all bladder cancer cases globally. As he explained, it's most commonly found in African countries and linked to a water-carrying parasitical infection called schistosomiasis. I hadn't visited any high-risk countries so in my case it was attributed to the repeated urinary tract infections (UTIs) I had suffered from any early age.

The cancer was found late. My first symptom was passing faeces in my urine. Initially, I thought it was blood and yet another UTI. I had suffered and had been treated for UTIs on and off since I was seven years old. The two to three years leading up to my diagnosis had seen the frequency and severity increasing, and each episode was treated with antibiotics.

Due to the advanced stage of my bladder cancer, it was through the bladder wall and into my pelvic area, and difficult to diagnose the origin. Indeed, initially it was believed to have started in my bowel. Confirmation that the origin was in my bladder only came 29 days after surgery when the pathology results came back, although the numerous pre-operative scans had started to point to an origin in my bladder.

Specialist surgery

The surgery I had was a total pelvic exenteration (TPE), which is considered radical surgery. As it is very invasive, it can only be carried out by specialist colorectal and urology surgeons trained in the procedure. In Scotland, for example, there were only three specialist doctors who were trained to carry out the surgery at the time of my operation. Two of them were involved in my operation.

A TPE is only carried out when there are absolutely no alternatives and when the cancer is contained within the pelvic area. It involves removing all organs from the pelvic area and results in the creation of two ostomies: an ileal conduit and a colostomy.

Most often used for recurrent gynaecological cancers, such as cervical cancer, a TPE carries double the mortality rate of a normal operation, and post-operative complications are likely in almost every of case.

So why the surgery? Firstly, in my case, it was the only option to save my life. I had about two weeks to live at the time of surgery. Secondly, despite the complexity of the operation, it is done with the goal of curing rather than treating the cancer.

Life beyond

Five and a half years on, I am currently still cancer free. I had my last annual scan in November 2022.

So, what is life like with two ostomies? Well, it is often double the work! They each need to be cared for and looked after in different ways.

My ileal conduit bag (urostomy) needs to be changed daily or more in my case. (Many people with a urostomy can wear their bag for two to three days or longer before changing.) In between times, I empty it throughout the day. At bedtime, I attach a night bag, which means I sleep through without needing to get up to empty my bag.

> "Thank you to UA for raising awareness, fighting stigma and everything else they are doing to create better understanding for me and others like me so that our voices don't go unheard."

My colostomy is quite different to deal with daily. The output from a colostomy can vary greatly and will determine the type of ostomy bag and care needed. My output is quite similar to how it was before my surgery - similar to the output of someone without a bag, ie quite well formed. This allows me to wear a closed bag, which I change rather than empty. It depends on what I have eaten, but normally I only need to change it once or twice a day.

When I had my operation, my colostomy filled me with more fear than my urostomy. I had visions of odour issues and all sorts. I am not a parent and at that point I had never changed a nappy, so for me poo was a taboo!

I quickly realised though, that my relatively predictable colostomy was much easier to manage than my retracted urostomy.

Diet wise, I have little to consider with my urostomy. What is absolutely key with a urostomy, and even more so with two stomas, is to keep hydrated.

Forever thankful

I live a good life, working full time as a Global Service Delivery Manager and enjoying cooking and long haul travel to the Indian Ocean and the Caribbean. I also volunteer with Flight Bladder Cancer.

My five-year scan isn't far off. Annual scans are my confirmation that everything is all right, and coming up to this fifth and final one, I'm feeling a little bit scared but I know that's only natural.

I have adjusted well to life with two stomas and am grateful for every day my medical team and my life-saving surgery have afforded me.

Education, education, education

The work the Urostomy Association is doing, building relationships with healthcare professionals so they have more understanding of the specific needs of people living with a urinary diversion, is really encouraging and so necessary.

My GP didn't understand much about my urostomy. He was fascinated and wondered how I only changed my bag every couple of days. I showed him, explaining how I opened and emptied it, as urostomies don't have a closed bag. My stoma nurse didn't have much experience with urinary diversions either, as she is based in a local hospital that only does colostomy surgery so rarely comes across urostomies.

Thank you to UA for raising awareness, fighting stigma and everything else they are doing to create better understanding for me and others like me so that our voices don't go unheard.

CHIEF EXECUTIVE'S REPORT

In my last report I wrote "thank goodness for a nice, warm office". In our attic room, we go from one extreme to the other, as it is currently 26 degrees and rising and my admin colleague Dave has resorted to wearing shorts to work.

It's the Association's **AGM** on **Saturday 21st October**, so please look out for details in our next newsletter.

Sending out members' voting papers and then processing the responses kept us even more busy than usual earlier this summer. Thank you to everyone who took part in the Extraordinary General Meeting vote on whether or not to make UA membership free of charge. Some of you included in your responses notes and letters to be read out at the meeting, and whichever way you voted, we appreciate you taking the time to get in touch.

The vote, which went in favour of reducing the subscription fee to £0, will enable more people with urinary diversions to get the support they need for however long they need it, and the Association remains committed to ensuring a high-quality of service for both current members and new people joining.

If you are contacting the office, you may like to bear in mind that I am now not working as many hours as I was, and Dave is part time, so we cannot always answer the telephone or respond to an email instantly. We will get back to you as soon as we can, but it may not always be the same day. Thank you for your understanding.

I would like to thank Brian, our Chair of Trustees, who has picked up some of my external meetings, giving me more time in the office.

Thank you, Carmel

I would also like to thank Carmel Brady, whose contract with us came to an end recently. Carmel was managing 'Project 50+: shaping the future' and has been a great help during the time she was with us. As a team, we only met physically once, having arranged to meet for (a very long, as it turned out!) Saturday lunch in Bristol, but our small team has worked very well together and we are sorry to see Carmel leave us. I am sure we will be keeping in touch, though.

Volunteering

We held our first online volunteer induction session at the end of April, and now have new volunteers ready and willing to speak to new and existing members. All our volunteers have a urinary diversion (in most cases, urostomy) and have undergone DBS checks, along with data protection and safeguarding training.

We are already looking forward to our next induction session in September.

Funding from the National Lottery and Hospital Saturday Fund is helping to fund this work, which is greatly appreciated.

If you are thinking about volunteering with us, we'd love to hear from you. Please visit our website at www.urostomyassociation.org.uk/support-our-work for information about the various ways you can get involved.

50th Anniversary Afternoon Teas

Our 50th anniversary events, much delayed by Covid, have now been completed, and you will see a full report elsewhere in this magazine. However, I would like to add my personal thanks to all of you who attended one of the events, and to our Gold Sponsors Salts Healthcare and Hollister. Organising the events was a lot of work, but they were all thoroughly enjoyed, with scones, sandwiches and cake being eaten, and tea drunk. I understand that one or two even had a drop of something stronger.

It was a good thing that I did not attend all of the events, or I wouldn't be able to fit through the office door by now!

There are still other events going on, either in our local Branches, or open days organised by stoma care nurses or companies, so do keep a check on our website for details.

To conclude

Do remember that if you have any queries, or we can assist you in any way, we are here. Much of our information is available on our website, but you can also telephone our helpline on 01386 430140 (which is also our general office number for enquiries) to order literature, update your contact details, arrange to chat to one of our volunteers, or give a donation. We will always do our best to help!

With best wishes

Hazel Pixley
Chief Executive Officer

> "If you are thinking about volunteering with us, we'd love to hear from you."

Trustee opportunities

As a charity, we rely on our Board of Trustees to provide robust governance and set the strategic direction of the Association. These kind-hearted volunteers give their time, skills and experience because they are passionate about making a positive difference to the lives of people with a urinary diversion.

Would you like to join them and be part of a dedicated team working together for a cause close to your heart?

We have vacancies coming up for two roles, that of Chair of our Trustee Board and Members' Representative, for which we are seeking nominations by **31st August 2023**.

Being a trustee can be a very rewarding way to use your unique skills to help make things better for others. It is also a great way to get involved in our community, find out more about the charity sector and enhance your professional development. As a trustee, you are part of a team and will have the opportunity to apply your experience while learning from others. Working closely with a passionate team of people who have different perspectives is often one of the most enjoyable aspects of the role.

As the Association is a company limited by guarantee as well as a charity, both our Chair and Members' Representative are company directors in addition to being trustees.

Chair

It is our Chair's responsibility to provide leadership to our Trustee Board, enabling members to work effectively, and to support the work of the Chief Executive. He/she is required to chair four meetings of the Board per year and attend the National Annual General Meeting of the Association.

Nominees for the role of Chair will need to have experience of running a business, big or small, and/or previous experience of charity governance.

Members' Representative

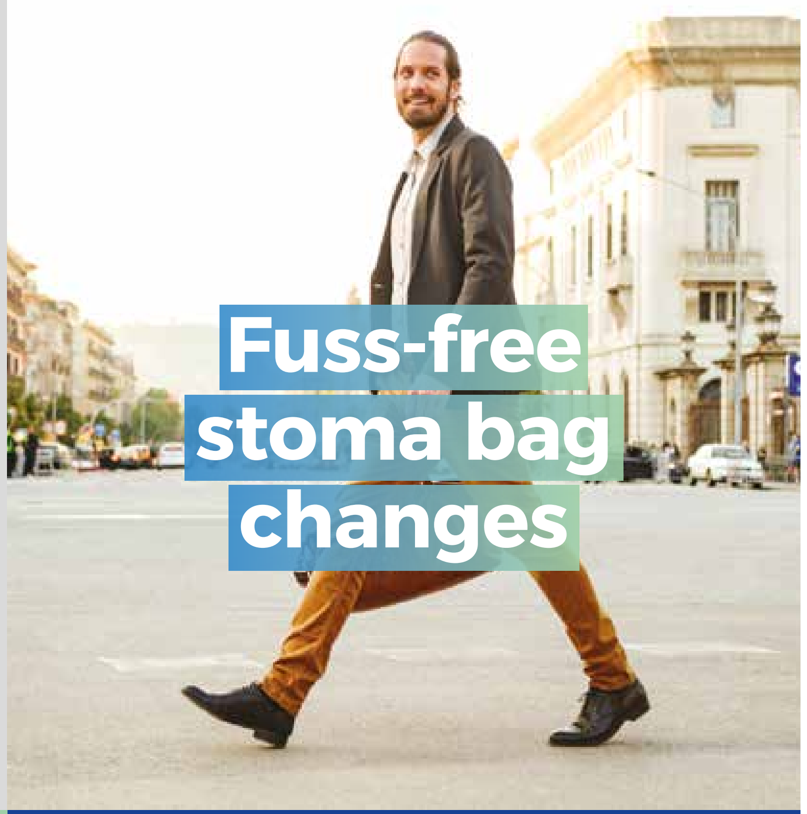
As the title suggests, our Members' Representative is on the Board to represent the people who make up our membership.

To be eligible, you will be someone with a urinary diversion who has been a UA member for at least 12 months. Good communication skills are essential and previous experience of the charity sector is desirable.

For both these voluntary roles, election is for three years, with the option to stand for re-election at the end of that period. This means that, if they would like to, our current Chair and Members' Representative can re-stand.

For more information about the role of Chair or Members' Representative, please email *info@urostomyassociation.org.uk* or call 01386 430140.

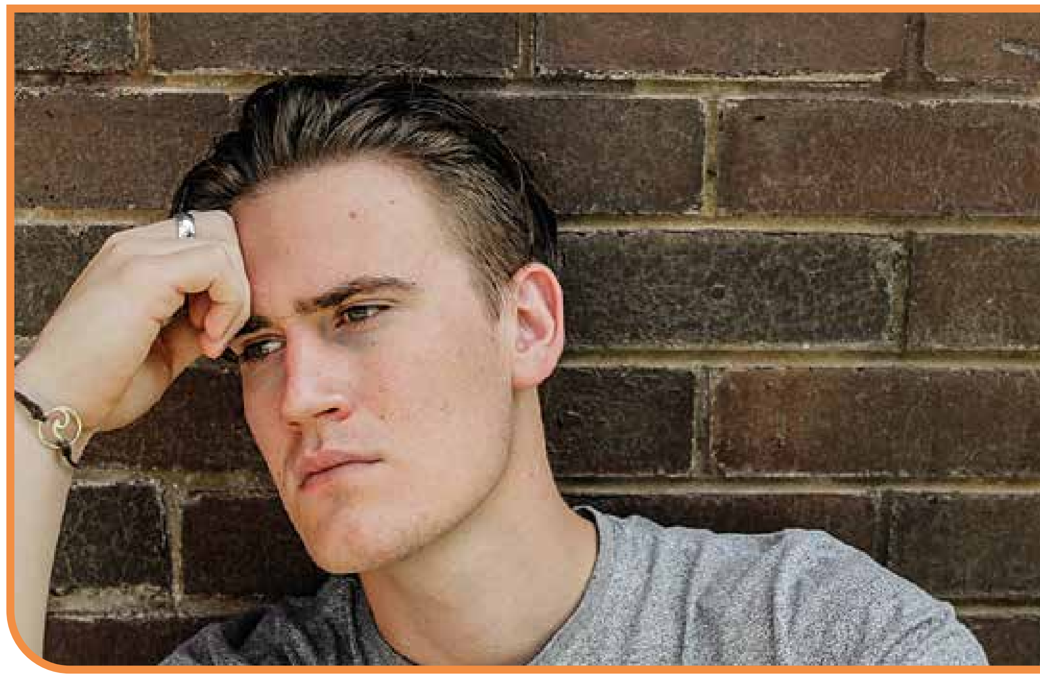
We need your nominations by 31st August latest, please, ahead of our Annual General Meeting (AGM) on the morning of 21st October. Members will be invited to attend the AGM in person or online, and further details will be included in your next newsletter.



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

Boys **Need** Bins

Just like national charity Prostate Cancer UK, we want to every public toilet to have hygiene bins within their facilities for men, so men and boys of every age can dispose of incontinence pads, stoma products and other hygiene waste items easily, safely and with dignity.



That's why, along with other charities, we're putting our weight behind the organisation's Boys Need Bins campaign*, lobbying for legislation that will make this vital difference, alleviating any feelings of anxiety or embarrassment.

"It is not satisfactory that men are told to use a disabled toilet to accommodate their needs," said Brian Fretwell, UA's Chair of Trustees, who lives with a urinary diversion.

"We're proudly supporting the Boys Need Bins campaign to get legislation updated so that men have access to sanitary bins in toilets everywhere they go, just as women do. With coverage on the BBC and Channel 4, as well as in many print publications, the campaign is gaining in profile and momentum, but there is always more that can be done. "I urge everyone who supports this initiative to contact their local MP about it. Prostate Cancer UK's website has a template you can use to send a letter."

This September, Brian will be speaking on behalf of the Association and those we represent at a Parliamentary event bringing together MPs, industry representatives and patients to push for this positive change for men and boys across the UK. Watch this space - we'll update you as soon as we can.

**UA is supporting Boys Need Bins as part of our Safe Spaces project – please see page 22 for details.*

Thank you for your support!

FROM LIGHTBULB MOMENT TO LONDON FASHION WEEK

With more than a billion people globally having some form of disability, it's incredible there's so little to choose from when it comes to 'adaptive' clothing that's as practical and comfortable as it is stylish. London-based designer Victoria Jenkins is on a mission to change this through her trailblazing brand Unhidden, which is making designs for all bodies and giving choice to this growing market.

All photography by Deb Burrows

Victoria takes up the story: "As a garment technologist, I have worked with many well-known brands - from the high street to high end - over my career. When I became disabled, it should have been then that I realised that not all of my old clothes were suited to my new needs.

"But it wasn't until a hospital stay in 2016 that I met a fellow patient who changed the course of my life and a lightbulb went on in my head. This lady had survived cancer, but was left with multiple other conditions. She had a stoma and also had lines in her arm and chest to deliver medicine. She was in hospital to have a chest port fitted.

"Every time the doctors came round she had to remove all her clothing, usually in front of a team of doctors. She couldn't access her own stoma, arm line or chest port without removing clothing or exposing herself in some way throughout her daily life. Pyjama tops and loungewear were her only options - she told me she longed to dress in nicer clothes, but nothing was suitable on the highstreet.

"Struck by this, I turned to Google, fully expecting to find companies out there to help, but my search returned very few results and none of them were sustainable. It was then that the idea of Unhidden was born.

"In 2017, while still working full time, I registered Unhidden with Companies House, dedicating every spare moment to researching other adaptive fashion brands and the needs of the community. I quickly spotted the obvious gap for something that wasn't leisurewear. There's an assumption that disabled people don't need any other forms of clothing, but they have to work too, and have social lives; they should be able to dress how they want to."

Unhidden launched officially in November 2020, on Victoria's birthday. Having started with made-to-order, the ground-breaking label now sells ready-to-wear direct-to-consumer online, and via occasional pop-up stores in the UK. The seasonless collection is transparent in its pricing; not fast fashion pricing because they pay their garment workers a living wage and are committed to ethical supply chains.

As demonstrated at London Fashion Week in February, where Unhidden became the first adaptive brand to show as a solo brand in the UK capital, the brand's designs cater to the various needs of the disabled community. The latest collection offers both standing and seated versions of trousers, taking into account the comfort of those in wheelchairs. The removal of excess material at the front of the hip and back of the knee ensures greater comfort and helps prevent pressure sores.

Tops also come in standing and seated versions, with openings for easy access to the arm for those undergoing chemotherapy or radiotherapy and those with diabetes or a long-term PICC line. The dresses have openings for stoma bags or feeding tubes, eliminating the need to remove clothing. Pockets are strategically placed for easy accessibility, and snap fastenings replace buttons, making dressing easier for people with limb differences or reduced dexterity. Soft jerseys are also available for those with sensory needs.

"To ensure our designs work for the disabled community, I consult with doctors, patients and disabled influencers, including people with stomas, listening to their experiences," said Victoria.

"I also analyse reviews and comments on other adaptive wear brands to identify areas for improvement.

FROM LIGHTBULB MOMENT TO LONDON FASHION WEEK

CONTINUED

Very few designers and brands use models with visible disabilities or show adaptive fashion on the catwalk, but for Unhidden's debut at London Fashion Week, Victoria chose a mix of models with disabilities, invisible disabilities and those with visible differences, regardless of whether they were professional models or not. "It was important to me to show the real diversity within the community," the entrepreneur explained. The brand featuring in the pages of fashion bible British Vogue was another watershed moment for Unhidden's founder and her small, closeknit team. "It is literally a dream come true," said Victoria. "But now, we're aiming for the cover!"

Clothes on Unhidden's website are signposted according to who they can help, and the company's smart tailoring and shirting in particular has significant advantages in office environments. "Not being able to dress for job interviews is a huge employment barrier," said Victoria "And don't get me started on occasion or bridal wear! It's as though no-one has realised disabled people go on date nights and get married."

Unhidden is one of the first adaptive clothing brands to operate with a responsible output. To minimise excess fabric waste and stock, items are made to order or in small batch quantities and manufactured using materials like certified organic cotton surplus bamboo silk, in a factory that uses renewable energy on the Isle of Wight, or one run by women in Bulgaria.

Eco-minded and forward-thinking, Victoria hopes to inspire the next generation of designers to think more inclusively. "Fashion students are reaching out to me directly to discuss adaptive design, so we can see that the next generation of designers are genuinely inspired by this work, and that's what we want to keep encouraging," she said.

We couldn't think of a better role model for them. Talented, compassionate and driven, this savvy change-maker isn't just bringing choice, quality and style to the adaptive clothing market, she's showing mainstream brands it's high time they woke up to the needs of disabled customers.

Systemic change is what we want to see because being different should never mean having to stay hidden.

www.unhidden.com

Safe Spaces

For many, getting immersed in the rich heritage of an historic property and uncovering captivating stories of the past is an enjoyable way to spend a day out, but if you have a urinary diversion, it's a trip that can feel fraught with anxiety and difficulties if the facilities aren't user friendly.

Over the past few months, we've been running a pilot project called Safe Spaces, where a group of UA members have considered what is needed to make a venue a good place to visit, particularly within the first 12 months of recovery after surgery.

You spoke, we listened

Initially, our group met online to define the set of criteria we could use to set the standard - it was fascinating to hear everyone's thoughts and together, we created a well-defined list.

What do we want?

Feeling 'safe' begins before leaving home. To help, we need…

- information on how far the toilets are from the car park
- a map showing the distances between key points of the property and where the toilets are in relation to them

When it comes to toilets, we need…

- a double hook on the toilet door for coat, other clothes and kit
- a clean shelf with a mirror behind it
- Clean toilets (with spray sanitiser available in case required)
- cubicle doors that go down the floor
- hygiene bins in the men's toilets just as there are in women's
- a 'Not all disabilities are visable' sign on the accessible toilets
- good lighting

We agreed that staff and volunteers at properties need…

- awareness of hidden disabilities/needs
- discretion not to ask a lot of questions when asked for support
- an attitude of compassion and understanding if there has been a leakage

Other important features…

- a map showing facilities and benches
- Non-upholstered chairs to sit on in every room and benches around the estate/gardens

Visits to Shugborough Hall and Attingham Park

Having defined our criteria, we put them to the test during visits to two National Trust properties, Shugborough Hall in Staffordshire and Attingham Park in Shropshire, where we met with staff to discuss our community's needs. Both properties are part of the Trust's wider Changing Places programme that's all about how the organisation can adapt its properties to better meet the needs of visitors.

"The staff were very open and positive, and understood how small changes, including providing key information to people before their visit, can make a huge difference to how reassured they feel," said Rachel Shepherd, who works with the Urostomy Association and is leading our Safe Spaces pilot.

"We assessed the toilets at both properties. I've never been in toilets with so many people before! The information we fed back to the National Trust teams was well received and the 'quick wins' will be actioned by their facilities teams in the near future."

"Arry Cain, from Shugborough, and Jodie Furniss, from Attingham, have both been in touch to ask if the Association would support the properties further by providing training for National Trust volunteers and access staff across the region. They've also expressed interest in partnering with us to develop this project and roll it out across other Trust properties in the UK.

"We're feeling really positive about the impact of our initiative to help make things better for our community, and will continue to keep you updated on the progress of UA's work with the National Trust as well as future projects.

"Thank you to all our volunteers who've kindly made time to be involved in shaping Safe Places pilot, including being part of our property visits. Your openness and support have made the pilot the success it is, and the changes that will be made within the National Trust are because of you."

So, what happens now?

Informed by the report Rachel is preparing for our trustees on the success of the pilot and how it could be developed into a UK-wide project, UA's Board will make its decision this September.

There's still time to get in touch if you'd like to add your comments and highlight any other criteria for what constitutes 'our safe spaces'. Also, if you want to recommend places with great facilities that help alleviate any anxiety on a day out, we'd love to hear! Please email Rachel at **Rachel.Shepherd@urostomyassociation.org.uk** or write to us at Urostomy Association, 2 Tyne Place, Mickleton, Chipping Campden, GL55 6UG.

> "Thank you to all our volunteers who've kindly made time to be involved in shaping Safe Spaces pilot"

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

Coloplast

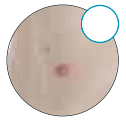
Take the Ostomy Check and check your stoma health

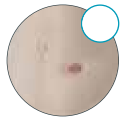
We understand over time that the size of your stoma, your body shape and lifestyle can all change. That's why it's so important you regularly check your stoma care routine and stoma health. As well as ensuring that you are still on the best product solution to fit your body shape, you will feel secure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

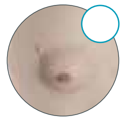
Why not take the Ostomy Check today to help you identify common issues such as sore skin, or problems with adhesion and leakage. We'll then review your answers and a member of our dedicated Coloplast Clinical Services team will contact you.

Please tick in circles where appropriate

Which best describes the area around your stoma?


○ 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: ____________________ Surname: ____________________

Email: ____________________ Telephone No.: ____________________

Signature: ____________________ 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/

Inspected and rated
Outstanding ☆
CareQuality Commission

Our Clinical Services team is rated **Outstanding** by the Care Quality Commission (CQC), who independently regulate the care our teams provide.

Coloplast

OC_OSTOMYCHECK_DTC_ADVERT_UA

Remembering Betty

Betty at Sheffield & District's 30th anniversary alongside two past branch Presidents, the late John Williams and John Anderson.

On the 22 April 2023 UA's Sheffield & District Branch lost one of its longest-serving members, Betty Palmer. Ill health had sadly prevented Betty from attending our group meetings post-Covid, but for many years she had been an integral part of the branch, having joined the Urostomy Association in 1981, shortly after the inaugural meeting of the Sheffield & District Branch.

Heart of gold

As has been said many times, if you had met Betty, you would remember her! She was a wonderful lady with a heart of gold who, as many of us will recall, could also speak her mind. For many years she held the position of branch fundraiser, and every summer, supported by her husband Jeff, and members of her family, she would host an afternoon tea to raise funds for the Sheffield & District Branch. Those of us who attended will remember tables laden with cakes of every description and flavour, not forgetting, of course, Betty's wonderful homemade scones served with strawberries and cream.

Betty and Jeff's garden was always a picture of colour, and whether we were huddled under the gazebo out of the rain or slapping on the sunscreen, there was always a lot of laughter around the tables.

When Jeff sadly died, Betty continued her annual fundraising event. I'm not exactly sure how much Betty raised for our branch over the years, but I know it certainly ran into several thousands of pounds.

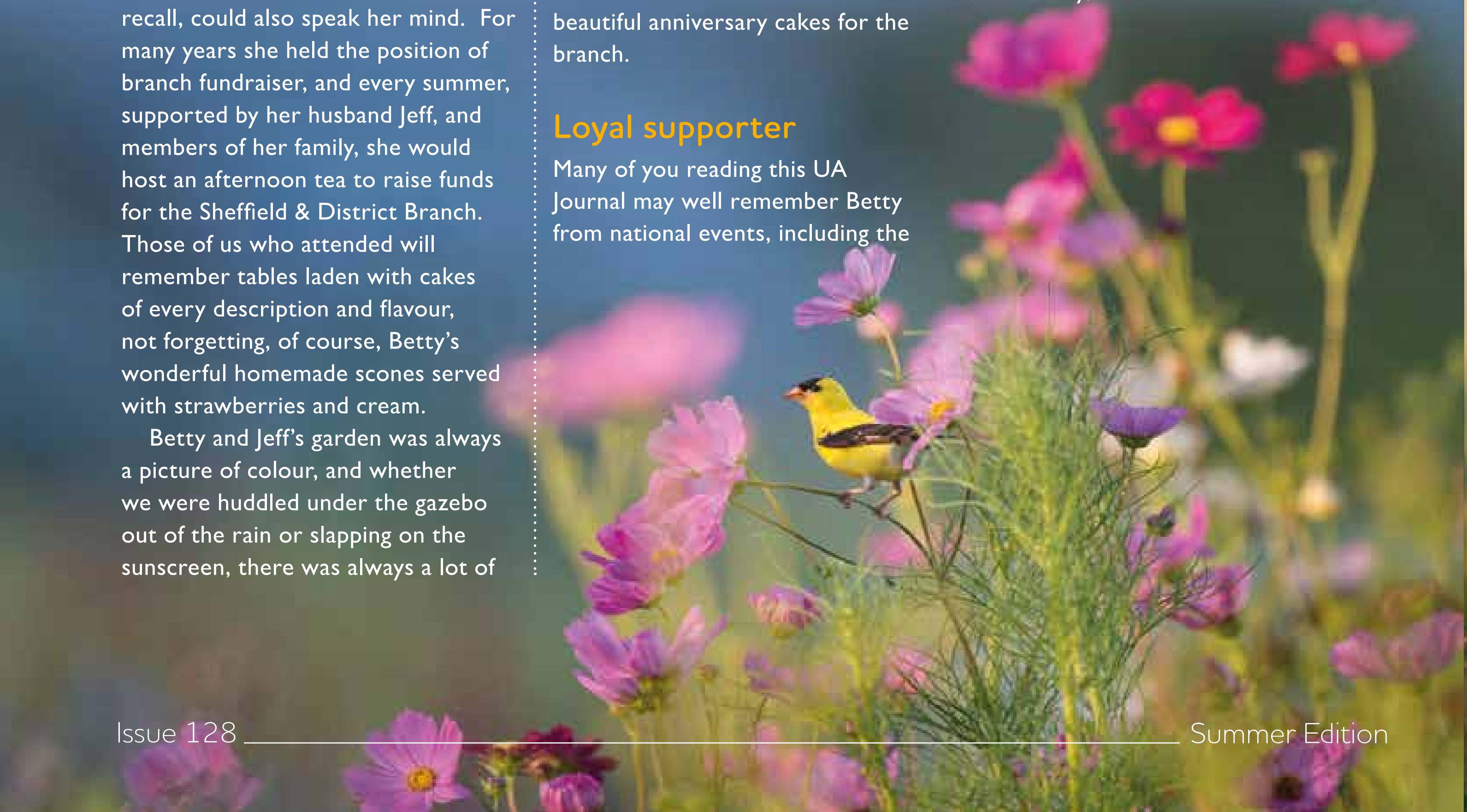
Still with her fundraising hat on, Betty was one of the most enthusiastic seller of raffle tickets I have ever known. If she had you in her sights, you were not going to escape her endeavours; even if you had already bought some, there might be a winner in a book of different coloured tickets! Alongside her daughter Joanne, she would source some wonderful raffle prizes – her cuddly toys could certainly rival the 'Generation Game'! Betty and Joanne have also baked and decorated some beautiful anniversary cakes for the branch.

Loyal supporter

Many of you reading this UA Journal may well remember Betty from national events, including the AGMs when these were held over a weekend. Betty thoroughly enjoyed these weekends away, spending time with her UA pals from around the country, always looking forward to catching up with everybody.

Betty was a fervent promoter of the work of the Association, and through our Sheffield visitor programme, she supported many ladies as they underwent urostomy surgery, and was always on hand to offer encouragement and friendly advice when asked. Her sense of humour and a positive approach to life have been an inspiration to many of us over the years, and she will be sadly missed.

Mary Milner
Secretary, Sheffield & District Branch



Self-care for carers

Did you know there are 5.7 million carers across the UK, holding families together, enabling those they care for to get the most out of life, making an enormous contribution to society and saving the economy billions of pounds? If you are one of these selfless, dedicated people, chances are you might be feeling stretched to the limit, juggling care with work and family life while perhaps struggling to make ends meet and battling poor health yourself. While it is a privilege to look after a loved one - and can be very rewarding - it can also feel isolating, relentless and exhausting.

With mental health in mind, we've put together some practical tips for carers – a toolkit of useful, actionable suggestions to help boost wellbeing and resilience. These tips are not prescriptive. What's important is finding what works best for you. Whether you try them all or pick out one or two to add to your existing routine, we hope you'll find them helpful.

Share how you feel

It can be stressful being a carer, no matter how much you love the person you are looking after. And while you don't have to share anything you don't want to, it's important not to bottle up your feelings.

Meeting a trusted friend or relative for coffee, having a chat with them on the phone or even swapping a few texts can help you destress while feeling more connected.

If you want to meet other carers, who will understand what you're going through, you could try the online meet-ups run by Carers UK.

Find time to relax

When you're caring for someone it can be easy to keep putting their own needs before your own, but taking regular breaks is important for you and the person you care for. This could be anything from taking a walk in nature or joining a yoga class to seeing friends or a trip away.

Carving some time out to recharge your batteries could also improve your relationship with the person you care for, giving you new experiences to talk about.

> *Please remember, reaching out is an act of courage and there is always someone to turn to.*

Try to stay organised

Let's face it, modern life can often feel rather chaotic. As such, it can be easy to lose track of tasks, which can lead to feels of anxiety.

Fortunately, it's never been easier to stay organised. Whether you're 'techie' and use scheduling apps or prefer a traditional diary or notebook, honing your organisational skills can help you feel more in control.

Keep active

Regular exercise doesn't just benefit your body, it's important for maintaining mental wellbeing as well.

We're not talking running for miles every day – unless that appeals! – just moving regularly and being active, from climbing stairs and walking to the shops to a gentle swim, a bike ride or even a bop around the kitchen.

As well as providing a way to decompress, exercise boosts focus, stamina and concentration, and can improve sleep quality, too.

If it's getting too much, reach out

It can feel really hard to reach out for help, even if it is desperately needed. From natural aversion to vulnerability, to fear of rejection or even judgment, asking for support can seem daunting. Please don't let this stop you. Talk to your GP, contact your local NHS mental health helpline, or get in touch with a charity, such as one of those listed below.

Please remember, reaching out is an act of courage and there is always someone to turn to.

If you or the person you look after has a urinary diversion, UA's helpline is available to you, free of charge, on 01386 430140.

We can also put you in touch with one of our trained volunteers in your local area, who will listen and provide emotional support.

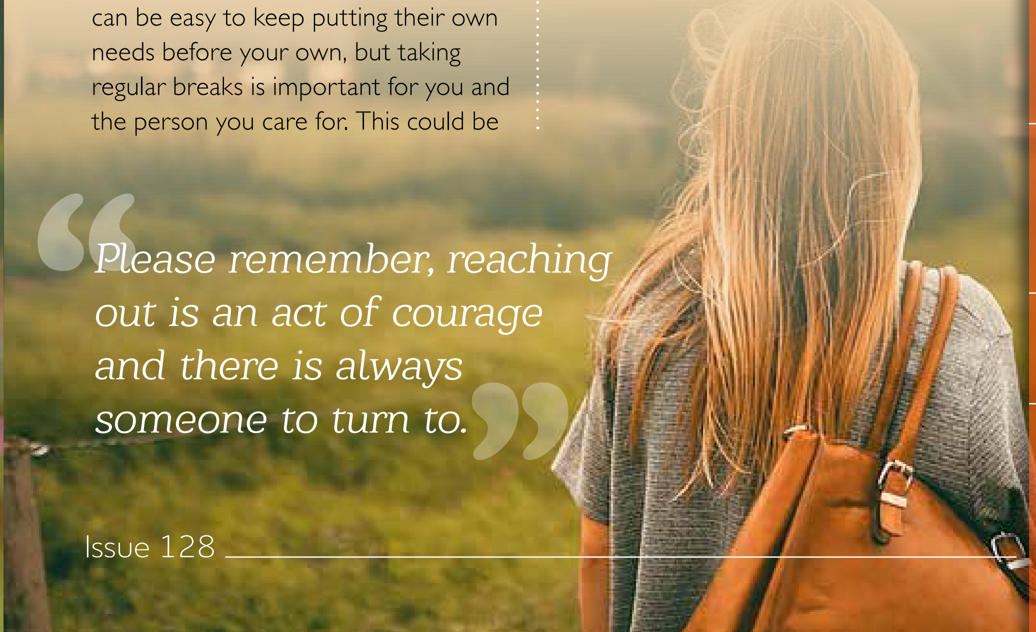
Contact details:

Carers UK
Telephone: 0808 808 7777
Email: advice@carersuk.org
www.carersuk.org

Samaritans
Telephone: 116 123
(free of charge, 24 hours a day)
Email: jo@samaritans.org
www.samaritans.org.uk

Give us a Shout
Telephone: 85258 (free text service)
www.giveusashout.org

SANE
Telephone: 0300 304 7000
(4 – 10pm)
Email: info@sane.org.uk
www.sane.org.uk



Fundraising

by Rachel Shepherd

It has been wonderful to connect with so many members of our community over the last few months and hear how the Association has helped them regain their confidence following surgery.

As our charity continues to evolve to meet the needs of people who contact us seeking information and reassurance, it's lovely to see so many of you supporting each other, whether that's through giving some time as a volunteer, sharing your story, making a donation or raising sponsorship by doing something you enjoy.

At the Association, we recognise the impact the cost of living crisis is having and that some of our members are not able to support our small charity in the way they would like to, while others who can afford to are contributing more. This really shows what a caring and kind community we have, where people can support each other when they need it.

However you choose to get behind UA, thank you for being such a great bunch!

Rachel
Rachel Shepherd, Fundraising Consultant working with UA

Supporting positive change

Making membership free of charge has made UA a more inclusive organisation, in keeping with our values and enhancing our appeal, but at the same time, we still need funding to keep our crucial services running. We're so encouraged that many of you are choosing to keep your standing order in place as a donation, and increasing the amount if you want to and have the means to do so. Thank you.

If you find it more convenient to give another way, such as over the telephone, via our website or by sending a cheque, please see page 6 for details.

Do good as you shop

Thank you to everyone who has signed up to support UA through easyfundraising.com. You've raised over **£1,000** already by just shopping as normal - with no catches and no extra costs.

If you haven't explored ***easyfundraising.com*** yet, you can download the app to your phone or go through their website so every time you shop online with Amazon, Tesco, Sainsbury's and most high street stores you will be raising money for us at no cost to you.

Lots of travel companies and hotel chains are part of the scheme, too – Tui, Jet2, Hoseasons, Travel Lodge and Holiday Inn to name just a few – so if you're booking your break with any of these, remember that if you go through easyfundraising.com to do it, you'll give our small charity a boost.

You can find out more at ***www.easyfundraising.org.uk***.

Big-hearted birthdays

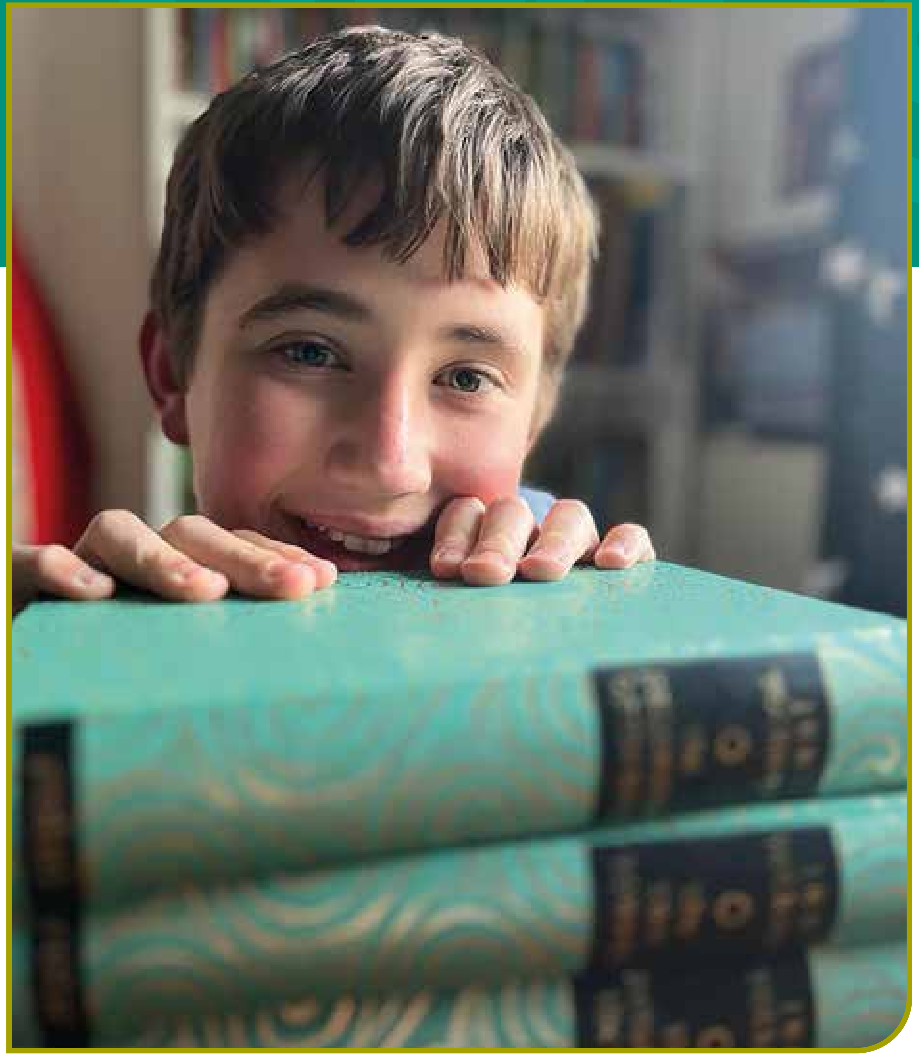
As we get older, it's often the case that the more 'stuff' we accumulate, the more it weighs us down. That's part of the reason there's a growing trend to forsake birthday or anniversary presents and ask friends and family to support a cause close to your heart instead.

Just Giving and Facebook make it straightforward for people to donate. Not sure how to set up a fundraiser this way? We have a new guide on our website at ***www.urostomyassocation.org.uk/UAyourway.***

UA your Way

UA your Way is all about making fundraising for the Association fuss free and fun by doing something you enjoy.

If you love baking, why not sell buns, brownies or cakes to raise some dough for our charity? Or get on your bike for a sponsored cycle ride? Perhaps hosting a coffee morning or quiz night is more your style. Be as creative as you like – as long as it's safe, we'll support you every step of the way!



A huge thank-you to big-hearted ten-year-old Alex Shepherd (pictured right), who has gone above and beyond to raise a fantastic £300 for our charity, after learning there are people who have to adapt to weeing differently and that they often face stigma because of this.

Alex, who lives in Bromsgrove, said: "I love books so I decided to ask people to sponsor me to read for 100 consecutive nights. I really enjoyed it and read everything from 'Swallows and Amazons' to 'The Beano'. My favourite was the 'Lord of the Rings' trilogy. That was extra special because the set of books was given to me by my godmother Karen, who inherited them from her mother. I really treasure them!

"A big thank-you to my family and friends who sponsored me, helping to make things better for people who are recovering after a big operation, getting used to weeing differently and living with a bag."

UA's Chief Executive Hazel Pixley said: "The Association's services are a lifeline to many, but as a small national charity we are only able to keep providing these thanks to kind-hearted supporters like Alex. Taking on a sponsored challenge just as he did is a fun way to help us continue to be here for everyone who needs us whether that's before their surgery, as they recover or further down the line."

Well done, Alex, you have done our community proud!

We also want to say a big thank-you to Ian and Janet Ball from our Cambridge Branch. The couple donated £755 from a fundraiser organised as part of the celebrations for their 50th wedding anniversary, a generous gesture that will help UA ensure more people who need support feel heard, reassured and encouraged. Congratulations on your Golden Wedding Anniversary, Ian and Janet!

Join our **fantastic fundraisers**

Fundraising for our charity is a great way to show your compassion – it means we can help more people adapt to life beyond surgery, listening, answering their questions and providing encouragement when they need it most so they can live life more confidently.

On our website, you'll find ideas and inspiration to get started with fundraising your way – visit ***www.urostomyassociation.org.uk/uayourway.*** Let us know what you're planning – we're here to support you.

Have fun!

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 already 200+ Club subscribers, to consider taking a number for

Just £2 per month

We are always keen to welcome more members who would like to take part in the draws to win cash prizes.

Please join now and help us to continue to donate over **£3,000** per year to national funds.

If you can afford **£2** per month, please get in touch with me, Toni Haines, on *01952 400971*, 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 5th draw, on 1st April 2023

1st prize	of **£250**	No 8	**Jennifer Wickenden** (*Jennifer kindly donated* ***£50 back to UA***)
2nd prize	of **£150**	No 205	**J E Smith** (*Mrs Smith kindly donated* ***£50 back to UA***)
3rd prize	of **£100**	No 152	**Margaret Wilcox**
4th prize	of **£50**	No 66	**Leslie Badley**

Results of extra draw on 10th May 2023

1st prize	of **£100**	No 220	**Lynne Brown**
2nd prize	of **£91**	No 54	**Brian Fretwell**

Results of the first draw of 2023/2024, on 10th May 2023

1st prize	of **£250**	No 201	**Mark Pitchford**
2nd prize	of **£150**	No 8	**Jennifer Wickenden** (*Jennifer kindly donated* ***£50 back to UA***)
3rd prize	of **£100**	No 220	**Lynne Brown** (*Lynne kindly donated* ***£50 back to UA***)
4th prize	of **£75**	No 262	**Bertram Leslie**
5th prize	of **£50**	No 287	**Alison Sinfield**

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**

Make a lasting **impact**

Leaving a legacy is the final chapter of your story. It’s an act of kindness that can leave the world a little better than you found it.

Naturally, you want your will to make provision for your nearest and dearest. If you also want to leave a gift to charity, you might find it helpful to think about what inspires you, resonates with your values and feels like the best way to help future generations.

At the Urostomy Association, we know that leaving a gift in your will can make a vital difference to people as they recover from major surgery and adapt to their ‘new normal’, learning to urinate differently and getting used to life wearing a bag. At what can feel a very anxious and lonely time for them, with not just physical challenges but emotional and practical ones too, support from our friendly team can feel like a lifeline, gradually increasing their confidence and bringing hope for a brighter future.

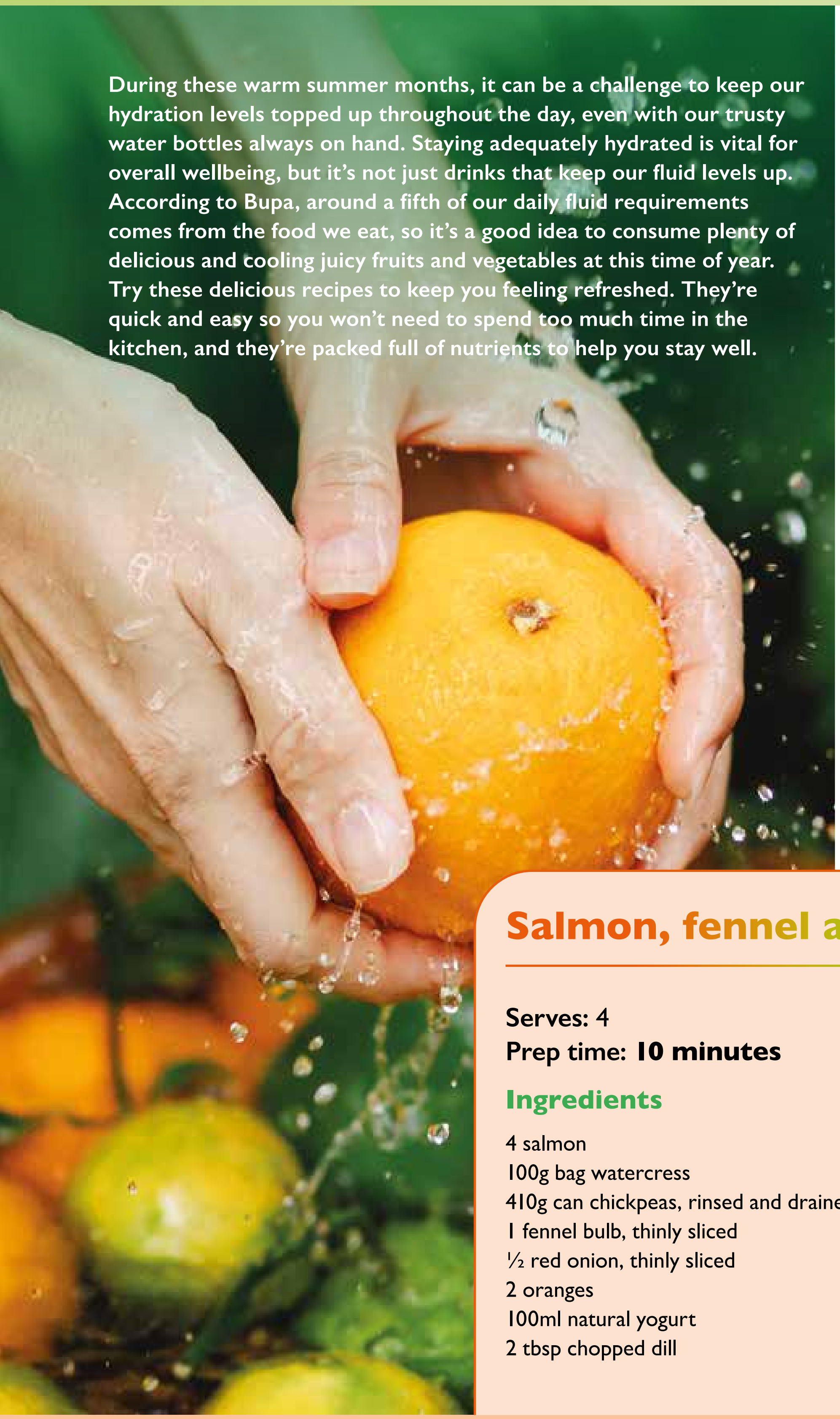
To find out more about making a gift to the Association in your will, please visit ***www.uroatomyassociation.org.uk/support-our-work*** or telephone **01386 430140.**

“The Urostomy Association has helped me so much. I want to make sure other people get the same support when they need it most.”

Hannah, UA supporter

> “…it is the intention behind the gift that says so much about the person who has written it into their will.”

Heavenly hydration



During these warm summer months, it can be a challenge to keep our hydration levels topped up throughout the day, even with our trusty water bottles always on hand. Staying adequately hydrated is vital for overall wellbeing, but it's not just drinks that keep our fluid levels up. According to Bupa, around a fifth of our daily fluid requirements comes from the food we eat, so it's a good idea to consume plenty of delicious and cooling juicy fruits and vegetables at this time of year. Try these delicious recipes to keep you feeling refreshed. They're quick and easy so you won't need to spend too much time in the kitchen, and they're packed full of nutrients to help you stay well.

Greek salad

Serves: 4 people as a side
Prep time: **15 minutes**

Ingredients

4 large vine tomatoes, cut into wedges
1 cucumber, peeled, deseeded and roughly chopped
½ a red onion, thinly sliced
16 Kalamata olives
1 tsp dried oregano
85g feta cheese, cut into chunks
4 tbsp Greek extra virgin olive oil

Method

This one's really easy – just put all the ingredients in a bowl and season lightly. Then serve with crusty bread to soak up the juices.

Salmon, fennel and orange salad

Serves: 4
Prep time: **10 minutes**

Ingredients

4 salmon
100g bag watercress
410g can chickpeas, rinsed and drained
1 fennel bulb, thinly sliced
½ red onion, thinly sliced
2 oranges
100ml natural yogurt
2 tbsp chopped dill

Method

Put the salmon in a microwave-proof dish, cover with cling film, then cook on High for 3½-4 mins until the salmon is just cooked. Peel the skin away and flake into large chunks.

Toss together the watercress, chickpeas, fennel and onion, then arrange on a large platter. Zest one of the oranges, cut away the skin and pith from both fruit, then segment them both. Squeeze the juice from the middles of the oranges into a bowl and mix 2 tbsp of it with the yogurt, dill, zest and seasoning.

Scatter salmon over the salad, then serve drizzled with the creamy orange dressing.

Please get in touch with your recipe, plus a photograph of you (sent as a jpeg attachment) – and if possible, your creation - at editor@urostomyassociation.org.uk.

Green gazpacho

Serves: 4
Prep time: **15 minutes**

Ingredients

2 medium cucumbers
1 medium white onion
1 medium green bell pepper
1 clove garlic
1 medium avocado
1/4 bunch fresh parsley
1/4 bunch fresh coriander
2 tbsp olive oil
1 tsp salt
1 tbsp lemon juice
1 cup water

Method

Remove the ends from the cucumber and slice it in half lengthwise. Scrape the seeds out with a spoon and then chop the cucumber into chunks. Remove the seeds from the bell pepper and cut it into chunks. Dice the onion. Add the cucumber, bell pepper, onion, and garlic (peeled) to a food processor. Process until the vegetables are minced.

Pull the leaves from about 1/4 of the parsley and coriander bunches. Add the leaves to the food processor along with the olive oil and the flesh from the avocado. Purée until smooth.

Add the water, one tablespoon of lemon juice, and one teaspoon of salt. Purée until smooth again. Taste the soup and adjust the salt or lemon juice if desired.

Serve immediately or chill until ready to eat.

Enjoy!

Peach, apple and carrot smoothie

Serves: 2
Prep time: **10 minutes**

Ingredients

1 small to medium carrot, peeled
2 medium size apples, peeled and deseeded
1 medium size peach, peeled and stone removed
5 tablespoons of fat free yogurt
5 tablespoons of milk

Method

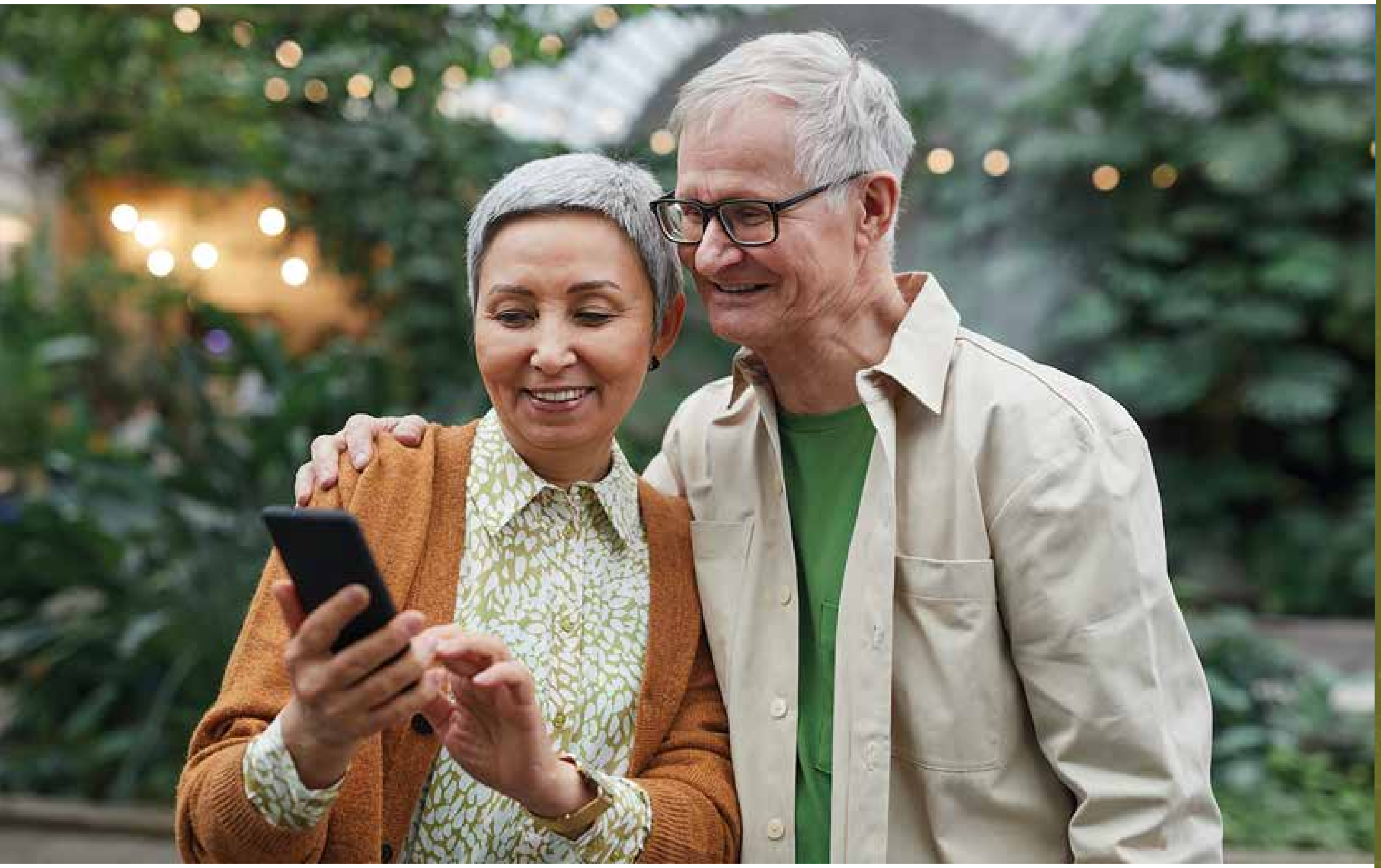
Chop the carrot, apples and peaches into bite-size pieces and place them into a blender.

Pour the yogurt and the milk and blend until smooth.

Serve immediately.

Find us on Facebook

For many people who access information and support from UA, Facebook is a handy way to keep in touch with others in our community and with the Association itself.



Private members' group

We're delighted that lots of you are already benefiting from being part of our growing Urostomy Association Members Group on Facebook, a private group just for people with a urinary diversion, and and their family and carers too. This welcoming, friendly group is growing daily, and it's heart-warming to see members swapping stories and providing encouragement to each other, no matter what they are facing or have already overcome.

Public page

Having a thriving private Facebook group is important, but to tackle the stigma that exists around urinary diversions and help create more understanding for those who have them, we need to be communicating with the world at large, busting myths and challenging stereotypes.

To help us do this, we're have a public Facebook page, and one of the most effective ways you can show your support for the Association is to follow us there. Not only is it handy for keeping up to date with all things UA, it will encourage more open, honest conversations about what it means to have a urinary diversion and help us reach more people who would benefit from the information, advocacy and support our charity provides.

It's on our public page that we share stories, publish useful tips and keep you abreast of our news, events and campaigns. So, please follow, 'like' and 'share' our content to help us make a difference for more people.

We really appreciate your support!

WONDERS OF WALKING

Given the choice, would you walk when you've got an errand to do? Or would you jump in a car even if your destination was just ten minutes away? Walking is vastly underrated as a physical activity that's good for mind and body, so what's stopping us walking more?

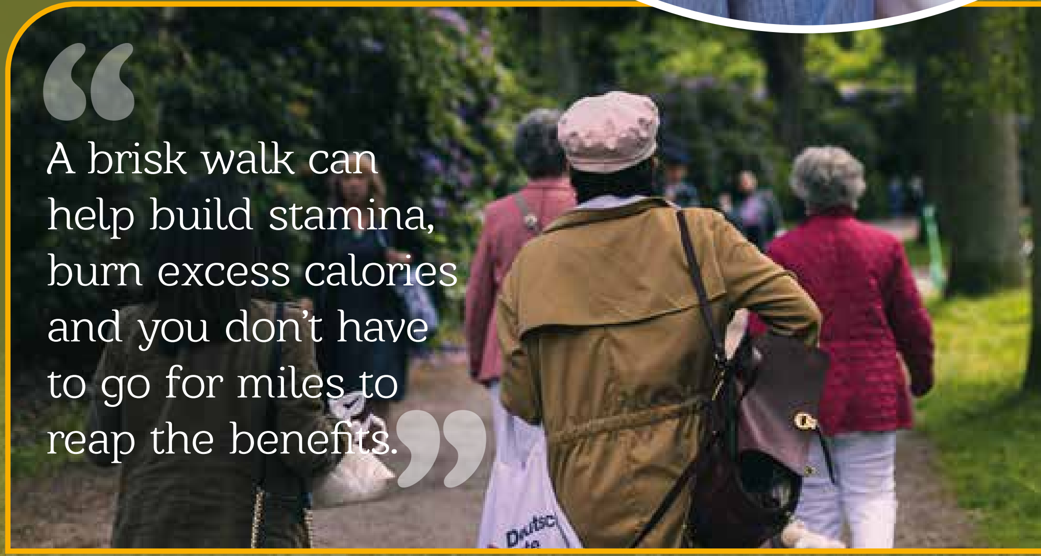
Walking doesn't require any expensive equipment and it's one of the easiest ways to be more active, stay healthy and connect with our surroundings, whether that's lush countryside, scenic coastlines or urban hustle and bustle.

A brisk walk can help build stamina, burn excess calories and you don't have to go for miles to reap the benefits. NHS guidance is for us to undertake a recommended 150 minutes of weekly exercise. Taking a brisk walk for just ten minutes a day counts towards that total. For anyone wondering, brisk is about three miles an hour and put it this way, if you're talking easily while striding out, you're probably not going fast enough! But even if you prefer a more leisurely pace, simply being active outdoors is beneficial, boosting mood and fitness.

Walking is one of life's simplest but most versatile activities. Far more than getting you from A to B, it offers a wealth of possibilities for socialising, exploring, and relaxing.

Enjoy time out

If you prefer heading out on your own to get those steps in, taking a solo walk is a great way to clear your mind or gather your thoughts. It's a proven stress-buster, and an opportunity to catch up with a podcast or listen to some of your favourite tunes.



> "A brisk walk can help build stamina, burn excess calories and you don't have to go for miles to reap the benefits."

Get social

Walking is the perfect social activity. You could try asking friends and family about their favourite trail and join them on their next walk, or join a local walking group. The beauty of being part of a group is that whichever walk of life you come from, you have your love of great views, fresh air and nature in common.

Feel inspired

Can you guess what Tchaikovsky, Steve Jobs and Charles Dickens all had in common? They insisted on a lengthy walk as part of their daily routine. Dickens scheduled a three-hour stroll each and every afternoon to invigorate his mind before a solid night's work. In fact, throughout history, some of our greatest artists and thinkers saw walking as their single greatest source of inspiration and relaxation. So, now's your chance to get out there and contemplate that great idea you've had for years!

If you're not very active, it's best to increase your walking distance gradually. If you're not active because of recent surgery or a medical condition, do seek advice from your GP before starting or increasing exercise.

Fancy a dip?

Living with a urostomy can present challenges but it shouldn't prevent you from doing the activities you enjoy. If that includes swimming – great! It's a fantastic way stay fit and healthy, and of course, it's refreshing too.

Most people are advised to wait until six weeks after their stoma surgery before swimming again, but do check with your surgeon or stoma nurse before starting. If you've been wanting to dip your toe back in the water, here are our top tips to help you feel as confident and carefree as possible in the pool.

Preparing for your swim

Before hitting the pool or wading into the sea, it's important to properly prepare.

- Check your stoma bag for any signs of damage or wear and tear, and replace it if necessary.
- Apply skin barrier or adhesive paste around the base of the bag to create a tight seal and prevent leaks.
- Make sure your bag is securely attached to your skin, and wear loose-fitting clothing to avoid any pressure on the bag.
- Take extra bags and supplies with you, in case of any leaks or malfunctions.
- Wear what makes you feel the most comfortable. Swimming with a urostomy should feel good, whatever you choose to wear in the water. See 'swimwear option' below.
- If you're feeling unsure, it's a good idea to have a trial run in the bath to see how your pouch behaves under water. You need to feel confident that it's secure.
- If you're concerned about changing in front of people, try and locate a swimming pool that has private changing rooms, so you can go into a cubicle and change.
- Towel drying or changing your pouch after coming out of the pool is a good idea.

Swimwear options

Finding the right swimwear that feels comfortable and fits properly depends on the position of your stoma and pouch.

There are companies that supply stoma swimwear, including some with an internal pocket to hold your pouch secure when swimming. Many styles for women have ruching that can help disguise your pouch should you want to, while men's trunks are designed slightly higher around the waist to incorporate any stoma pouches under the waistband and make them feel more secure.

Swimwear on the high street also offers plenty of choice, so shop around to find a style that works for you, bearing in mind that specialist swimwear isn't the only option. Some men who prefer to go with non-specialist swimwear, find that wearing Lycra cycling shorts underneath swimming trunks works well. They come up a little bit higher and secure the bag nice and tightly.

Sun spot

While most of us welcome the warmer weather of these summer months, hot days can sometimes feel more challenging if you have a urostomy.

It's usual to have concerns around skin irritation, keeping hydrated and how stoma supplies hold up in the heat, so read on to help you stay safe and comfortable as the mercury rises.

Skin issues in the hot weather

Most stoma pouches are designed to withstand extreme weather. However, increased perspiration can interfere with your pouch and its adhesion to the skin around your stoma. As your skin becomes moist it can be tricky to keep your stoma pouch in place for the usual amount of time and you may find yourself having to change your pouch more often than usual.

The heat can cause the skin barrier to break down faster, so have plenty of supplies at home so that you can change your pouch more frequently if required. (Flange extenders around the edges of your baseplate may give you more wear time.)

The skin around your stoma (peristoma) may become irritated during the summer. Applying barrier wipes or powder usually helps, but when your skin is moist with the weather warm it can interfere with the pouch adhering properly. Make sure your peri-stomal skin is completely dry before applying your next stoma pouch.

Enjoying the sun safely

It's safe to sunbathe with a stoma, but apply your stoma pouch first, so it gets a good seal before you apply your sunscreen.

If you enjoy spending long periods of time in the sunshine, it is a good idea to ensure you have an opaque cover, or an additional stoma cover, as the plastic of the pouch can magnify the heat.

Bear in mind, too, all the general safety guidance around staying safe in the sun and avoiding sunstroke. Apply a reliable sunscreen regularly, wear a hat and take regular breaks to sit in the shade or go for a swim to cool you down.

Keeping hydrated

Hydration is even more important in the summer months, especially with a urostomy. It's best to aim for 2 to 2.5 litres per day. Fill a water bottle and always keep it with you. Re-fill it throughout the day and before bedtime. Rehydration solutions, such as Dioralyte, can be helpful to restore electrolytes.

Of course, it's fine to enjoy a tipple, too, but bear in mind that drinking alcohol dehydrates you. Keep yourself topped up with water and/or soft drinks to stay well.

Storage of stoma supplies

Stoma pouches and accessories need to be kept in a cool, dry place as the heat can affect the adhesive on your appliance. If you use any accessories such as barrier rings or flange extenders, they may not work as effusively if they are warm.

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 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 Rd, Shelford CB22 5JT
Branch Secretary: Jane Phillips
Email: secretary@urostomyassociation.org.uk

We have recently had a guided walk around the Cambridge Botanic Gardens followed by lunch. It was interesting to see the difference from the autumnal walk last year and once again, the weather was good for our visit.

In April, the Stoma Care Team at Addenbrookes Hospital arranged an open day – we had a table to help promote the Urostomy Association and, in particular, our branch. We met lots of people, new as well as familiar faces, and had the opportunity to walk around to see the other exhibitors – many of whom have given talks at our group meetings, and some we have booked for later in the year. It was a lovely day and well organised by the Stoma Care Team. I think our committee members walked away with half of the winning tombola prizes!

Most of our meetings this quarter have been more social gatherings, where we have swapped stories and tips, and we have welcomed some new members and discussed future meetings and trips out. The committee has just booked an afternoon tea event for members and guests for late summer.

As ever, we are keen to welcome new members to our group. We hold a prize draw each month, with half the funds from ticket sales as the prize and the rest going into the branch funds towards social events.

Diary dates: *We meet the first Tuesday of each month, from 10.30am.*

Jane Phillips

Newcastle

Venue: Maggie's Cancer Care Centre, Melville Grove, Newcastleupon-Tyne, NE7 7AW
Branch Secretary: Eileen Spraggon
Email: secretary.newcastle@urostomyassociation.org.uk

We held our Spring meeting in March, with stoma equipment companies joining us to talk about latest developments and products.

Jo Linton from Northumberland Age UK gave members an update about the wide range of services they offer. These include information and advice, advocacy, befriending, health and wellbeing support and homecare. There was certainly a wealth of very useful information. Most of these services are also available via other branches of Age UK.

Brian Fretwell, UA's National Chair, gave an update on latest news from the Association. He explained the reasons behind the proposal to hold a vote on whether or not to reduce the charity's annual subscription fee so that membership is free of charge to everyone.

The new UA postcards were on display so that members could take copies to share with their stoma care professional as well as anyone who might be in need of support from the Association.

We have attended several open days. People were interested to see 'Bags, bags, bags', UA's book which helps start conversations with young children so they can learn about urostomies.

Our informal monthly get-togethers continue. We enjoy a cuppa and a chat with lots of laughs, and new members are always welcome.

As we are enjoying beautiful sunshine at present it is now time for me to top up my Vitamin D! I hope lots of members are doing the same.

Eileen Spraggon

Sheffield & District

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

The Sheffield & District Branch held its spring meeting at Tapton Hall, Sheffield on Saturday 1st April attended by more than 40 members and guests. Introduced by our Branch and National President, Professor Derek Rosario, we were very pleased to welcome Martyn Oxley as our new Branch Chair, and he formally takes up his new role at our summer meeting in July.

Our preceding Chair, Derek Finney, was presented with a lovely portrait of his springer spaniel, Belle, by local artist Angela Wade, the wife of our committee member Alan Wade. A gift for our retiring Treasurer Anne Turner was shown to our members. Sadly, Anne was not able to attend the meeting, so we are arranging to present this gift to her at a later date.

Always appreciated, representatives from a number of appliance and delivery companies were on hand with displays of their products and services. There was also a craft stall selling handmade Easter goodies and greetings cards, as well as a colourful selection of stoma bags covers made by one of our members.

Our guest speaker was Mark Dawson, who spoke on the history of Henderson's Relish. If you were born in Sheffield, or have spent any time in the city, you will almost certainly know all about Henderson's Relish – so good we have tended to keep it to ourselves! Meat and potato pie simply isn't right without a splash (or two) of 'Hendos'!

Mark gave a fascinating talk about the history of the sauce, including the development and marketing of this unique product, as well as its commercial ups and downs since it was introduced to the Sheffield population in 1885. Happily, the Henderson's brand is continuing to grow, and you can now purchase Henderson's crisps and a cookery book dedicated to the product. You can even buy the sauce in a blue and white or red and white striped bottle, thus enabling fans to demonstrate allegiance to their preferred Sheffield football team at the dinner table!

Some sad news to end our summer report – over recent weeks we have lost two of our longer serving members, Dorothy Cook and Betty Palmer. Dorothy had been a member of the Sheffield & District Branch since 2005 and regularly helped out at our meetings. Betty had been a member since 1981, joining shortly after the inaugural meeting of the branch. Many of you reading this may well remember Betty, who attended many national UA events over the years. In fact, if you had met Betty, you will have remembered her and it is also most likely that she will have sold you some raffle tickets! A number of us from the branch had the privilege of attending Dorothy and Betty's funerals. Both ladies will be sadly missed.

At the time of writing, we are looking forward to our July meeting, when our guest speaker will be Alan Wade, who will talk about 'Treading the Boards'.

Diary dates: *Branch AGM and lunch - Saturday 4th November.*

Mary Milner

News from the branches

Shropshire, Wales and the Marches


Bicton Village Hall

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

We finally held our first branch meeting of the year on Saturday 1st April, having been forced to cancel the original date of 11th March because of quite severe snowy conditions. Despite these difficulties, we had a good turnout and even some company representatives.

On the 6th April we had a visit to the Pelican stoma products factory in Cardiff, mainly for our South Wales members, but Graham and Gwen Catherall were also invited. Natalie Smith from Pelican and Nikki Baker from Respond looked after us very well the evening before and we enjoyed a fascinating visit to the factory. After our lunch on the day, various members of the factory team were keen to hear of our experiences as urostomates.

On 10th May, again in South Wales - Bridgend this time - we were very pleased to help celebrate UA's much-delayed (because of the pandemic) 50th anniversary celebrations. Everything went well and we plan on having the first South Wales Christmas lunch at the same Bridgend venue in late November. South Wales members and the company representatives are all very keen on a Christmas lunch, so we look forward to seeing everyone again later in the year. The hotel is easy to get to, so I think it is very likely that we have found a new home for South Wales meetings in the future.

As usual, my husband Don and I were fundraising for UA at the Norbury Canal Festival on the May bank holiday. Unfortunately, the weather wasn't kind to us and we didn't sell quite as much as we usually do, but I am sure sales will pick up over the warmer months.

We are looking forward to our July meeting with our usual buffet, and Don will be representing the branch at Newcastle the same month, as they celebrate not only their 50th anniversary but also 50 years with the indefatigable Eileen Spraggon as Secretary. She is such an amazing example to us all!

Toni Haines

Yorkshire & Humberside

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

We held our first meeting of year in May 2023 due to the planned March meeting being cancelled because of the heavy snowfall.

Our Committee is in the process of planning social events, one being afternoon tea, the first one being held at the Tingley Garden Centre Leeds on the 16th August.

Hopefully, if there is enough interest shown from members, there will be events in North Yorkshire and in the Humberside area. Please get in touch if you are interested in attending - see contact details above.


Salvation Army Church, Hunslet

Diary dates:
Our next meeting is on 19th August.

David Legood

Northern Ireland news

In Northern Ireland, our volunteer **Donna Watson** leads a popular support group for people with a urinary diversion. Group get-togethers, such as the summer picnic, are sociable and full of camaraderie and mutual support.
If you would like to join the group, please contact the Association on **01386 430140** for details.


The Urostomy Association NI picnic
Saturday 29th July 2023
12pm to 2pm
WARD PARK, BANGOR
BESIDE THE BANDSTAND

Eileen, we salute you!

With this year being the 50th anniversary of our Newcastle Branch, we want to say a huge thank-you to the big-hearted lady who has given such sterling service in the voluntary role of Branch Secretary for every one of those 50 years – the indomitable Eileen Spraggon.

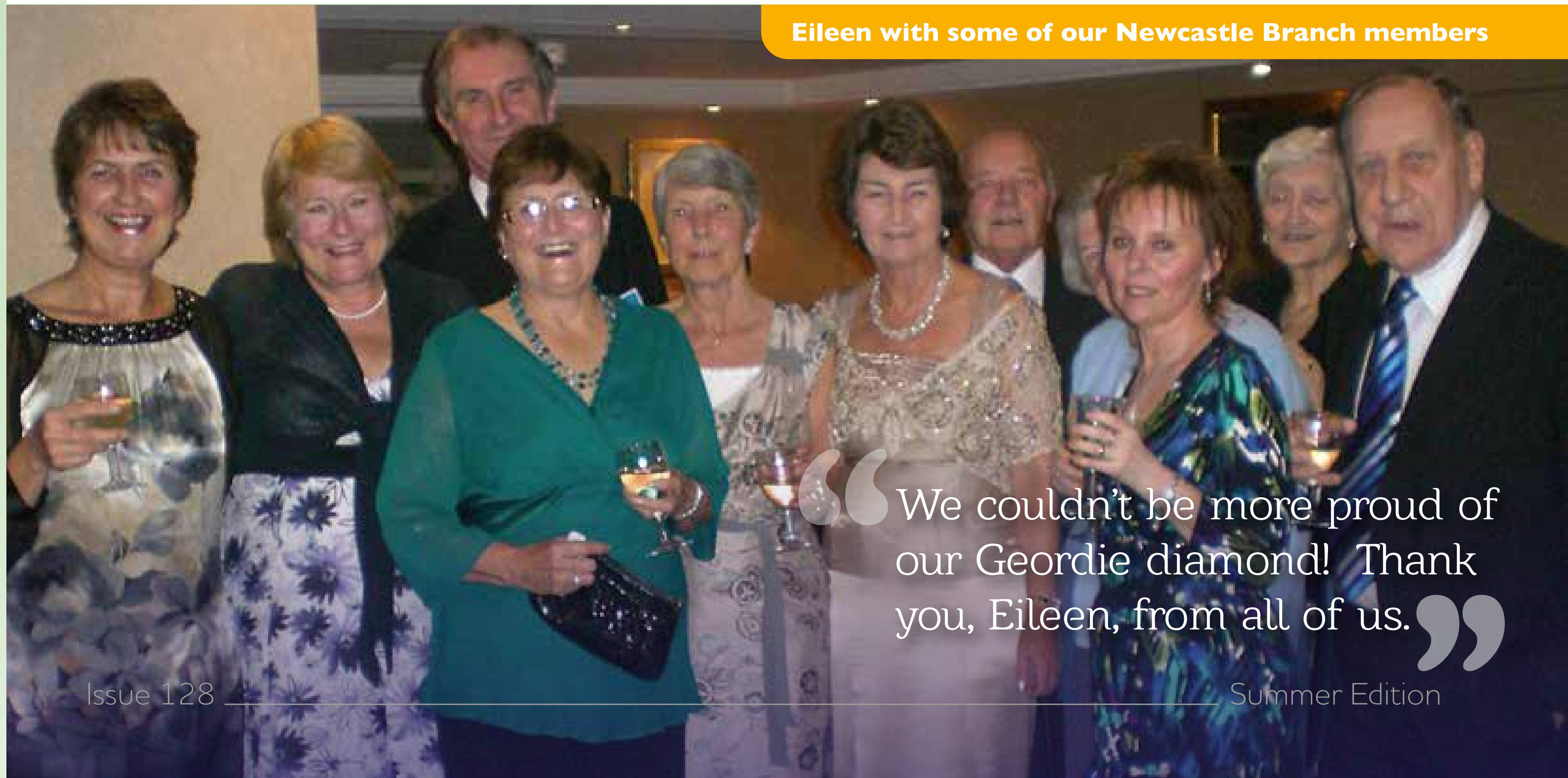

Eileen with Branch President Philip Powell

In her time, Eileen has been a UA trustee as well as representing the Association in Newcastle. As warm and compassionate as she is hardworking and tenacious, the former stoma nurse is a force to be reckoned with, and we couldn't be more grateful for her unwavering dedication to people who, like her, are living with a urinary diversion.

Running a branch is a team effort, of course, and we really appreciate all our volunteers who give their time and use their skills to make a difference. We think you'll agree though, that it takes a very special person to keep going above and beyond for her community for 50 years, despite her own health struggles.

We couldn't be more proud of our Geordie diamond!
Thank you, Eileen, from all of us.

Eileen in her nursing days


Eileen with some of our Newcastle Branch members

> We couldn't be more proud of our Geordie diamond! Thank you, Eileen, from all of us.

Your letters Summer 2023

Reading the letter from Toni Haines (spring Journal 2023) made me chuckle, "out of the mouths of babes". My tip to completely dry the tube after emptying. I take a piece of toilet paper, fold it in half, then in half again, twist the end and insert it in my urostomy bag to completely dry it. Love the magazine - very informative and friendly.

Thank you.

Mrs Jacky Rayner (Yorkshire & Humberside Branch)

Yesterday I attended Yorkshire & Humberside Urostomy Association Branch Meeting and saw the book 'Bags, Bags, Bags'. I would like to order a print copy of the book and I have just made a donation to the Urostomy Association.

I think the book is fantastic, and my first branch meeting was also really enjoyable and informative. I've already started to share my feelings on social media.

Thank you, Urostomy Association

John Turner

It is important, in my opinion vitally important, that UA should not forget all those hundreds, possibly thousands, of members that for whatever reason, choose not to be part of the technical world. Their handwritten experiences, their handwritten requests for help, their contributions are equally, no, not equally, more important, as they've no one else to go to. They should not be left behind, their handwritten words should be offered too and an address for them should be readily available. Every member is deserving of the same opportunity. Nothing more. Nothing less. I would recommend that if you are a member of UA and feel you'd like to share an experience, do not be put off by sharing with your fellow urostomates just because of personal preferences not to be part of the technical world. Get writing.

Best wishes to you all.

Colin Hobbs, Journal Ex Editor/ Advertising Manager

Thank you for your views, Colin, as part of your longer submission. We welcome all members' feedback, letters and questions for the Journal, whether handwritten, typed on paper or sent by email, and publish our contact details, including our postal address, in several places within the magazine.

While we are happy to type up short, handwritten letters, there is no capacity within our very small team for transcribing from handwritten articles that run into hundreds of words. This is why we politely request that all articles submitted for consideration for the Journal are sent as Word documents.

Please get in touch at *editor@urostomyassociation.org.uk*
or at Urostomy Association, 2 Tyne Place, Mickleton, Chipping Campden, GL55 6UG.

New chapter

Typically, writing is a solo endeavour, but being part of a writing group can be a great source of enjoyment and inspiration, as UA member Marion Sangster (right) has found.

Says retired teacher Marion: "I should imagine that, like most of us, my diagnosis of bladder cancer was almost unbelievable. First slight indication of blood in my wee in May, bladder removed in August 2022 at the Royal Devon and Exeter Hospital.

"I had prided myself on my fitness, enjoying swimming four or five times a week. We live in Sidmouth, in Devon, and my route to the pool takes me right along the seafront. I adore watching the patterns form on the surface of the sea and seeing the waves coming ashore but I am never tempted to swim in the sea. I am not a masochist. I like my swim water to be in the twenties."

Storytelling

"Since a young child, I have enjoyed writing short stories. I loved writing stories for my children until they decided reading mum's stories was not really that cool. When I returned to teaching in a large secondary school, I realised that so much poor behaviour was associated with poor literacy skills and I began to adapt texts and books to make them accessible these pupils.

"After a while I was very privileged to be given the post of improving the reading levels of the disadvantaged in the school. I often wrote articles and stories that would engage these lads - they were mostly boys. With a lot of hard work and the use of a phonics programme, I am very proud of the progress they made, and I held that post until I retired.

"On retirement I said to our four children, "Right, I am retired now. I don't mind which one of you does it but I want to be a grandma." Of course, they did as their mother told them! Within 18 months we had four wonderful grandchildren. We are now fortunate to be grandparents to nine diverse, delightful grandchildren and I have a new audience for my stories."

Reading, writing and games

"On retiring I joined the U3A (University of the 3rd Age) writing, reading and storytelling groups. I now run three groups, reading, writing and a games group. My writing group comprises ten people and we choose a title and then spend a month writing. We have incredibly insightful poets, and others who are excellent at descriptions and creating atmosphere. Many are general all-rounders, and I love writing stories and creating a plausible twist at the end. We then read our piece to the group."

The Box

A large plain cardboard box stands in my hallway. It has my name on it, address and an indecipherable code but nothing to suggest where it came from or what it contains. I am not excited to see the box but I am relieved. I have no reason to be worried as the box arrives each month on the predicted day and even within the hour advised. I am anxious however, anxious as the box contains everything I need that will allow me to lead a near normal life.

The day before my life as I knew it changed I walked to my favourite place. For the clifftop the glowing red cliffs make a perfect backdrop to the shimmering blue sea. I love it up there with just the gulls and birds circling around. Looking to the West, there is no sign of the activity of man. Looking to the East there is still no evidence of man, a truly remote spot. I stood absorbing the view and wondering when I would be able to climb and scrabble to this point again.

The next day I was remarkably calm, ready to accept my fate. I did everything I was asked to do, including meekly scrawling my signature in the knowledge my life would never be the same. The irony of it all was that I felt so fit and well. It was only through their tests and scans that I reluctantly accepted I needed such major surgery.

I don't let the box linger in the hallway too long. I quickly stow the contents in a cupboard, recently cleared for this purpose. I do not want all the paraphernalia I need to be visible, a constant reminder of my disability.

Yes, my body has changed and I have had to learn new skills and adopt new routines. However, I have not changed. I am still me with the same loves, aspirations and zest for life. I am working on building up my strength and it won't be too long before I am on that clifftop again.

Mole Sangster, 2022

Join our friendly community

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 and post it to us at the address given there.

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.

Join the UROSTOMY Association

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			
☐	**Ileal conduit/urostomy**	☐	**Bladder reconstruction/neo-bladder**
☐	**Continent diversion** *(eg Mitrofanoff)*	☐	**Other**
☐	**Not applicable**		
Reason for operation			
Hospital			

How did you hear about the Urostomy Association?			
☐	**Nurse/GP/other healthcare professional**	☐	**Open Day**
☐	**Google/Bing/etc**	☐	**Facebook**
☐	**Advertisement**	☐	**Other** *(please specify below)*

Form continued overleaf

Join the UROSTOMY Association

UROSTOMY ASSOCIATION
Registered Charity Number:
England and Wales 1131072 Scotland SCO47740

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**	
☐	**By email**	☐	**By email**
☐	**By post**	☐	**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.)

☐ **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

Merchandise

Registered Charity Number:
England and Wales 1131072 Scotland SCO47740

UA-branded **sunflower lanyards**

Urostomy Association-branded, and officially sanctioned by *Hidden Disabilities Sunflower*, part of *Hidden Disabilities Sunflower Scheme Limited*, a private company based in the UK.

Lanyard £2.50 **Badge £1.75**

The official **RADAR key**

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

Official **RADAR** Key **£3.50**

All prices include p&p within the UK

To place your order, please fill in the form below and post it to the Association, call **01386 430140** to pay by credit or debit card, or visit our website at ***www.urostomyassociation.org.uk/shop.***

Please send me:

Sunflower lanyard	Quantity	
Sunflower badge	Quantity	
Raydar key	Quantity	

Name

Address

Postcode

Send cheques, payable to 'Urostomy Association' to:

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

Email: *info@urostomyassociation.org.uk*