URostomy Association

journal

Issue 127
Spring 2023

WHEELSandWINGS

REBECCA GIDDINGS

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Registered Charity Number: England and Wales 1131072 Scotland SCO47740

Welcome to the Spring Journal

Paola Simoneschi
Acting Editor

Contributions to the Journal are always welcome. Please send your letters, stories and articles for the summer edition to *editor@urostomyassociation.org.uk* by **15 June 2023.**

Your contributions should be submitted as Word documents and any related images as jpeg attachments.

Whether you live in the city, on the coast or in the countryside, the lightening of the days – and along with it our mood, food and in a couple more months (hopefully!) our clothes – are all part of the seasonal cycle that influences our lives. Emerging from winter into spring can feel like a time of hope and new beginnings, which has made me think about how it must be to go through major surgery and emerge not always instantly better – because recovery is not to be rushed and requires a lot of patience, 'true grit' and self-compassion – but at least on the road to feeling more like yourself again. And, with the right information and support, gradually getting back to the things you enjoy doing.

In this edition, two strong ladies – Rebecca and Marita - share their stories of going from just about surviving to thriving, telling how they met and overcame the huge obstacles in their way to get to the point where, thankfully, they are enjoying life again even if the going is not always smooth. Huge thanks to them for being so open about their experiences.

Without prompting, both Marita and Rebecca credited the Association for providing them with invaluable support and reassurance along the way, which made a very difficult time that bit easier for each of them to navigate – which, in turn, encourages our small team at UA, who work so hard to provide members with the best possible service.

Speaking of encouragement, there's plenty in this edition to help you if you're feeling in need of a lift, from support for your mental health to some delicious and nutritious recipes!

I hope you'll enjoy reading the journal as much as I have putting it together with help from kind contributors. Please let me know what you think – your opinion matters and can help shape the Journal as we move further into the year. You can reach me me at ***editor@urostomyassociation.org.uk***.

Until next time,

Paola

PS. Life with a urinary diversion doesn't have to be bland, so please send in any favourite recipes that tickle your tastebuds. To see some of ours, turn to page 40.

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

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

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UA Journal

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

Photo credits

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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.

Contents

Contributions are very welcome

We welcome your contributions to the Journal, so please get in touch with your stories, articles and letters.

We can't promise to print them all, but they will certainly be considered.

Please send your contribution as a Word document to **editor@urostomyassociation.org.uk**

Wherever possible, your submission should include some good quality photos as jpeg attachments.

Thank you.

Deadlines are as follows:

Summer Journal
June 15th

Winter Journal
October 15th

Please note: The same deadlines apply for advertising.

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.

Membership

Full membership is for people who have a urinary diversion. Associate membership is for those who do not have a urinary diversion but would like to join the Association for another reason, perhaps because their partner, parent or someone else in their family has had the surgery, for example.

For full or associate members living in the UK, subscription is free for the first year and £16 per year thereafter.

Company membership is available to organisations providing services relevant to our members.

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.

Supporting the Association

As a registered charity, we need to fundraise to help us meet the cost of providing our valued service. We welcome your support, whether you'd like to make a one-off donation or give more regularly, organise a fundraising event such as a coffee morning or quiz night, take on a sponsored challenge or leave a gift to the Association in your will. Please visit our website or call us (see contact details below) for more information about this. Whatever you can afford to give will be so appreciated.

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***.

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all are Directors and Trustees of the Association

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

www.urostomyassociation.org.uk

Postcard power

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. How are we going about this? Well, one of the ways is simply a case of 'answers on a postcard' – details of who we are and how we can help incorporated into an eye-catching, handy postcard pointing them in our direction.

Listening to feedback from our members and speaking to stoma care nurses, we created our 'postcard for patients' (pictured here) as a resource the nurses can turn to when they want to signpost a patient – or their family member – to the services UA provides. Then, even if that person doesn't contact us straight away, they can hold on to the postcard for whenever they might feel in need of chat or have questions they want to ask us.

Having recently circulated a sample of the postcard to the nurses in our database, we're delighted to report that they've been a big hit, with well over a hundred requests for further copies. By the time you read this, we're likely to have heard from many more nurses, which is great news for the growing relationship between these healthcare professionals and our charity.

"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.*

"Our postcard is proving that often it's the most simple ideas that are the most effective. We're also sending copies to our branches for them to pass on to hospitals, clinics and GP surgeries in their areas and hand out at open days and other events to raise more awareness.

"This just the beginning though. We're developing the resources section of our website to make it more comprehensive and user friendly for you, whether you're a member, a healthcare professional or someone else seeking trustworthy information. Watch this space!"

If you'd like to receive UA's postcard to give your stoma care nurse, another person involved in your care, or anyone you know who could benefit from our services, please get in touch at *info@urostomyassociation.org.uk* with your details.

UROSTOMY ASSOCIATION

Hello

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.

CHIEF EXECUTIVE'S **REPORT**

As I write this, I can't believe that we are in March already. The snowdrops and crocuses are now flowering in our back garden, and the new bed we created in the front last autumn is full of bulbs starting to sprout, bringing hope of spring, although it is a bitterly cold, frosty morning – thank goodness for a nice, warm office!

Dave Page, UA's Admin Officer.

Both Dave (our Admin Officer) and I have been busy booking our holiday dates for the year, and I am sure that some of you are thinking of this, too. Don't forget that you can find travel insurance details on our website, and also order sunflower lanyards and badges. We also have travel certificates, which state that you have a urostomy - in lots of different languages - available from the office.

If you are telephoning us, please leave a message if we are not available. Dave and I are the only in-house employees of UA, and with me often in meetings and Dave working part time, we cannot always answer the telephone. We will get back to you as soon as we can though, or alternatively, you can email us at ***info@urostomyassociation.org.uk***, or send us a message via the website.

Talking of meetings, we are continuing our weekly meetings on a Thursday, when I get together with Brian Fretwell, UA's Chair of Trustees, and our small group of experienced freelance contributors, who cover project management, communications and fundraising on a part-time basis. This is when we discuss plans and make sure we are all up to speed with each other on the work we are doing to keep UA moving forward. We all find this very helpful, as most of the team are working remotely.

The Trustee Board is currently meeting every six weeks, as we continue to work through this period of transition for the Association. Meanwhile Rachel (fundraising) and Paola (communications) met virtually with Branch Officers recently, and it is hoped that this will become a regular event, providing a chance to catch up on what everybody is doing, and share news and good practice. With plenty of external meetings to attend, too, there is certainly plenty going on!

50th Anniversary Afternoon Teas

Yes, we know that our 50th Anniversary was two years ago(!), but there are still a few celebratory events to come – all of which are free to attend! Confirmed dates so far are:

18th April – Bournemouth
19th April – Exeter
26th April – Nottingham/Derby
18th May – Northern Ireland
23rd May – Birmingham

Hopefully, an event in South Wales will be held on 10th May, date/venue to be confirmed.

Full details are listed on our website, or you can telephone Admin Officer Dave on **01386 430140** to book your place.

Details of branch meetings, open days and other events are also listed on our website, so it is worth checking on a regular basis: ***www.urostomyassociation.org.uk/events.***

Volunteering

Unfortunately, we have had to delay our first induction session for volunteers, which will now take place in April, but we are steaming ahead with informal interviews, DBS checks and data protection training so that our newcomers are fully up to speed. We are already planning a second induction day in September, so do check our website for volunteering opportunities available. We'd love to hear from you, and if you choose to give a bit of your time as a volunteer, we'll support you every step of the way.

National annual general meeting (NAGM) 2023

Planning is just starting for this meeting, which is likely to be in November. Further details will follow, as they are confirmed.

To conclude

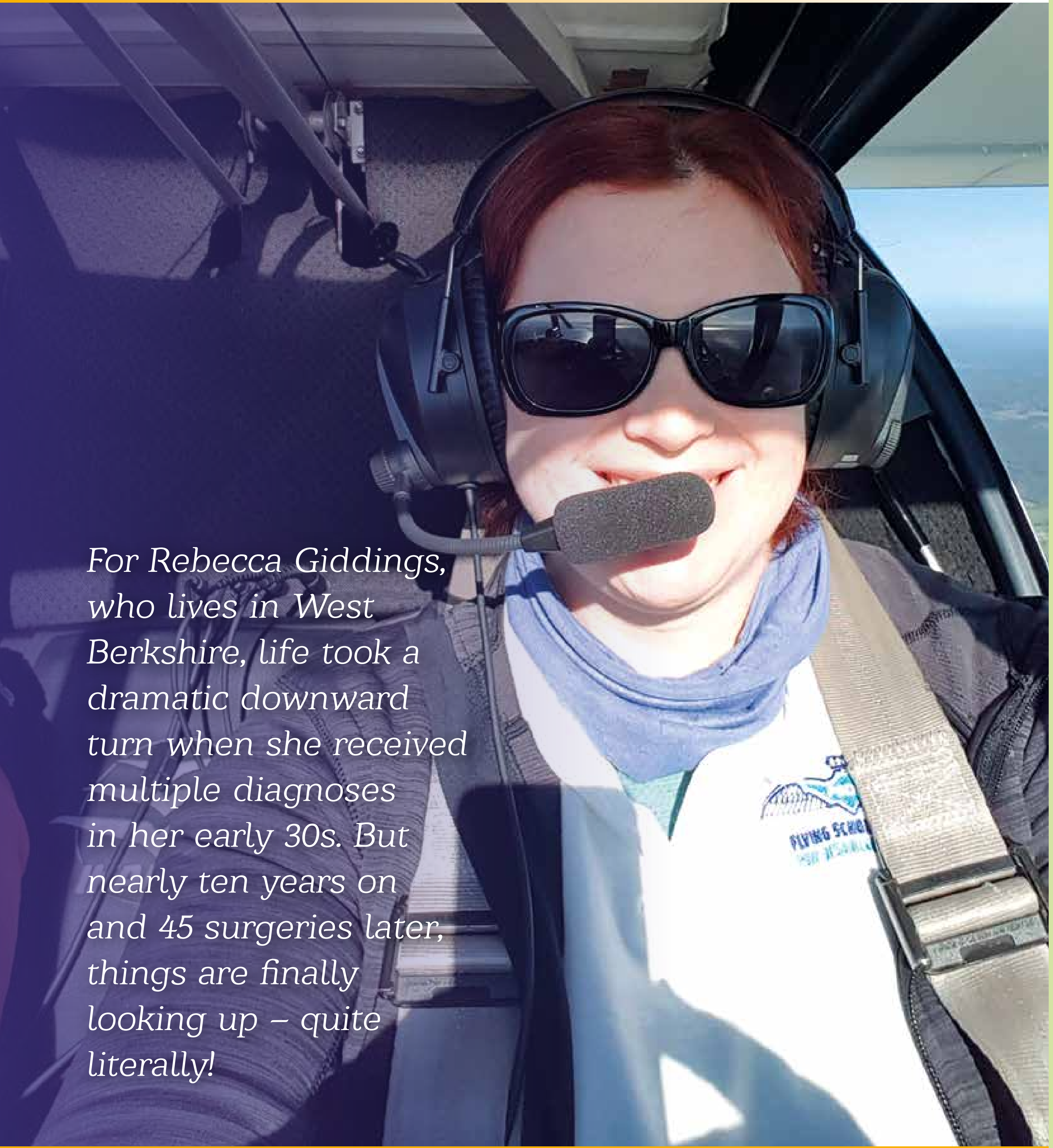
Do remember that if you have any queries, or we can assist you in any way, we are here. The office telephone number is also our helpline, where you can order literature, arrange to chat to one of our volunteers, or pay subscriptions/donations. We will always do our best to help!

With best wishes

Hazel Pixley
Chief Executive Officer

WHEELS and WINGS

REBECCA GIDDINGS



For Rebecca Giddings, who lives in West Berkshire, life took a dramatic downward turn when she received multiple diagnoses in her early 30s. But nearly ten years on and 45 surgeries later, things are finally looking up – quite literally!

> *The turning point for me came in 2017, when I was awarded a scholarship with Flying Scholarships for Disabled People, and I started learning to fly.*

My story starts in 2014, when my husband Dave and I went to Mexico for a break. Life had been really busy – not only was I working crazy hours in my job in banking, I was also a year into my part-time PhD, juggling all of this with being a wife and also a step-mum to three amazing children.

I came back from Mexico feeling unwell and suffering with chest pain. Being only 33 at the time, I put this down to my stressful job and carried on with life. However, during a board meeting in June the chest pain became quite bad. Rather than excusing myself and seeking help though, I attributed it to stress - or something I had eaten - and ignored it. A couple of days later the pain was still there and my husband persuaded me to get it checked out. At the chest pain clinic my cardiologist told me he suspected I'd had a heart attack, and I was sent for an angiogram.

The day that changed everything

Little did I know what a pivotal point this would be for me. Not only was I diagnosed with a rare heart condition called prinzmetals angina but also, unbeknown to me, that day was the last of my working life.

Things went from bad to worse, my body just not wanting to work as it had done previously. I struggled to walk or do the simplest of things, and it was clear there was more going on than just the heart condition. My cardiologist sent me to several different doctors and eventually, two years later, I received a diagnosis of Ehlers Danlos syndrome, a rare connective tissue disorder that affects almost every part of my body. Many of my joints are now so lax that they dislocate at the slightest movement.

My autonomic system is severely affected, meaning regulation of my temperature, blood pressure, pulse and so on doesn't work effectively. I have something called Mast Cell Activation syndrome, which means my immune system doesn't function properly and produces excess histamine, resulting in uncontrolled allergic reactions. My vascular system is also heavily affected and I get vascular spasms throughout my body, the worst being in my heart. I also have gastroparesis, leaving my stomach paralysed, so I have to be fed through a tube directly into my small intestine. I've had 45 surgeries, including spinal operations to fix fractures in my vertebra caused by my spine being hypermobile.

I went from being extremely active and busy to being a full-time patient. Ehlers Danlos is a progressive condition and living with it takes its toll, not just physically but mentally.

> *I went from being extremely active and busy to being a full-time patient. Ehlers Danlos is a progressive condition and living with it takes its toll, not just physically but mentally.*

Learning to fly

The turning point for me came in 2017, when was awarded a scholarship with Flying Scholarships for Disabled People, and I started learning to fly. I took that incredible feeling of freedom that flying brings and started to turn my life and mental health around. This felt like a new beginning for me. It was time to take back control, to stop looking backwards and trying to get back to who I was and instead start looking forward to what I could be.

After learning to fly, I came back to earth with a bit of a bump and was straight back to hospital appointments. I was diagnosed with interstitial cystitis (IC) and embedded bladder infections. After months of antibiotics, I was taken into hospital to have a PICC line fitted so I could have IV antibiotics at home, but even after four different types of these, the infections still weren't under control. As a last-ditch attempt, my urologist suggested self-catheterising and injecting an antibiotic and saline flush directly into my bladder. This was successful and for about two years we managed to keep the IC at bay with flushes and various medications.

WHEELSandWINGS

CONTINUED

I felt I'd changed so much from the person I was when Dave and I got married, that I asked him to marry me again. Thankfully, he said yes! In May 2018 we renewed our wedding vows at a beautiful ceremony in Japan.

Stoma surgery

By Christmas 2021, however, medication was no longer working and the pain was disabling, affecting everything in my life. My urologist tried a couple of other things and started to discuss with me the option of a cystectomy, removing my bladder and using some bowel to make a urostomy. Due to previous abdominal and bowel surgeries, the surgeons at my local hospital said my case was too complex, so I needed to be referred for more tests and to a specialist centre in London.

It was during this time I discovered the Urostomy Association and received some great advice for the operation via the Facebook group and picked up many tips from others posts. As my skin reacts badly to a lot of things, particularly adhesives, I tested different bags before my surgery, so I knew what my skin could handle. After a couple of false starts, I got referred to the most incredible team at Guys Hospital London, and last September I underwent ten hours of surgery to remove my bladder and urethra, do a bowel resection and create a stoma.

The surgery was tough and the first 24 hours were particularly hard. However, within that time I also knew my surgery had been successful. I no longer had the excruciating bladder and urethra pain that had been so debilitating, and five days later I was discharged home.

Living with a bag

It was on the way home I had my first leak. Making a conscious choice to laugh, I turned to Dave and said, "I think I just peed in your car!".

My stoma nurse said to me, leaks are occasionally going to happen but at the end of the day, it's just a bit of wee. I have only had one other leak and that was because I hadn't connected my night bag properly. I am sure if I had a leak in public, I would feel very different and be mortified.

I'm conscious of my bag and dress to disguise it a little – scarves are very handy to cover a full bag! However, I'm trying really hard to carry on with my life, especially as I feel good now that I'm not in the constant bladder pain but rather back to my 'normal' level of everyday pain.

Reaching milestones

Four weeks after my surgery was my PhD graduation ceremony, which I was so thrilled to be part of. While I was in hospital my goal was to make it to the event and I told everyone. The staff were probably sick of hearing about it! I sent the surgeons and stoma nurses an email with pictures of my graduation, and I think they were as happy I made it as I was.

Just before Christmas came another milestone - I made the decision to order a new motorbike. I haven't been able to ride for several years because of everything, and as I don't have full use of my left hand or foot because of nerve damage, I thought I would never ride again. But, with a special gearbox I don't need my left hand side, and I found biking dungarees which are comfortable to wear over my feeding tube and urostomy bag. Just recently, I bought my new set of wheels!

I am still tired from the surgery, but for the moment I am enjoying the fact I currently don't have any surgeries planned – the first time in eight years! I can't sit still, so I am throwing myself back into charity work and writing a book.

I was even asked to be a model for a lingerie company, and in January I had a fantastic modelling shoot and got my bag out in front of other people. Hopefully in the future, I will even get back up flying again – though fully clad, of course!

> *"Just before Christmas came another milestone - I made the decision to order a new motorbike."*

Remembering **Les**

It is with sadness we report that Leslie Butters, former Chair of UA's Yorkshire and Humberside branch, died on 2nd November 2022. Here, David Legood, Branch Secretary, pays tribute to the man many knew as Les.

Les and Barbara at UA's national annual general meeting dinner, 2009. They loved this annual event and the opportunity it gave them to meet people from other branches.

Born and raised in Leeds, Les attended West Leeds Boys Grammar School, where he excelled in his studies. He often said that he loved school.

In 1956, Les met his wife Barbara at the Armley Baths. They both enjoyed dancing and they married four years later, in 1960. They lived in Armley for four years until moving to Pudsey with their two children. Les worked at ICL, first as a computer analyst and then as a computer consultant, where he was well respected and spent much of his working life in London. He never had a computer in his own home though - he used them every day and was sick of the sight of them!

Les was a family man and encouraged his children to bring their friends home, where they were always welcome, sometimes popping in to see Les and Barbara even when their children were not at home. In time, Les and Barbara became proud grandparents and great-grandparents. Les adored all his grandchildren and they loved him.

After leaving ICL, Les got a part-time job delivering teeth to dental clinics around Leeds. He gave his grandchildren little plastic teeth and told them to put them under their pillows for the tooth fairy. He also placed a few jelly babies on a tree in his garden, which led to all the local children knocking on his door to ask about the jelly baby tree!

Les had various interests, including stamp collecting, and he became a master bridge player, representing both Leeds and Yorkshire. In one tournament held at the Hilton Hotel in Leeds, he couldn't find anyone to go with, so Barbara reluctantly agreed to keep him company. She was glad she went because the famous Egyptian actor and bridge player Omar Sharif was there that evening.

Les was a very sociable man, who made everyone welcome at our branch meetings. He is missed by all who knew him.

Reaching young minds

As part of our ambition to help people everywhere understand what it means to live with a urinary diversion, our children's book 'Bags, Bags, Bags' will soon be ready for you to share with a youngster in your life, whether it's your child or grandchild, niece, nephew or another little person aged seven or under. Full of colourful illustrations by professional artist Lynda Nelson, and written in an age-appropriate way, we've created 'Bags, Bags, Bags' as a conversation-starter so that it's there if you want to talk to a child about your own experience. We hope it will help you speak to them, and answer their questions, at the time and pace that feels right for them and you.

"It makes good sense to reach young minds so that more children grow up knowing it's fine to talk openly about weeing differently," said Hazel Pixley, UA's Chief Executive, who has a urostomy. "While it can sometimes feel a bit awkward starting these conversations, there should be no stigma or shame."

Thank you for your support

Before Christmas, we invited you to donate towards the cost of publishing 'Bags, Bags, Bags', which - as far as we know - is the first book of its kind created by a stoma charity. We're delighted to let you know that so far, we've received the fantastic total of £6,670!

Rachel Shepherd, part-time Fundraising Consultant for UA, said: "A big thank-you to everyone who donated to our Just Giving campaign, and for your messages of support.

"We are also very grateful to our corporate sponsors Coloplast, Hollister Dansac, Salts and Fittleworth for their sponsorship of our book.

"However you got behind 'Bags, Bags, Bags', it's so appreciated, from providing feedback to pre-ordering your copy. The book will be available to download from our website – free of charge – from mid-April, or you can order a printed copy by emailing *info@urostomyassociation.org.uk*."

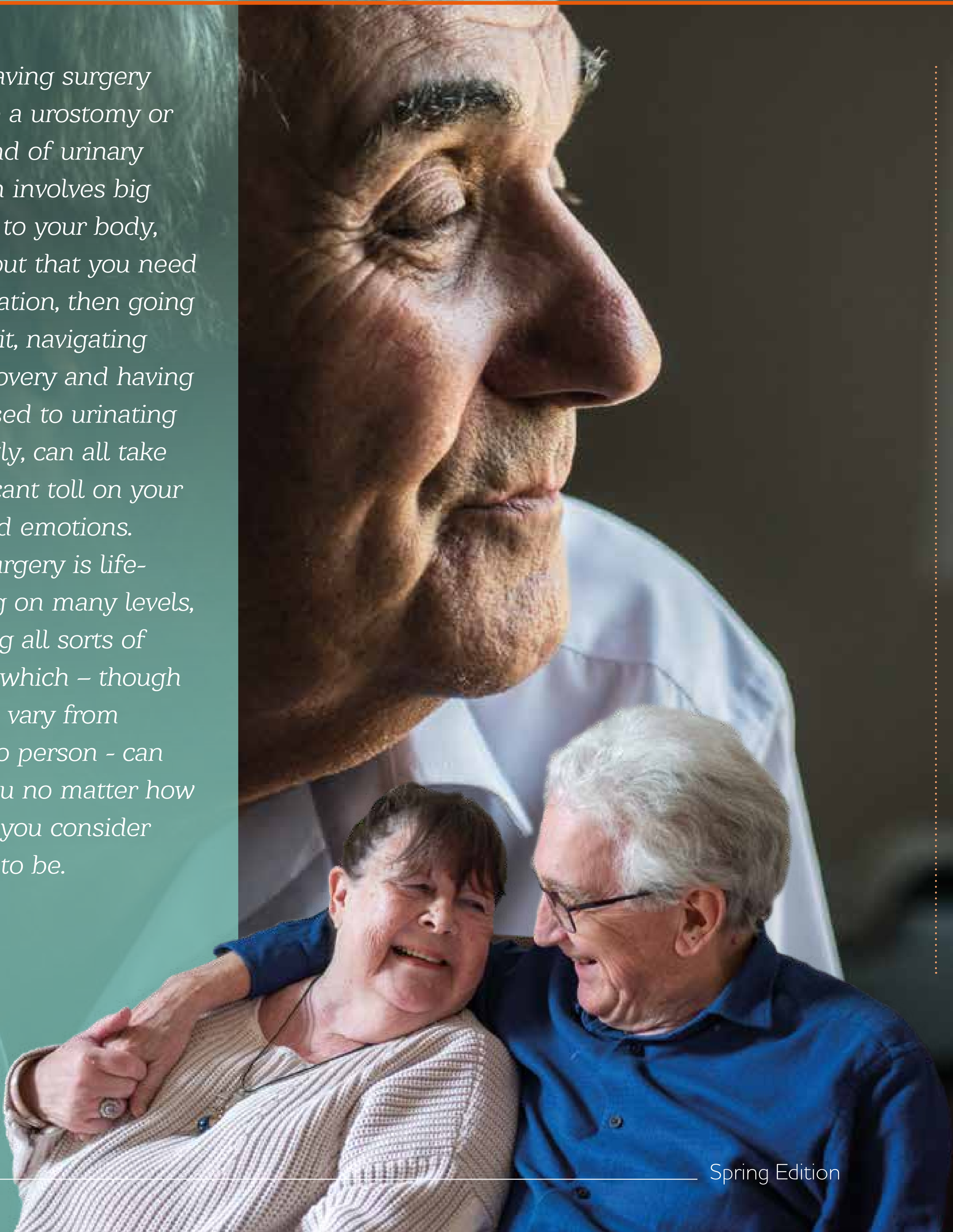
We're delighted to report, too, that news of our innovative children's publication has also been welcomed by stoma care nurses, who recognise its value in presenting a still somewhat 'taboo' subject in a fun, engaging and easily accessible way.

Mind matters

While having surgery to create a urostomy or other kind of urinary diversion involves big changes to your body, finding out that you need the operation, then going through it, navigating your recovery and having to get used to urinating differently, can all take a significant toll on your mind and emotions. Major surgery is life-changing on many levels, triggering all sorts of feelings which – though they will vary from person to person - can affect you no matter how resilient you consider yourself to be.

Acknowledging that emotional wellbeing and physical health are so closely linked is nothing new, of course, and indeed it's why the Association came into being more than 50 years ago to inform, reassure and support people on their journey. For the first of a new series of articles focussing on the importance of looking after your mind, we sat down to talk with Jane Belinda (pictured above), an accredited counsellor with many years' experience. In her current role, Jane is Counselling and Wellbeing Service Lead at Your Healthcare CIC, supporting NHS key workers with the mental health challenges their roles bring. This has given her intensive experience of working with people with anxiety, depression, anger, burnout, trauma, chronic pain, PTSD and bereavement.

"Many of my clients have gone through sudden changes to their body that have impacted their wellbeing, at the same time as supporting others going through ill health as NHS clinicians," said Jane. "I have found that, with the right support, people are extraordinarily adaptable to the emotional, physical and mental challenges life often brings."



Managing your emotions after surgery

Following your operation, it's natural if the emotions you experience feel very intense. After all, the changes to your body are sudden and significant. Getting through the first few weeks and months following surgery can be especially tough. This is when you are adapting to your 'new normal', and it can feel very challenging.

"It's human nature to find a transitionary period unsettling. Our nervous systems are designed to experience sudden change as a threat so it's important to be kind and nurturing with yourself," said Jane. "To support your mental wellbeing at this early stage, surround yourself with safety: people who love and care for you, a calm and stable environment, gentle, mindful activities and, if you can, keep to a familiar routine."

Emotional stages during your recovery

After surgery, it's very common to mourn the way your body used to be. While there is no 'right' or 'wrong' way to grieve, you may go through several stages as you gradually come to terms with the way things are now.

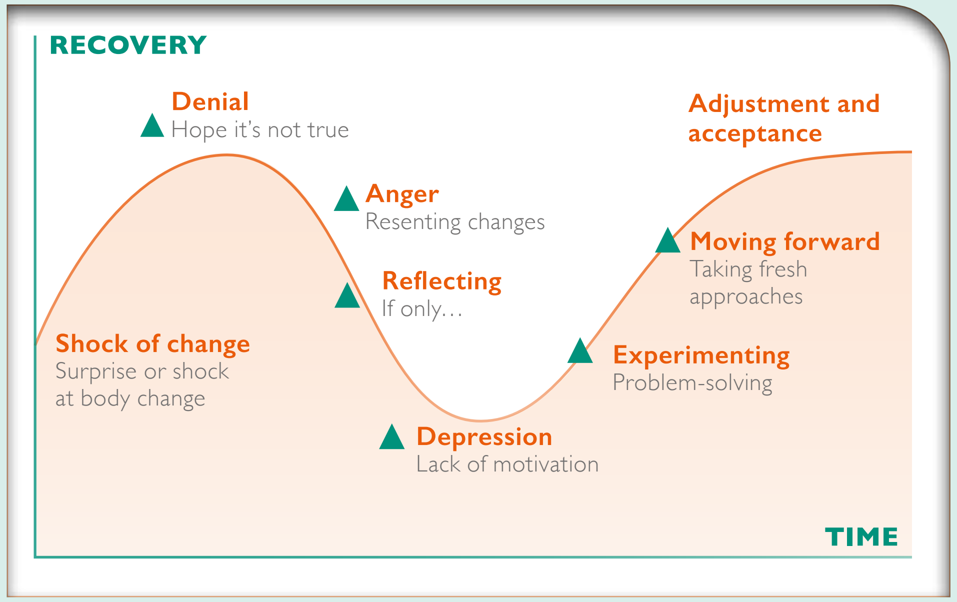
These 'stages of grief' – shown in the diagram below - can happen in any order, moving back and forth in what can feel like waves, and gradually moving closer to adjustment and acceptance. Being aware of this can help you understand your feelings and recognise these emotions when you are suddenly having an awful day after a several days, weeks or months of doing well.

A sense of loss

The grief many people experience after surgery comes from a profound sense of loss. This isn't just about bodily function - it's about the person you used to be and the life you used to live. There can be other aspects too, such as loss of confidence generally.

"Grief isn't a linear process and no two people grieve the same way," said Jane. "If you can, reduce any expectations on yourself to 'get over it' by a certain time or feel that you 'should' be moving on from one stage to the next. Giving yourself permission to grieve in the way that feels authentic to you is vital at this time. Your journey of grief will be unique to you, but while it may feel that others are unable to understand your experience, loss is something that ultimately unites us all and an experience with which we can all empathise."

Take heart because just as with other losses you may have experienced in your life, you can come to terms with what you have been though, and are still going through, by taking one step at a time and with the right support along the way.



Coping with anger

Following surgery, you might experience anger, even if you are also relieved to be feeling better physically. Some people ask, "Why me?", which is a natural part of the grieving process.

Working through your anger can give you strength and help you realise that you can overcome your challenges. However, anger can sometimes turn into a very damaging emotion. Simmering anger can sap energy, or lead to aggression aimed at those around you. Anger directed at loved ones can damage close relationships, so it's important to manage this phase.

"Grief is messy and you may feel out of control of your emotions, particularly anger," said Jane. "Anger is more commonly described as a secondary emotion, the purpose of which is to protect a more vulnerable feeling underneath, such as shame, fear, guilt or hurt. Exploring the emotion below your anger and sharing this will help bring loved ones closer to you, rather than pushing them away."

The following tips may help:

Talk through your feelings and any 'anger triggers' with someone you trust knows you well.

Be proactive and find a way to diffuse your anger – through physical exercise or deep breathing, for example, or relaxation exercises.

If you're in an intimate relationship, **try not to direct your anger at your partner**.

"Another way to release anger is by writing it down," said Jane. "Allow the page to hold your anger so you don't have to."

Dealing with anxiety

You might also find yourself worrying about your illness returning, or whether you'll adjust to using a pouching system. You may also feel anxious about how your relationships and social life will be affected, and many other uncertainties. These concerns can trigger stress and may cause you to withdraw from the very people who love you the most, such as your partner, family and friends.

However, sharing your worries with your partner, close family member or friend, and opening up to them about your fears, can help reduce your stress. They might also be able to suggest some possible solutions.

"It's natural to worry and anything can be a trigger, particularly a change that is new as we don't have an experience to fall back on that may be reassuring," said Jane.

"If you find that your worries are becoming consuming, it may be helpful to distinguish whether you're experiencing real problems or hypothetical worries. Ask yourself the question, "Is there something I can do about this worry?". If the answer is no, then attempt to release the concern by self-soothing: talking to a friend, having a bath, listening to calming music or cuddling with a loved one. If the answer is yes, write a list of options you can take right now and act. Taking control of your worries will help you to shift from feeling powerless to powerful."

Speaking to a professional

If your concerns are medical, it's important to discuss them with your stoma care nurse or another healthcare professional. Just getting an expert opinion can help relieve unfounded worries.

If your anxiety persists and is holding you back, ask your GP or stoma care nurse for support. They may make recommendations, such as seeing a counsellor or psychologist, or speak to you about medication that could help. Of course, whatever you decide needs to be what feels right for you, and your options are not limited to medicine and/or speaking to a counsellor – social prescribing is an approach that connects you to activities, groups, and services in your community to meet the practical, social and emotional needs that affect your health and wellbeing.

"Surgery and recovery can feel frightening and it's natural to experience negative thoughts about your body, your life, yourself and possibly other people," said Jane. "It's important to remember that our thoughts aren't facts, they are just thoughts. For every one negative thought, try and think of four positive alternatives. This will help increase your appreciation of how truly amazing you, and your body, are."

A final word...

The intense emotions you may be going through after surgery are a normal and appropriate response to what has happened. Asking for support when you need it is a strength – it's better to get your feelings out into the open with someone you trust so you can gradually look to your future with hope and positivity.

In addition to support provided by the Urostomy Association, available to you via our telephone helpline on 01386 430140 (Monday – Friday, during office hours) or by email at *info@urostomyassociation.org.uk* - and through our service matching you with one of our friendly, trained volunteers local to you - the charities below provide services to help your mental wellbeing.

Mind:
0300 123 3393
www.mind.org.uk

Samaritans:
Freephone 116 123
(available 24 hours a day, seven days a week)
www.samaritans.org

Rethink Mental Illness:
0808 801 0525
www.rethink.org

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

Safe Places: volunteers needed!

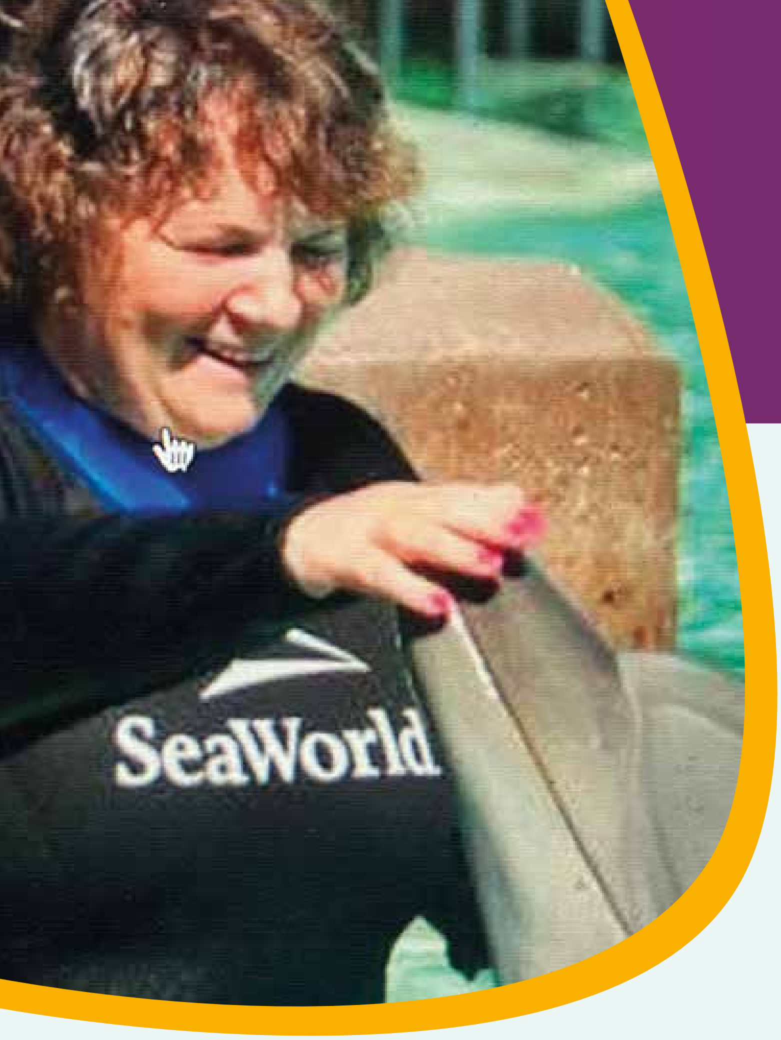
Here at UA, we enjoy speaking with our members, hearing how our branches and volunteers are supporting people like them who live with a urinary diversion, and how rewarding they find it getting to know and reassure them.

In particular, we've been discussing the resources needed to make UA's support even more helpful, and the project that's beginning to take shape focuses on the need for 'safe places' people can visit post-op to aid their physical and psychological recovery. We're making this a priority because we understand the natural anxiety people feel when they're thinking about that first day out, away from the security of home, as they recover after surgery. Understandably, it's all about knowing of a place they can visit for a day that has all the facilities to meet their needs and help them feel safe.

"This is where we need your help!" said UA's Rachel Shepherd. "We're looking for volunteers who would be part of a focus group helping us identify the criteria for what constitutes a 'safe place', and take part in pilot visits to the National Trust properties Attingham Park, in Shropshire, and Shugborough Hall, in Staffordshire.

"We're stronger together, using our collective experience and voices to make things better for everyone living with a urinary diversion. If you'd like to be involved with our 'Safe Places' project, the initial meeting of our focus group will take place online in April. It will be in the evening, for no more than 45 minutes, so we won't take up too much of your time.

"If you would like to join in and help by talking from your own experience about what a 'safe place' looks like for you, please email me at *rachel.shepherd@urostomyassociation.org.uk* by **Tuesday 18th April 2023.** I look forward to hearing from you!"



The long road to my wonderful life

by Marita Hughes

A couple of years ago, I visited my GP and after looking through my notes, he asked me why I had a urostomy. I told him I had suffered from interstitial cystitis.

"Goodness me!" he said. "You had your bladder taken out just for that?". "But it was chronic," I replied, trying to justify myself. "It couldn't have been that bad, surely?" was his next comment.

> *How marvellous to be without pain! I could go for a two-hour walk or sit and enjoy a concert without having to leave my seat several times.*

Well, I don't know how I didn't burst into tears! I was so upset and angry that an experienced GP could be so ignorant and flippant about this terrible illness. I'll tell you how it affected me for over 30 years, and how eventually I received the right care and support, which gave me back my life.

As the eldest of nine children, life had always been hectic but very happy and enjoyable most of the time. As a child, I was always a real worrier so, when I visited my doctor at the age of 23 because I was having to empty my bladder more often than was normal, he told me that I just needed to calm down and stop being so anxious.

Initially, I accepted his advice, but the problem continued and got steadily worse. I loved my work as a teacher of RE and art at Willingsworth High School in the West Midlands, but the frequency with which I was having to visit the toilet was becoming a nuisance and by now the problem was uncomfortable, so back I went to my GP. He referred me to a gynaecologist, who diagnosed an erosion on the neck of the womb. A simple operation would sort this out and hopefully, the problem would go away but, guess what? It didn't. In fact, after just a few weeks, I needed to see my doctor again. As he was on holiday, my appointment was with one of his colleagues. He thought a problem with my kidneys or bladder could be at the root of my pain and referred me to a urologist at the Queen Elizabeth Hospital in Birmingham. A few weeks later, I attended my appointment for tests, which revealed blood in my urine. This was when I was told how chronic my condition was, although it wasn't given a name. I was prescribed medication, which I hoped would help.

I was just 24, and this was the beginning of another 30 years of trying different treatments, with varying degrees of temporary success.

In 1989, I moved back to North Wales, which is where I met Nigel. We married in 1993. He was a great support and shocked to see how much the illness took over my life, or should I say, our lives. My consultant was Miss Christine Evans, a very well-respected urologist. She diagnosed interstitial cystitis, an extremely debilitating and chronic condition. When she retired, she referred me to Mr Alan da Bolla at the Maelor Hospital in Wrexham, an expert in this condition. I continued receiving various treatments, with only marginal success, causing a great deal of upset and frustration for me and, of course, Nigel.

At this time, I was teaching at Brynhyfryd Secondary School in Ruthin, where I had been a pupil. I enjoyed my time there and somehow managed to cope with my condition with support from my colleagues.

After some years, I was appointed as a teacher of Welsh and art at Prestatyn High School. However, my health deteriorated and I was forced to take time off. By now, I was going to the toilet up to 20 times a night and taking strong painkillers. In addition to my declining health, the knowledge that my absences were a nuisance for my colleagues caused me great anxiety. Some didn't understand what a horrendous condition interstitial cystitis is, commenting that it's 'just cystitis', and often dismissing it as a 'women's problem' even though men suffer from it, too.

Eventually, I felt I had no choice but to retire at 48 because of ill health. Although retirement meant I had more time to rest, my condition went even further downhill, and my social life suffered. I certainly couldn't travel, and life became very depressing.

It was after my last cystoscopy performed by Alan Da Bolla that he told me firmly, "Marita, you need to have your bladder taken out." Whereas I would have been scared at the prospect some time before, I readily agreed. Could life be normal for me after all these years?

Alan is a former National President and Local Branch Chair of the Urostomy Association. He mentioned that I might like to get in touch with Toni Haines, Secretary of my local branch. Chatting to Toni made me feel much better about what lay ahead of me, and she put me in touch with another member, Mike Jarvis, who had suffered from the same problem and now had a urostomy. He visited me at my home and explained how the operation had changed his life. Being a member of the Association for the past ten years has been one of the best decisions I have made. Nigel and I have met many others like me, who live very rewarding lives. I have a lot to thank UA for!

My urostomy took place on 23 May 2012. I felt both nervous and excited as I waited for the anaesthetic to take effect. Six and a half hours later, I awoke in the recovery room, feeling a little nauseous. I was then wheeled into the high-

> Life now has no bounds. I enjoy my hobbies – sewing, knitting, baking and gardening. I can take my dog, Medi, for long walks. It seems that I do everything to excess.

dependency unit, where I remained for four days. That evening, Nigel visited me, and the first thing he noticed was that the pain had already gone from my face. Eleven days later I was home and feeling wonderful.

Too wonderful, I think, because I was out weeding the strawberry bed in no time! I couldn't remember when I had last not had to get up to go to the toilet in the middle of the night, and those horrible bladder spasms had gone. However, when I visited the stoma nurse a couple of weeks later, she really did tell me off for doing too much too soon! I needed to heal internally and therefore had to rest and be very, very careful.

Another thing I hadn't considered was that although I no longer needed strong painkillers, I couldn't suddenly stop taking them. After taking two years to wean myself off, I knew what a drug addict must feel like! I began to feel extremely tired and eventually learned that because my ileum had been removed to make my stoma, my body was unable to absorb vitamin B12, which was why I was feeling exhausted. The problem was easily resolved after being prescribed B12 injections every 12 weeks.

My health began to improve and we visited Joanna and Mike, my sister and brother-in-law in San Diego. This was a holiday which would have been inconceivable before my urostomy. I'd always dreamt of going to Hollywood, and here I was placing my hands in the very spot where Cary Grant had placed his, so many years before. I was like a child in a toy shop! I also got to realise my dream of swimming with dolphins.

Plotting out the nearest toilet was no longer a consideration unless my bag leaked, and this was, I must admit, an early problem. Having found a bag that suits me, leakage is now a rarity.

How marvellous to be without pain! I could go for a two-hour walk or sit and enjoy a concert without having to leave my seat several times. To Nigel and me, this felt like a new beginning!

Having retired so early from teaching, I now wanted to go back to work but in a different field. My neighbour was an elderly Australian with no family in this country. He was adamant that he did not want a religious funeral. After a long discussion, I offered to preside at his funeral in what, we hoped, would be the distant future. When the time came, I did indeed conduct a non-religious service for him at the local crematorium. It gave me so much satisfaction that I decided to train as a celebrant, which is now my profession.

Feeling that life was moving forward at last, I was able to spend time with my grandchildren, Deri and Gwydion, going ten pin bowling and even bouncing around on the huge underground trampolines at Zip World! I could also run around with our three-year-old great granddaughter, Nia.

Looking back at what were very difficult years, I really don't know how I would have coped without my fantastic husband, my parents and the rest of my family.

Life now has no bounds. I enjoy my hobbies – sewing, knitting, baking and gardening. I can take my dog, Medi, for long walks. It seems that I do everything to excess. I don't just have a few garden pots. I have a hundred! Recently, I entered some of my pots, plants, baking, chutneys and jams, sewing and knitting in the local shows and was thrilled to have won many prizes and trophies. I'm really making up for lost time!

Ten years ago, life was pretty awful. I'd lost my career and my social life because of interstitial cystitis, a really horrible and life-changing illness. Now, I have a new career, Nigel and I can travel anywhere in the world, and I'm loving my hobbies and even winning prizes for them. What a wonderful life!

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 need more people to replace those 200+ Club members that we have lost.

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.

Draw on 5th Nov 2022 at branch meeting in Shrewsbury

1st prize	of **£250**	No 13	**Mr J Tunstall**
2nd prize	of **£150**	No 258	**Mr M Price**
3rd prize	of **£100**	No 141	**Mrs P Twelvetrees**
4th prize	of **£50**	No 24	**Mr D Simmonds**

Draw on 10th Dec 2022 at NAGM

1st prize	of **£250**	No 29	**Mr H McMichael** – ***Thank you*** *to Hugh for donating all* ***£250 to UA***
2nd prize	of **£150**	No 243	**Mr A Davies**
3rd prize	of **£100**	No 91	**Mr D Howell-Richardson**
4th prize	of **£50**	No 46	**Mrs L Dickenson**

Draw at Zoom meeting on 2nd Feb, 2023

1st prize	of **£250**	No 197	**Mrs M Wainwright**
2nd prize	of **£150**	No 12	**Mrs G Hurd**
3rd prize	of **£100**	No 87	**Mr J Eaton**
4th prize	of **£50**	No 152	Mrs M Wilcox

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**

Fundraising UPDATE

by Rachel Shepherd

Time seems to have flown since I wrote my last update for the Journal – so much has happened! Thank you to everyone who supported UA last year through volunteering, fundraising, donating and sharing their knowledge and experience with us. Without such loyal supporters we could not give those with urinary diversions the focused, bespoke support they need. As we move into spring, I'm looking forward to a year of activities and ensuring we are able to continue supporting everyone within our community.

UA your Way

Excitingly, we've launched a new fundraising campaign that we've call UA your Way because that's exactly what it is: fundraising for our charity your way by harnessing your hobbies and interests to do good for others. Find out more on page 30.

Grant funding for volunteer training

I'm delighted to let you know that our grant-funded volunteering project is underway, thanks to support from the Lottery and also the Hospital Saturday Fund. Our first training day for new volunteers is in April, and due to high demand we will be running another in September. Volunteering for the Association is a great way to show your support if you have some time to spare – our volunteers often say how rewarding they find using their experience to encourage others, so if this is something that appeals to you, please visit ***www.urostomyassociation.org.uk/volunteering*** to find out more, or call the office on 01386 430140.

Birthday gifts

Many of us reach a time in our lives when we no longer want to accumulate more ‘things’ that take up precious space in our homes. That's part of the reason there's a growing trend for people to show their support for their chosen charity by asking friends and family for donations to that cause in lieu of birthday presents. A big thank-you to Stephen Moriarty, who kindly fundraised for UA this way and sent us £945 towards the running of our services for those who need us. Such a generous – and much appreciated – gesture.

Read all about it!

Our supporters, both individuals and corporates, have done us proud by kindly donating towards/sponsoring Bags, Bags, Bags, our innovative book for children under seven. Thank you so much for getting behind our project to help create more awareness and understanding for people with a urinary diversion! Read more about this on page 14.

Donate as you shop – at no extra cost!

Amazon Smile is stopping its support for small charities like UA, which is disappointing as the scheme helped us raise nearly £600.

However, there are other really simple – and free! – ways to show your support for the Association while you shop online at outlets such as M&S, Tesco, John Lewis, Dunelm and hundreds of other well-known stores.

When you sign up to reputable sites *www.giveasyoulive.org* and/or *www.easyfundraising.org.uk*, which is really straightforward to do, these platforms will make a donation to our charity every time you buy goods - be they groceries, clothes, books, electrical items, etc - book a holiday or choose your car insurance. It won't cost you any extra pennies at all!

All you need to do is name us as your charity, so please consider supporting us in this no-cost way. Every little bit really does help us continue providing our services so that more people with a urinary diversion can live life to the full.

“It makes me feel more secure – I feel it has the right fit to my body.”

It can be difficult to find a baseplate to fit over curved body areas around the stoma without getting creases and folds. The SenSura® Mio Concave has a star-shaped baseplate that is specifically designed to grip the curved area for a snug and secure fit - even when bending and stretching.

Camilla didn’t think SenSura Mio Concave was relevant for her at first because she thought it was just for hernias. She reconsidered because she always experienced leakage at the same place by the curvy area around her stoma. She now feels more confident because it wraps around her bump for a secure and discreet fit.

The unique, patented colour on all SenSura Mio products is discreet underneath all clothing, even white. The neutral fabric weave is soft, smooth and more gentle against your skin. The textile is water-repellent so dries in seconds meaning you don’t always have to change the bag after each shower or swim.

A built in stability ring supports the stoma at the centre of the baseplate while the star shape hugs the body.

The SenSura Mio Concave arrives inverted - a unique design to make the baseplate easier to apply over curved body profiles.

*By filling in the coupon, one of our Clinical Specialists will contact you to discuss which is the right solution for your needs before sending any free samples. Simply post back to FREEPOST COLOPLAST (no further postal address details or stamp required) and we’ll be in touch.
Alternatively, visit www.coloplast.co.uk/UA

Request your FREE sample

First name ______________________

Surname ______________________

Date of birth ______________________

Email ______________________

Date of Stoma Surgery ______________________

Telephone No. ______________________

Signature

How your information will be used - By providing your personal and sensitive personal data on this form, you are consenting to Coloplast Charter using it for administration and analysis purposes and to process your order. We may share this information with healthcare professionals and other companies required for the delivery of your products or as required by law. We may also contact you to ask you to clarify your requirements and to ask you to complete customer satisfaction or other surveys, and may use 3rd parties to handle this as outlined in our Privacy Policy which can be found at Coloplast.co.uk/privacy. We often keep customers up to date with the latest information on the products and services we offer. Please indicate if you would like to be kept informed by:

Email ☐ SMS ☐ Phone ☐ Post ☐

Inspected and rated
Outstanding
CareQuality Commission

*Our team are registered with the CQC (Care Quality Commission) who independently regulate the care we provide.

OC_EVERYSIDE_DTC_ADVERT_UA

Coloplast

Introducing **UA your Way**

> “Through our campaign UA your Way, your fundraising is as individual as you are.”

When it comes to showing your support for UA, there’s no age limit! Our fundraisers range from ten to 100 years old, and we couldn’t be more grateful to them for making a positive difference for our community.

If you, too, would like to pay forward some of the kindness, support and encouragement UA has provided for you or a loved one, we’ve made it really simple and straightforward for you through our campaign **UA your Way**, where your fundraising is as individual as you are.

Rachel Shepherd, who manages fundraising for the Association, explains: “Some of you are doing fantastic fundraising for UA simply by doing what you enjoy, using your hobbies and interests to support our services in your own way. UA your Way is our ‘banner’ for the fundraising you do and the important difference you make by doing it, whether you bake and sell cakes, organise a raffle or quiz night, crochet or take on a sponsored challenge such as a run, swim, walk or even a skydive.

“However you’d like to raise funds, as long as it’s safe, we’ll support you. You’ll be doing something compassionate for others and making us a more sustainable charity so we can keep doing what we do. Please have a look at our new fundraising pack at www.urostomyassociation.org.uk, or email us at info@urostomyassociation.org.uk and we’ll send one to you.

“If you’d prefer to make a donation of whatever you can afford, it’s easy to do on our website. You can use the QR code here, which will take you straight to it, or go online in the usual way. Every gift, whatever the size, really does make a difference – perhaps more than you will ever know.”

Meet some of our **fantastic fundraisers**

Mary Milner

As well as being one of our big-hearted volunteers, Sheffield Branch Secretary Mary Milner gets crafty to support UA.

Mary said: “My main fundraising now is handmade cards and crafts. I usually have a craft stall at our UA branch meetings and also occasional stalls at local small craft events, which is also a good way to promote the Association.

“My mum used to help, too, by making marmalade, which was very popular when she was selling it to support the Association.”

Alex Shepherd

One of our youngest fundraisers is ten-year-old Alex Shepherd, who is being sponsored by kind friends and family to read for 100 consecutive nights and has already raised over £200.

Alex, who lives in Bromsgrove, said: “One of the things I like best is having fun with my family, but when someone is ill it can affect everyone around them. I’m supporting the Urostomy Association so they can keep on helping people to make a good recovery and enjoy their family time again.”

Well done, Alex! Our thanks also go to the gentleman who generously donated £395, money he received in lieu of birthday presents when he celebrated reaching the milestone his 100th birthday. Congratulations, sir! We are so grateful for your support.

Toni Haines

Another of our community-spirited volunteers is Toni Haines, who as well as being UA’s Branch Secretary for Shropshire, Wales and the Marches, uses her artistic talent to fundraise for us.

Toni said: “I had painted some plates for our boat and someone saw them and asked me to paint a half-churn. I agreed, but explained it might take a while as I needed to practise.

“I practised on the boat, and while we were at the Cropredy music festival, and people kept asking me if I sold painted things. I eventually finished the churn and I was given £60, which I gave to the Association. Since there appeared to be a market, I started painting to sell. I literally painted anything I could find that could be a present or souvenir and sold them from the boat. We then began going to a few of the boaters’ traders’ markets, as well as selling at UA annual general meeting weekends, and profits went to the Association.

“My painting funds the local UA branch, as well as allowing us to make a yearly contribution to the charity’s national funds. Quite by chance, I not only found a satisfying and therapeutic hobby, but something that also brings in a fair bit money. Just as importantly, we have raised the profile of the Association - our boat is covered with UA stickers and we have a big A board, telling everyone who we are and where the money will go.

“I’m positive that if anyone in the boating fraternity ever has bladder cancer, there are loads of people who would now automatically send them our way. I like to think we are helping to make ‘wee’ less of a taboo subject!”

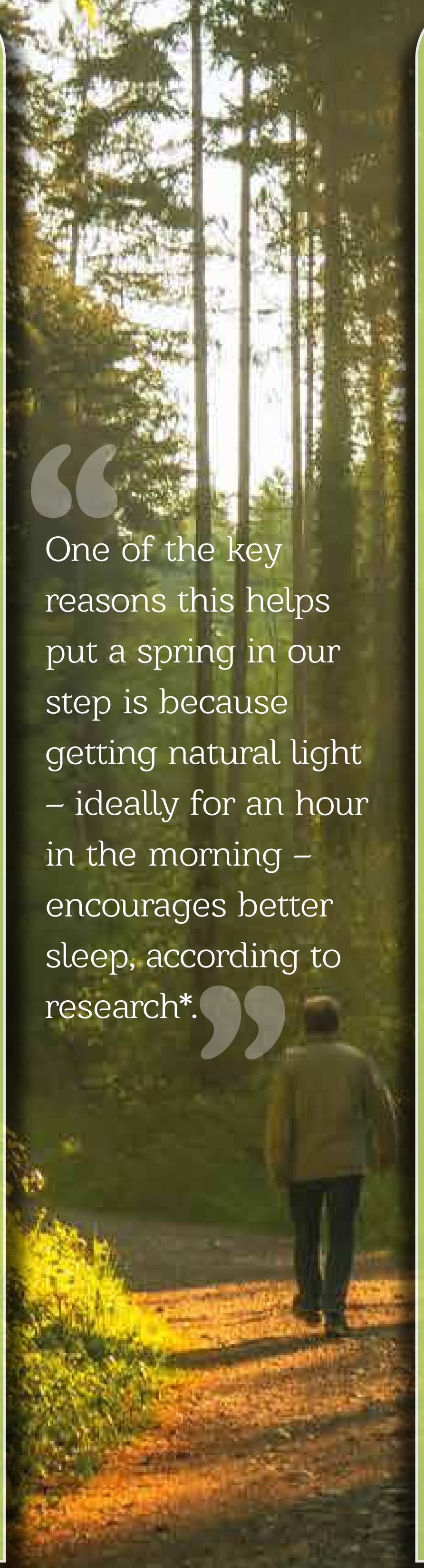
Health and wellbeing watch

Through both traditional media and via social media, it feels as though we're constantly bombarded with news and messages about health and wellbeing, from the latest breakthroughs in medical research to the newest fitness trends. Our quick and easy read rounds up just some of the more recent and helpful news from trusted sources, helping you to take action if and where you want.

Lighten up

Doesn't it feel good now the days are lighter for longer? One of the key reasons this helps put a spring in our step is because getting natural light – ideally for an hour in the morning – encourages better sleep, according to research*.

Sunshine regulates the body's circadian rhythm (the 24-hour internal clock that co-ordinates a wide range of processes, including sleep). This rhythm is controlled by a small part of the brain, known as the circadian pacemaker, that is powerfully influenced by light exposure. So, the more daylight exposure you can get, the better your body will produce melatonin, a hormone naturally made by the body, the production of which is closely tied to light – when it's time to go to sleep.



> “One of the key reasons this helps put a spring in our step is because getting natural light – ideally for an hour in the morning – encourages better sleep, according to research*.”

If you can, it's a good idea to break free from your four walls each day and get outside into natural light. This doesn't need to be for hours, just squeezing in a morning walk or sitting on your patio can help you reap the benefits. While getting more of this tonic isn't the answer to everything, we all tend to feel better after a decent sleep, so what's not to like – especially as it's free?

For more on this, plus plenty of other advice to help you get good shut-eye, visit the Sleep Foundation at:* ***www.sleepfoundation.org*

Bright and beautiful

Did you know that eating brightly coloured fruit and vegetables – such as strawberries, oranges, apples and peppers - daily can reduce your risk of developing dementia by as much as 20%? That's according to Harvard University scientists, who studied the diets of more than 77,000 middle-aged men and women over a period of 20 years, asking them how often they ate particular foods containing flavonoids (powerful antioxidants which occur naturally in plants).

Participants were asked to report their levels of cognitive decline twice during the study by answering seven questions about their memory and cognitive function. They answered questions such as: “Do you have more trouble than usual remembering recent events?” and “Do you have more trouble than usual remembering a short list of items?”

The researchers found that the people who ate the most flavonoid-rich foods (around 600 milligrams per day), had a 20% less risk of cognitive decline than those eating just 150mg each day.

The study also looked at individual flavonoids. Flavones, found in some spices and yellow or orange fruits and vegetables, had the strongest protective qualities, and were associated with a 38% reduction in risk of cognitive decline, which is the equivalent of being three to four years younger in age.

Study author Walter Willett, MD, DrPH, of Harvard University said: “There is mounting evidence suggesting flavonoids are powerhouses when it comes to preventing your thinking skills from declining as you get older. Our results are exciting because they show that making simple changes to your diet could help prevent cognitive decline.”

Excuse us while we tuck into some fruit! You can read more on this, and all sorts of other findings to benefit your brain, on the Brain Health Network website at ***www.brain.health.***

Help for hay fever

According to Allergy UK, up to 49 per cent of the UK population report having hay fever symptoms – that's an awful lot of streaming eyes and itchy noses, and of course symptoms may become more severe when the pollen count is high.

Grass pollen is the most common allergen (May to July), but tree (February to June) and weed (June to September) pollens can also cause the allergic reaction we know as hay fever. In perennial allergic rhinitis the symptoms continue all year round and usually relate to indoor allergens, such as house dust mites, pets, including birds, or moulds.

Besides making you miserable, hay fever can affect how well you perform at work and can generally interfere with your life. There's help available though, so you don't have to put up with annoying symptoms - you can learn to avoid your triggers and find the right treatment. Allergy UK is a great place to start if you're looking for information and support – call **01322 619818** or visit ***www.allergyuk.***

Are you sitting comfortably?

One of the lasting effects of the pandemic is that more people are continuing to work from home, with many organisations choosing to embrace remote working fully or adopt a hybrid model where staff go into the office part of the week and work from home the remainder.

So, being mindful of working-from-home ergonomics (how we interact with the physical systems in our environment: for example, how we sit at our desks) could end up being a skill many of us will use for years to come.

We can't be productive when we're in pain, so it's important to adopt the right posture, whether working at a desk or from the dining table. There are numerous guides on this available online, but make sure you refer to reliable sources, such as the Health and Safety Executive: ***www.hse.gov.uk/msd/dse/good-posture.htm***.

It won't come as a surprise to hear the best way to avoid muscular and joint aches and pain is regular movement. You could try having your printer in a different part of the room, taking phone calls standing up, and taking time out to stretch on a regular basis. Even small chores can increase your activity levels. Who knew unloading the dishwasher could double up as a mini-workout?! Aim to move from your desk every half hour (you could set a reminder on your phone). You'll also be surprised at how this can help productivity and alleviate stress. Your body will tell you when it is starting to get stiff – listen to it!

Women at the frontier

*When urology trainee **Kathryn (Kassie) Ball** was touring the British Association of Urological Surgeons (BAUS) Virtual Museum at www.baus.org.uk, she spotted an obvious gap.*

*Struck by the lack of any exhibits relating to female pioneers of urology, she reached out to Consultant Urological Surgeon **Jonathan Charles Goddard**, who edits the History of Urology section of 'Urology News' magazine (www.urologynews.uk.com), saying: "As a female trainee I sought an inspiring story of perseverance, accomplishment and a journey through the life of a famous female urologist. Disappointingly, there was nothing to be found, but surely this can't be right?"*

The following is based on the 'Urology News' article (2022; 26(2): 15-16) Jonathan and Kassie then collaborated on to shine a light on the women who – with great tenacity - helped pioneer the specialism of urological surgery.

Our thanks to Jonathan, Kassie and Pinpoint Publishing Scotland Ltd for their kind permission.

On 17 March 1945, Reginald Ogier Ward was elected the first President of the new British Association of Urological Surgeons. Invited to attend this inaugural meeting were 39 consultant surgeons, known to have an interest in the practice of urological surgery. Discreetly listed among these founding members is the name of a single woman, Emily Catherine Lewis (1882-1965). During a second meeting in May 1945, a further 27 foundation members were added, including Helen Frances Wingate (1895-1985), the only other female representative.

Who were these women that immediately stand out amongst a wealth of their male counterparts? Clearly present at the birth of BAUS, to date they do not readily appear in its history.

Catherine Lewis

Emily Catherine Lewis (left) – known as Catherine – was the youngest of four children, arriving some 13 years after her two half-brothers and sister on 29 May 1882. The family lived in Hampstead by the time Catherine was born but maintained strong Cornish roots reflected in her father James, a Lieutenant in the Royal Navy and her older brother, Sir John Anthony Hawke, who served as a Member of Parliament for St Ives as well as Attorney-General to the Prince of Wales and latterly a High Court Judge.

Her mother was widowed for a second time when Catherine was age three, but nevertheless educated her daughter in the arts, and Catherine became an accomplished pianist and music teacher. Following her mother's death in 1906, she took up residence with her older half-brother, now Dr Edward DH Hawke, and it was perhaps this time that ignited her passion for medicine. Taking the bold move to relinquish an established career in music, Catherine graduated from the London School of Medicine for Women in 1917 at the age of 35.

At this time, the Royal College of Surgeons of England had finally conceded to the tireless petitioning of Elizabeth Garrett Anderson, Dean of LSMW from 1883-1903, to admit women for examination. Pioneering the path for future women surgeons, Catherine became the second female fellow of the RCSE in 1919 (the first was ENT surgeon E Davies-Colley (1874-1934) in 1911), which led in rapid succession to her appointment as the first female General Surgeon of a London teaching hospital, The Royal Free.

Class photograph, London School of Medicine for Women showing Catherine Lewis (second row from the back, sixth from the right). Thank you to The Royal Free London NHS Foundation Trust and the London Metropolitan Archives, City of London, for this photograph, H72/SM/Y/01/001.

A 'sound surgical opinion'

Described as 'almost unapproachable' in her early career, due to her shy and reserved nature, Catherine softened as her experience grew. Amongst her colleagues at The Royal Free she successfully established herself as a 'sound surgical opinion' through her meticulous operative skill and thorough, considered approach to patient management. She contributed fully to the general surgical workload, but her main area of interest developed in urology.

Catherine honed her urological skills at St Peter's Hospital for the Stone and, in another first for a woman, was appointed as clinical assistant to Mr Clifford Morson, second BAUS President and prime instigator for use of radiotherapy in urological cancers.

> "Her courage in pursuing a previously disregarded cause was testament to her resilient and tenacious character; justifiably awarding her recognition as a trailblazer for women in urology."

Forging a particular interest in urological disease in women, Catherine defied her colleagues who warned that this very specific practice would 'never prove financially profitable' and was 'of minor importance'. On returning to The Royal Free, she succeeded in forming and presiding over the Department of Urology and even wrote a short book titled 'Urology in Women'. Her courage in pursuing a previously disregarded cause was testament to her resilient and tenacious character; justifiably awarding her recognition as a trailblazer for women in urology.

In the year of the advent of the National Health Service, Catherine retired to Ely, Cambridgeshire. Ever the practical perfectionist, rather unusually she turned her talents to the study of precious stones, alongside indulging in her first love of music. Although she had never married, she was popular and maintained a close-knit circle of friends, yet her fierce independence prevailed to the end of her life. In a sense almost coming full-circle, Catherine developed obstruction secondary to bowel carcinoma and died at the Royal Free Hospital in October 1965, the very place where she endeavoured to put women in urology on the map.

Women at the frontier

Continued

Helen Wingate

The early 20th century also saw Helen Frances Wingate establish herself as Scotland's first female surgeon specialising in urology.

Affectionately nicknamed 'Nell' by her family, Helen was born in October 1895 in Greenock, a port town to the West of Glasgow. She attended the local Greenock Academy and later the Mount School before gaining her place at Glasgow University. During her early education she was injured in a fire and suffered burns to her face, no doubt exposing her to the medical profession from an early age and perhaps steering her towards a future career in surgery.

In 1914, Helen enrolled as a medical student at Queen Margaret College, the ladies' medical school attached to Glasgow University. She graduated with commendation in 1920 and was amongst a small group of women doctors who pioneered their way into the unyielding world of the Glasgow teaching hospitals.

Displaying meticulous care

Helen took an initial house job in the Glasgow Royal Infirmary, shortly followed by appointment to the university department of pathology under the eminent Professor John Teacher and Thomas Bryce. The Teacher-Bryce ovum No1 was discovered in 1908 and described for the first time the youngest human ovum to exhibit all three germ layer cells. Helen displayed meticulous care in her post-mortem examinations, acquiring the knife skills and anatomical knowledge that would later excel her surgical career. Her attention to detail was rewarded in 1924, when she found a well-developed corpus luteum during a routine post-mortem examination and diagnosed an early pregnancy - the Teacher-Bryce ovum No2.

In 1933, Helen joined the staff of Arthur Jacobs' newly formed urology unit at the Royal Infirmary. Arthur Jacobs was an expert in performing urinary diversion to manage genito-urinary tuberculosis, and was one of the first to describe hyperchloraemic acidosis in this patient group. Jacobs was BAUS President from 1957 to '59. Also working in the unit alongside Helen was Willie Mack, who became BAUS President in 1969. Jacobs sent Helen to the internationally renowned endoscopic surgeon Hans Rubritius at the Poliklinik Hospital in Vienna, to complete her postgraduate training in urology. On returning to Glasgow she became a fellow of the Royal Faculty of Physicians and Surgeons of Glasgow in 1937, and in 1940 was appointed as Consultant General and urological surgeon to the Redlands Hospital for Women.

Alongside her clinical work, Helen was a representative on the Medical Women's Federation Board of Redlands Hospital and later a member of the Marriage Guidance Council. She married Alfred Lochead in 1943, an established Glasgow architect by profession and decorated First World War Veteran. Lochead survived the Holzminden prisoner of war camp and heroically helped many fellow prisoners to escape through his legendary forging of identity documents.

Going against the grain

In a rather modern move - and against the grain of the expectations of women at the time - Helen continued to work as a surgeon following her marriage until her retirement from clinical work in 1962. Inspired by her husband, she developed a deep interest in architecture, which married well with her love of the Scottish countryside, nature and gardening.

By taking a leading role in the foundation of BAUS, at a time of gross underrepresentation of women in surgery, both Lewis and Wingate paved the way for future generations of female urologists. Perhaps unconsciously, they have also pioneered support for women surgeons throughout their careers in both their clinical and personal life choices.

The representation of women in urology has continued to grow in strength and number, and remarkably we now have a cohort of 37% female urology trainees. In 2022, we welcomed the first ever female President of BAUS – this landmark moment arguably made possible by the female pioneers breaking ground for women in urology from the beginning of BAUS history.

Acknowledgement

We are very grateful to Mary Garthwaite, Chair of the Urology Foundation, who is also the Museum of Urology's Artist in Residence and Curator of the BAUS Art Gallery, for the portrait of Helen Wingate, which she skilfully painted from photographs from Helen's family and the BAUS archive.

www.theurologyfoundation.org

Photo to left – Arthur Jacobs' Urology Unit. Helen Wingate rear left. Arthur Jacobs seated second from right. Willie Mack seated left.

Welcoming new faces

Introducing Liz Ogilvie and Guy Eccles

If you receive UA's regular newsletter (and if you don't but would like to, please sign up!), you'll know we've recently welcomed two new faces to our Board of Trustees: Liz Ogilvie (left) and Guy Eccles (below). It is great to have them both onboard!

Liz, who started her working life as a graduate trainee with Procter & Gamble, runs her own business as a facilitator and organisational development consultant working with universities in the UK and abroad. She and her colleagues facilitate meetings with academics and industry to enable them to collaborate and work together on ground-breaking ideas for research.

Prior to this, Liz lived and worked in Dubai, and spent time in industry before becoming a Director of Kingston College, which provides further education and access to higher education courses.

With a wealth of experience in the charity and not-for-profit sectors, as well the commercial world, Liz – who splits her time between Wiltshire and Surbiton, in London - is Vice Chair of the Trustee Board of the school she attended in Salisbury, and recently retired as Chair of the Membership Council of a community health trust.

Liz first got to know UA when she and colleague Richard Plenty undertook the strategic review of our charity two years ago, and she has kept in touch with us ever since. She said: "It's a pleasure now to be part of the Trustee Board. I am interested in the strategic direction and future of UA, and believe as trustees we must ensure the Association is ready to respond to people's needs in 2023 and beyond. It's about ensuring UA has a strong presence and place in the stoma 'charity market place'."

Look out for our article on Guy, fellow 'newcomer' to our Board, in our summer Journal.

Looking back and forward

When long-serving volunteer Don Haines stepped down as Editor of the Journal and as UA Trustee, having made such a big contribution to our charity over many years, we couldn't let him go without asking for his reflections on his time with our charity as well as his thoughts on our direction of travel. Over to you, Don!

Thank you from us all: Don with UA's President Derek Rosario and Chief Executive Hazel Pixley.

Reaching the end of an era

Regular readers of this Journal will be aware that I had been its Editor for nine years when I decided to step down from the role, following the publication of the summer 2022 edition. In making that decision I had very few misgivings, having given my all to the role for so long, but the fact is that the process of assembling sufficient content, three times a year, had become increasingly challenging for me. However, it was with very mixed feelings that I also stood down from the National Executive Committee (NEC) at the national AGM in December.

I had been a Trustee and a member of the NEC for almost 18 years, having first been co-opted prior to my election to the role of National Fundraiser. During that period, I have had the pleasure of working alongside a number of different NEC Chairs and National Presidents, as well as some extremely capable Members' Representatives, Treasurers, and other NEC members. The one constant presence throughout the whole of that period has been our National Secretary (and now CEO) Hazel Pixley - I take my hat off to Hazel for her exceptional organisational expertise, and her unrivalled attention to detail.

NEC members are also members of the Board of Trustees, with a responsibility to make sure that the charity is run in the interests of the people it is there to support. They are also there to oversee the management and administration of the charity. In addition, and most importantly, the Board has a responsibility to ensure that our charity complies at all times with any and all relevant laws and regulations. It is this latter function that has sometimes led to somewhat spirited discussions with our members and with the Branches!

During my time as a Trustee, we have had to make decisions regarding such issues as data protection, risk assessments, and safeguarding, to name only a handful. Of these, data protection has at times been the thorniest of topics. Before the introduction of more recent GDPR laws, it was quite usual for Branch Secretaries and other Branch Officers to hold a database of their members names and addresses, not least because each branch took delivery of a number of copies of each edition of the Journal, with the responsibility for mailing them to the members.

These days, the importance of taking care of that database cannot be underestimated. Secretaries may still keep such a database, but it is not legally acceptable for instance, to send out an email addressed to all members, in such a way that every member's email address can be seen by every recipient of that email. Holders of such information also bear a responsibility for ensuring its security, such as when, for instance, an old laptop is replaced with a new one.

Moves to modernise

Within the past few years, the Board has increasingly had to turn its attention to the emerging challenges of the 21st century, predominantly because of the ongoing reduction in the number of UA members and in the numbers of fully functioning Branches. Most readers will, I am sure, be aware that changes to our Association are afoot, in the way that we perform as the go-to charity for anyone with, or contemplating, a urinary diversion. My personal view, and that of others, is that stoma care professionals have always been our gateway to attracting new members, but sadly, our success rates in this regard have been less than successful, with a few exceptions.

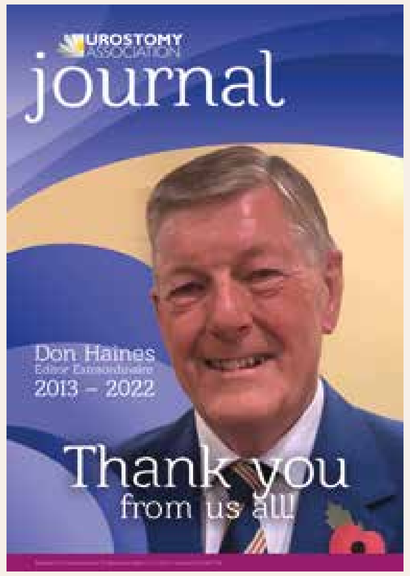
In recognition of the need for change, as well as the need for compliance with important areas of legislation, new members have been appointed to the board, increasing our levels of expertise. You will be aware, too, from recent UA newsletters, plus articles in the Journal, that Hazel and colleagues are making strides in developing a closer relationship between the Association and healthcare professionals as well as companies who supply stoma care products.

We have come to understand the increasing importance of the internet and of social media in providing information and support for urinary diversion patients, both old and new, and the importance of communication with existing and prospective members. In recognition of these issues, both our main website and our Facebook presence have both been the subject of some very beneficial modernisation. For instance, and to return to the subject of this Journal, visitors to our website at *www.urostomyassociation.org.uk* will find downloadable copies of the last three editions readily available, and regular recipients are being encouraged to receive their copy electronically – although the printed version will still be available for those who prefer a hard copy.

In short, the Urostomy Association, having operated very successfully for decades in its original form, is equipping itself to remain equally successful – and hopefully even more so - in the future, using every modern tool at its disposal. As a vital part of this process, we have sought and acted upon the advice of some very capable and knowledgeable professionals, who have studied our organisation carefully before making some very relevant recommendations.

Leaving on a high

The upshot of all this is that, having recognised the importance of making changes, we have also recognised that our existing resources in the form of our highly efficient permanent staff (just two people: Hazel, who is full time, and Administrative Officer Dave Page, who works part time) were already operating at much more than full capacity. Acting upon that recognition is not as easy as it sounds. Our bank balance is healthy at the moment, but we need to take steps to ensure it remains so, in the face of some very necessary expenditure, to which end we appointed an experienced Fundraising Consultant on a part-time basis, having failed to find a volunteer National Fundraiser.



UROSTOMY ASSOCIATION
journal
Don Haines
Editor Extraordinaire
2013 – 2022
Thank you
from us all!

At the age of 77, and while being fully supportive of the need for change, I decided that I was not best placed to continue as a Trustee, which is why I have relinquished the role in December. Having announced this at December's national AGM, I was delighted to be presented with a framed mock-up of a front page of the Journal, featuring yours truly in my Hadley Male Voice Choir uniform! I shall treasure that memento, which will remind me of some very happy times.

Don Haines

PS *Despite having stepped down, I'm not cutting ties with UA – far from it. My wife Toni, who has a urostomy, is Secretary of the Shropshire, Wales and the Marches Branch and also fundraises for the charity, so I'm always well within the loop of what's going on locally and nationally. I wish the Association every success for 2023 and beyond!*

What's cooking?

Just because you have a urinary diversion it doesn't mean meals, snacks and drinks have to be bland. The great news is that generally, there is no need to stick to a specific diet after your surgery, and you can eat and drink what you enjoy, including alcohol. It's very important to stay well hydrated though, so make sure you're taking in plenty of non-alcoholic drinks throughout the day.

In celebration of being able to enjoy what you like eating* and drinking, we're starting a regular series of recipes to tickle your tastebuds, and we'd love to feature your favourites here in the Journal. 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*. Don't forget to say why it's such a favourite and state how long it takes to prepare and cook/bake. We can't wait to find out what you most enjoy!

To start us off, three people involved in the work we do to bring you the Journal are each sharing one of their favourite recipes to whet your appetite.

Rachel Shepherd, who oversees fundraising for our charity, shares her recipe for the flapjacks she enjoys just as much today as when she first started baking them as student in the 90s.

"I found this recipe in my student cookbook and got hooked because they're so tasty and satisfying," said Rachel, who lives in Bromsgrove in the Midlands with her husband James and ten-year-old son Alex. "It's an easy recipe to follow and not too expensive either. Alex loves making them for his grandad, who can't get enough of flapjacks."

Rachel's really good flapjacks

Prep time: 10 mins
Baking time: 23 mins

Ingredients

100g/4oz	margarine (or vegan margarine)
75g/3oz	brown sugar
4tbsp	golden syrup
300g/10oz	rolled oats

Method

Melt the margarine, sugar and syrup in a saucepan over a low heat.

Stir in the oats until totally covered. Spoon into a greased baking tray and spread until about 1cm thick.

Bake in a pre-heated oven at 180C/350F/gas mark 4 for about 25 mins until golden. Leave to cool in the tray and then cut into squares.

**Though asparagus can give urine an unusual smell, it is not known to cause infections.*

Paola Simoneschi, who lives in Plymouth and manages UA's communications on a freelance basis, has a passion for pasta. "I had to stay true to my Italian roots and share a pasta dish," she said. "Pasta primavera is vibrant and filling - just right for spring and summer, especially. With all the veg in it, it's pretty healthy too."

Paola's pasta primavera

Prep time: 10 mins
Cooking time: 20 mins

Ingredients

75g young broad beans
(frozen if you can't get fresh)
2 x 100g pack asparagus tips
170g peas
(use frozen if you can't get fresh)
350g spaghetti or tagliatelle
175g pack baby leeks, trimmed and sliced
1 tbsp olive oil, plus extra to serve
1 tbsp butter
200ml tub fromage frais or creme fraiche
handful fresh chopped herbs
(mint, parsley and chives go well)
parmesan (or vegetarian alternative), shaved, to serve

Method

Boil a pan of salted water and place a steamer (or colander) over it. Steam the beans, asparagus and peas until just tender, then set aside. Cook the pasta following pack instructions.

Meanwhile, fry the leeks in the oil and butter for 5 mins or until soft. Add the fromage frais to the leeks and gently warm through, stirring constantly. Add the herbs and steamed vegetables with a splash of pasta water to loosen.

Drain the pasta and stir into the sauce. Adjust the seasoning, add the parmesan, and drizzle with a little extra olive oil.

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.

Chris Allen of the Upper Room design agency is the talented graphic designer whose work shapes the look of the Journal. Chris enjoys a good curry, so shares his favourite here.

"It's never too hot for a curry!" said Chris, who lives in Herne Bay. "So, whatever the season, it would still be on my menu. However, due to the doctor telling me I needed to lose a little weight, I rather reluctantly decided that these little indulgences would have to go! Imagine my delight when my daughter cooked us a chicken curry, given to her by one of her friends while sharing diet ideas! Now, as I am not one of those people who like to keep culinary finds a secret and this recipe was freely given to us, here it is for Journal readers to enjoy!"

Chris's chicken curry

Prep time: 10 mins
Cooking time: 25 mins

Ingredients

Chicken breasts
Olive oil
1 onion
2 cloves garlic
1 can of tinned tomatoes
Spices (turmeric, masala, coriander, ginger, ground cumin and hot chilli powder)
1 tin of coconut milk
brown, basmati or wild rice

Method

Cook diced chicken breasts in a hot pan of olive oil then put aside.

In the same pan, fry 1 sliced onion until soft, then add 2 cloves of chopped garlic.

Place the cooked chicken back into the pan and pour in 1 can of tinned tomatoes.

Add ½ tsp of each of the spices (you may want to add more of each, depending on your personal taste).

Let simmer for 10 minutes, then pour in 1 can of coconut milk and stir.

Serve with your chosen rice.

Enjoy!

Making a lasting **impact**

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

It was Winston Churchill who said, "We make a living by what we get; we make a life by what we give." All of us, when we die, leave a 'legacy' that can impact those who knew us for many years to come, in ways big and small. It's about the person you have been, who they hold in their memories, and in particular how you made them feel.

As a society, we still don't talk openly about death and dying - it's almost as though we fear that in talking about death we'll somehow hasten it. Not much is said about legacies either, and it's a common misconception that they are always about large amounts of money. But a person's 'legacy' is the work they have done throughout their lifetime, and the love and support given to family and friends. Usually, this isn't given much consideration until after they have gone. Often though, the impact of a person on our lives is significant, meaning we'll remember them for the rest of our days.

Even when we do talk about legacies that are financial or 'valuable', such as pieces of art or jewellery, it is the intention behind the gift that says so much about the person who has written it into their will.

In 2019, we were notified that UA member Martin Orksey, from the Cotswolds, had passed away. Throughout his life Martin was a keen supporter of the Association, and many other charities, so he very kindly decided to leave us a gift in his will, knowing the good it would help us do, supporting people during an anxious time in their lives and making sure they don't have to face it alone.

Martin's gift is enabling us to do the transformational work needed so that we become a more resilient, sustainable charity, here for our community for years to come. This doesn't mean we no longer need to find funding to keep our services running – far from it! – but it does mean we will be in a stronger position to support the people fundraising for us and be more attractive to grant-giving organisations and corporates. Martin's legacy will help us reach more people, the majority of whom never knew him. They will benefit from his generosity, kindness and compassion for those living with a urinary diversion.

Thanks to Martin's gift, we are…

- giving reassurance, comfort and accurate information to more people - both pre-op and post-op - through training new volunteers to provide crucial peer-to-peer support,
- creating a better connection between UA and our community, making sure we are delivering the service people need now and in the future, and
- improving the financial stability of our charity, ensuring we are able to fund our high-quality services for years to come.

"Although we are unable to thank Martin in person, we would like to express our gratitude to him for his kindness and his legacy that is making a lasting impact for our community," said Rachel Shepherd, UA's Fundraising Consultant.

"Every gift we receive – big or small - has a positive effect on a person, supporting them returning to life 'as normal' and encouraging them to live with confidence in a world where, without UA, this might not necessarily happen."

> We make a living by what we get;
> we make a life by what we give.
>
> Winston Churchill

News from the branches

Do you know about the Association's local branches? We have seven across the country: Birmingham; 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.

Group 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.cambridge@urostomyassociation.org.uk

Despite the very cold weather during December, the Cambridge Branch met up for our annual Christmas lunch at the Slepe Hall Hotel in St Ives. We enjoyed a delicious meal followed by a raffle, with top prize being 25% of the ticket sales and prizes donated by members. A good time was had by all.

This year, we hope to arrange more social gatherings and talks at the meetings. We have already had Coloplast give an informative presentation, and in June we have Cuiwear coming to talk about support wear. Following on from the successful autumnal guided walk around the Cambridge Botanic Gardens, we are going back in April for a spring walk followed by lunch in the Gardens café. We are also looking into an afternoon tea get together.

Our meetings bring members together in a comfortable setting, where they enjoy chatting to each other and swapping ideas and tips. Sometimes we have guest speakers, too.

Diary dates: *We meet at 10.30am on the first Tuesday of the month. We also have a table booked at the Stoma Open Day at Addenbrookes Hospital on 22 April.*

Jane Phillips

Lothian and Fife

Venue: To be confirmed
Branch Secretary: Rhona McLaughlin
Email: secretary.lothian@urostomyassociation.org.uk

We held our AGM in September 2022 - our first face-to-face meeting since 2019 due to the pandemic. It was lovely to catch up with members once again. Brain Fretwell, Chair of UA's Board of Trustees, gave talk on Project 50+, explaining how the Association will evolve and move forward to better reflect the needs of members through an exciting programme of change. We were delighted to receive an invitation to the Coloplast open day in Edinburgh so that we could represent UA.

As members are aware, we are seeking a new venue for our meetings as the SHSC Conference Centre is no longer available. We are finding the cost of alternative locations very expensive, and have been in touch with the Western General Hospital to see if they can help. However, there is nothing feasible at the moment so our search continues.

We will be in touch again once as we have dates of any future meetings.

Rhona McLaughlin

Newcastle

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

At our AGM, the Association's Chair Brian Fretwell outlined the changes to UA that were put to the national AGM in December.

Professor Chris Harding, Newcastle Branch President, gave a presentation on his recent research on 'Alternatives to prophylactic antibiotics for UTI prevention'. A request was made for him to write an article for a future edition of the Journal.

Honorary membership was awarded to Elizabeth Welton for her magnificent support to the branch. Elizabeth is an associate member who joined many years ago when her mother had a urostomy constructed. It is more than ten years since her lovely mother Grace passed away, but Elizabeth and her family have continued to support UA by selling at car boot sales, organising tombola stalls and table top sales, and preparing beautiful hampers for the Christmas raffle.

Some members enjoyed a great Christmas party, the first since before lockdown. As we are a registered charity, we appreciated being offered the function room free of charge. The raffle covered the cost of the buffet, which was all made by a local bakery, so a free party! Members who attended all remarked that it was a lovely afternoon. Our treasurer's daughter-in-law provided wonderful entertainment. A Christmas meal at the city golf club was also enjoyed by some members.

Our branch has purchased a stoma model incorporating all types of abdominal stomas. The urostomy stoma has stents protruding. The model will be donated to the Urology Stoma Care Department, providing a great asset for the education of both patients and staff.

Everyone is welcome to come to our meetings, no matter what the reason for your urinary diversion. We collect a donation at each meeting and were able to present Karen, Centre Head, and her team with £100 at Christmas.

A note to members: If you are not receiving emails from me, please make sure I have the right email address for you.

This year is the 50th Anniversary of the Newcastle Branch. We are organising a celebration meal midsummer. A special year!

Diary dates: *We meet on the last Friday of each month (1 – 2pm) at Maggie's Cancer Care Centre (see address above). On Saturday 26th March, we will meet at the Piano Room, Royal Victoria Infirmary, Queen Victoria Road, where our speaker will be Stephanie Howard, Benefits Advisor from Maggie's.*

Eileen Spraggon

News from the branches

Sheffield & District

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

It has been a pleasure writing this report in the knowledge that we were able to hold three face-to-face meetings during 2022, at long last! Our first meeting, held in April, was attended by 52 members and guests, which was very encouraging after our extended break. It was lovely to finally be able to meet up with old friends and welcome some of our newer members who had joined the branch during the pandemic.

In June, we joined with National Office in inviting our members to a special Afternoon Tea event at our usual venue, Tapton Hall, as part of the celebrations for the 50th anniversary of the Urostomy Association, having decided to amalgamate the event with our usual summer meeting. Nearly 50 people came along to enjoy a wonderful spread.

Along with UA National President Professor Derek Rosario, our branch hosted the event, supported by our Members' Representative, Julie Varley. Derek gave a presentation on the history of UA and its development over the past 50 years, growing from a small group of like-minded people meeting in Manchester to the national charity it has become; and yet its key aim remains unchanged – to support those undergoing, or who have undergone, urinary diversion surgery.

Eleanor Milner presented Derek with a cheque for £200, being royalties from her book '98.4°F – 37°C, The Memoirs of Eleanor Milner' (think 'Call the Midwife' meets 'Open All Hours'!). All royalties from the book will be shared between the Urostomy Association and Sheffield Children's Hospital.

On 12 November we were delighted to finally be able to celebrate the 40th anniversary of the Sheffield & District branch (albeit delayed by a couple of years!), which was attended by 76 members and guests. Once more, it was lovely for us all to meet for a celebration lunch to mark this milestone.

At this event we were also pleased to welcome UA's Chief Executive Hazel Pixley and her husband Miles. Hazel gave a presentation on 'Project 50+, Shaping the Future' explaining the exciting plans and forward vision of UA as it grows to meet the needs and expectations of the digital age.

Our celebration was tinged with a degree of sadness as Anne Turner, our Branch Treasurer, had decided to stand down from her role after 42 years. Anne has always played a pivotal role in the running of the branch from its very beginning and, without her hard work and dedication, we would certainly not be the successful branch we are today. She will certainly be missed. Our Branch Chair, Derek Finney, also announced that he had decided not to seek re-election after 11 years of holding the role.

Of course, there was also plenty of time for laughter (and a few poignant recollections) as we shared our memories over the past four decades; two people present had actually attended the inaugural branch meeting in 1980 - Janice Lee, the branch's first Secretary and Gloria McBean, who for many years took the minutes of our meetings.

The year ahead will see a few changes for our branch as we are in the process of recruiting new officers, and we are looking forward to building upon our success and working together to see the branch grow from strength to strength.

Diary dates: spring meeting - Saturday 1st April; summer meeting - Saturday 1st July; branch AGM and lunch - Saturday 4th November.

Mary Milner

Shropshire, Wales and the Marches

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

We are just at the end of winter and our branch events can recommence, since we tend to hibernate in the colder months. Our last meeting on the 5th November went off with a bang - not really, but I couldn't resist! We usually have our last meeting in Shrewsbury in October, just before the clocks go back, but because this was our first year at our new venue in Bicton Village Hall, we had to go into November. This year we will be able to go back to having our last meeting in October.

However, we did have two excellent Christmas lunches, one at the Faenol Fawr Hotel, Bodelwyddan and one at the Corbett Arms, Uffington, both well attended. We will aim for three next year and try to fit in one in South Wales.

At both venues members and partners said they not only enjoyed the food, but also being able to chat socially in a more relaxed atmosphere, as well as being able to talk naturally about their stomas. As more than one person said, that doesn't happen anywhere else. We are very fortunate that our branch can afford to subsidise these lunches to make them more affordable.

Our planned events for 2023 are almost all arranged, with only the usual North Wales event not quite decided upon.

Our Shrewsbury base is at Bicton Village Hall perfect, with a good-sized function room, an extremely well-equipped kitchen and plenty of tables and chairs, all easily accessible, with adequate parking space. We also have two members who are always willing to take charge of the keys, fetching and taking back. The Bicton Hall Secretary and I are extremely grateful for their kindness and reliability.

We have been using Zoom at Bicton Village Hall to allow as many members as possible to access our Shrewsbury meetings. It's not all been plain sailing, but we now have microphones as well as the webcam, so hopefully more members who find it difficult to travel will make use of this facility.


Bicton Village Hall

We have two events in South Wales this year – a factory visit to Pelican, in April, which promises to be very interesting, and a delayed 50th Anniversary Tea, at Bridgend in May. These will be our first events in South Wales since the pandemic. Hopefully, they will be successful with a reasonable attendance.

I think I can speak for everyone when I say that the fervent hope is that 2023 will enable us all to get back to a bit of normality, no matter where we live.

Diary dates: Branch meetings: **Bicton Village Hall, Shrewsbury, on 1st April, 1st July (AGM) and 28th October. All start at 1pm. Visit to Pelican Factory, Cardiff, on 6th April. UA 50th Anniversary Tea on 10th May at Best Western Heronston Hotel, Bridgend, 2 - 4pm.**

Toni Haines

Yorkshire and Humberside

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

Now that things are getting back to something like normal after the last three Covid years, it was pleasing to be able to meet both new and existing members at York Hospital and Pinderfields Hospital Wakefield open days.

The Association was represented at both events, with the Pinderfields Hospital open day being very well attended by the medical companies, existing members, and people who will hopefully become members.

Members, family and friends are all welcome to attend our meetings, and refreshments are provided.


Salvation Army Church

Diary dates: meetings are on Saturdays (2 – 4pm): 11th March, 20th May, 19th August and 18th November, and if you would like to meet the medical company reps to view their products, they will be available from 1.30pm. Leeds Community Healthcare NHS Trust has its annual Stoma Open Day on 13th September (9.30am – 3pm), at the Bridge Community Church, Leeds, LS9 7BQ.

David Legood

Northern Ireland news

Activities involving our support group in Northern Ireland, led by our volunteer there, Donna Watson, are ramping up. Local urostomates gathered for coffee in the garden (see picture) as part of their regular round of social events across the region.

Donna herself is returning to the two Northern Ireland airports after the Covid-19 hiatus to help train security staff in how to make air travel as straightforward and embarrassment-free as possible for people with a urinary diversion.

Meanwhile, the support group was hosted by the Eakin Healthcare Group in Comber, Co. Down, for a lunch and discussion with the company's research and development team. If you live in Northern Ireland and would like to join the group, please contact the Association's office for contact details.

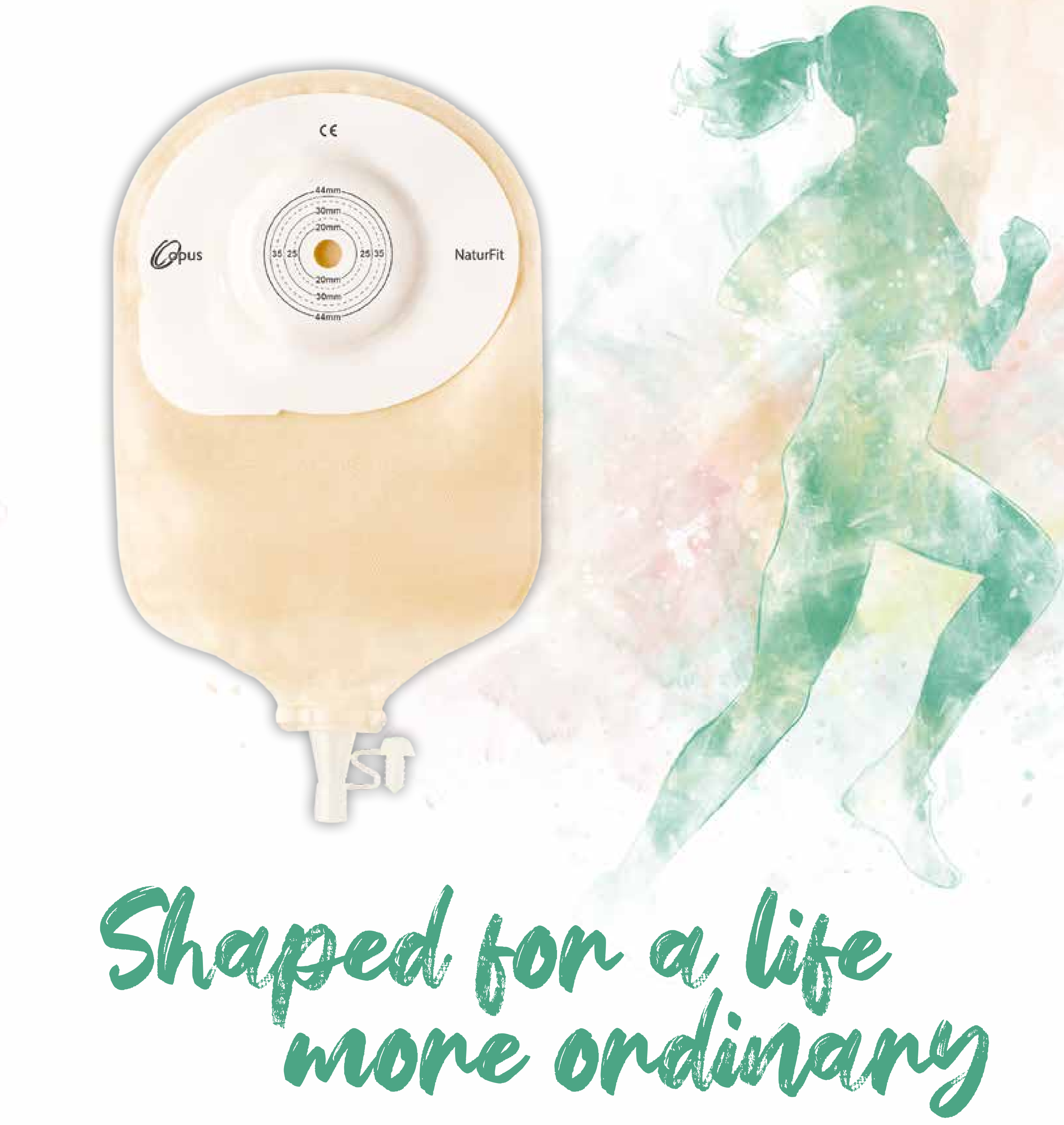
Have you found us on **Facebook?**

Having both a private group on Facebook as well as a public page is not only keeping people who need us feeling well informed and supported, it's driving up more awareness of the Association and the services our charity provides.

While our private group is solely for people who have a urinary diversion, and their families and carers, a space where there's mutual support in abundance, our public page is where we shine a light on our charity and the difference we can make for people who need us, highlight our events, challenge the stigma that often surrounds weeing differently, and encourage more awareness and understanding.

Following us on Facebook and sharing content from our public page is a great way to show your support for the Association and help us reach people who would benefit from what we do but may not be aware of us yet. We know it's working because far more people are now finding UA's website through our Facebook presence, so thank you for liking, commenting and helping us spread the word!

> "Following us on Facebook and sharing content from our public page is a great way to show your support."



Your letters Spring 2023

Seeing the funny side

UA's book 'Bags, Bags, Bags', which helps explain a urostomy to young children, brought to mind an incident that occurred when my granddaughter, now 22, was just four years old.

We were at a pantomime performance and during the interval I took her to the toilet. There was the usual long queue, but we managed to get into the first toilet, nearest the queue. She went to the toilet and I then emptied my bag, because I had made no secret of my urostomy and she had taken it completely in her stride. When my bag was empty, I shook the end, as I usually did, and sorted myself out ready to leave the toilet. In that very piping voice little girls of four have, that echoed around the toilet area, my granddaughter said, *"Grandma, do you shake it like that to get the very last drop out?"*

Toni Haines

Naked truth

My wife and I were first drawn to naturism at the age of 35 through a connection between two of our work colleagues and friends. It was at a party that we discovered our other close friends were naturists as well. When we asked about this, they promptly invited us to join them one bank holiday weekend on the Isle of White at Black Gang Chine Manor naturist resort. We accepted their offer - with some reservations, of course.

What we found were very friendly people enjoying life to the full, which encouraged us to try naturism as a leisure pastime. After two more years spending family holidays on Black Gang Chine beach, we were invited to join a club by new friends we met there. This was the British Naturist Foundation (BNF) in Kent, where we were accepted and had endless enjoyment as with other families.

It wasn't until 20 years later I was diagnosed with bladder cancer and then given several options of surgical correction. Some were very discreet and showed no outward signs but were still in their development stages. So, a decision had to be made which operation I should have. My surgeon recommended the conduit with stoma and bag as it was a proven method and offered longevity with little or no follow on remedial surgery.

This was a tough decision as I knew I would have to show my body and new bag to all. It was made easier though, due to a close friend at the BNF club who had a been living with a colostomy bag for many years, during which time she had run two marathons and was as keen on sports as we were. It was noticeable that nobody ever made her bag an issue – it was as though it did not exist because it made no difference to how the naturist community saw her.

So, I decided to have my urostomy operation in February 2004. My first appearance at the club was that April, and I thought I would be clever and wear a bum bag cut out at the back so my bag went inside. However, I was soon ordering the custom fit covers - more practical and not drawing any unwarranted attention, apart from the younger fraternity who would ask why I had this 'thing' on my stomach. My answer was always the same: *"I had a bad illness caused by smoking cigarettes when I was young"*, in the hope they would be discouraged from ever taking up the habit.

It wasn't long before I realised it was impractical not to have any support around the stomach as a bag with fluid in can get quite heavy and gradually pull on the stomach muscles, especially when playing sport.

On the advice of my great stoma nurse Janet, I started wearing the support band from Sportex that I get on prescription. This would be the final solution to being a urostomist in a naturist environment where – as the BNF motto says, 'Bare is Beautiful'. Now, at the age of nearly 80, I am still a naturist, playing tennis, golf, badminton and table tennis regularly. I also enjoy holidays, having spent vacations in Australia and the USA. My own motto is:

'Having a urostomy does not have to change your life, only the way you do some things within it'.

Rodney Clayden

First-class service

I wonder if I might, through your pages, recommend and extend my thanks to Joanne and the team at Salts Medilink in Cardiff. After 23 years of carefully managing my stoma supplies, always reordering when I start my last box, I found the last box was empty. Not a supplier fault but mine for forgetting to recycle and reorder. (In my defence, my wife was, at that time, in hospital and I was doing a bit of running round.)

Two weeks before Christmas and with postal strikes looming, I posted my prescription with little expectation that it would elicit a response. I backed that up with an email and phone call the next day only to be told that my pouches were out of stock. "Leave it with me," said Joanne and, incredibly, the next morning the delivery arrived.

If I have a problem with a company, I prefer to deal directly rather than bad-mouthing on social media. If they have just done their job efficiently it is what is expected and shouldn't elicit 'likes'.

However, when a company and/or its employees have gone above and beyond I believe that deserves recognition and praise. So... thank you, Salts.

Ian Willis
Dinas Dinlle

UROSTOMY ASSOCIATION

Registered Charity Number:
England and Wales 1131072 Scotland SCO47740

Application for membership

Title e.g. Mr/Mrs/Miss/Ms/Dr **Date of birth**

Surname

First name

Address

Postcode

Telephone

Email address

How did you find out about the Association?

Please tick the membership type required

☐ **Full membership** (i.e. you have a urinary diversion)
☐ **Associate membership** (i.e. you do NOT have a urinary diversion)
☐ **Company membership**

Please complete the following section regarding your operation

Type of operation Please tick type of operation

☐ Ileal conduit/urostomy ☐ Bladder reconstruction/neo-bladder ☐ Continent diversion (e.g. Mitrofanoff) • Other please state: ☐

Reason for operation

Hospital

Consultant surgeon

Age at date of operation

I wish to become a member of the Urostomy Association. I understand that membership is free of charge for the first year (UK and Ireland) and that an annual subscription (currently £16.00) is payable thereafter. Please make cheque payable to **Urostomy Association**.

Annual membership subscription FOC

Donation (optional) £

Total enclosed £

PLEASE ALSO COMPLETE THE REVERSE OF THIS FORM

UROSTOMY ASSOCIATION

Registered Charity Number:
England and Wales 1131072 Scotland SCO47740

Application for membership

My application for membership of the Urostomy Association is made subject to the Memorandum and Articles of Association of the Urostomy Association (Company Registration No. 06918246) (The Company'), to any rules for the time being made thereunder, and to any terms for membership applicable to the Company, and in the event of the Company being wound up while I am a member, or within one year afterwards, I undertake to contribute such amount as may be required, not exceeding the guaranteed sum of £1 for payment of the debts and liabilities of the Company contracted before ceasing to be a member, and of the costs, charges and expenses of winding up, and for the adjustment of the rights and contributories among themselves.

I agree that the annual accounts and Directors' report and Auditor's/Examiner's report on those accounts may be sent by electronic communication to the above email address (if any), published on the website of the Company at *www.urostomyassociation.org.uk* throughout the period of at least 14 days clear of the date of the meeting and notice of it instead of delivery or sending them by any other means.

Gift Aid declaration

If you are a UK taxpayer, we can reclaim tax on your subscription and any donations that you make. This is a valuable source of income to the Association as long as you continue to pay an amount of tax equal to the tax we reclaim on your donations and subscriptions. Please sign this declaration which will enable us to do so.

"I wish the Urostomy Association to reclaim tax on this and any future subscriptions and donations until advised otherwise."

Signed **Date**

Your privacy is important to us, and we want to communicate with you in the ways that suit you best, have your consent, and which are in line with UK law regarding data protection. As a result of a change to UK law, we need your consent regarding how we contact you, and for which purposes.

Please tick the boxes below to give your consent regarding how we contact you:

I consent to the Urostomy Association contacting me by: Email ☐ Text ☐ Telephone ☐ Post ☐

You can withdraw or change your consent at any time by contacting National Office at the Urostomy Association or by email: *info@urostomyassociation.org.uk* Please note that all processing of your personal data will cease once you have withdrawn consent, other than where this is required by law, but this will not affect any personal data that has already been processed prior to this point.

Please also tick one or more of the following boxes to give your consent regarding how we use your personal data, or leave them blank if you do not wish to be contacted by us:

☐ To keep you informed about the Urostomy Association's news, events, and activities *You can unsubscribe at any time*

☐ To send details of third party events (such as open days), products or services relevant to your urinary diversion *Please note: Any such information is sent from us, and your details will NOT be given to any third party*

☐ To pass your contact details to our mailing house for the purposes of sending our magazine

☐ If you become a member of one of our local Branches, to pass your details to the local Branch Secretary, who is a volunteer; so that they can send you details of local meetings, newsletters etc.

You can grant consent to all the purposes; one of the purposes or none of the purposes. Where you do not grant consent we will not be able to use your personal data (so for example we may not be able to let you know about forthcoming events) except in certain limited situations, such as where required to do so by law or to protect members of the public from serious harm. You can find out more about how we use your data from our Privacy Notice which is available on our website or from the Urostomy Association.

By signing this form, you are confirming that you are consenting to the Urostomy Association holding and processing your personal data strictly in accordance with our Data Privacy Notice. Copies of this can be found on our website or are available on request.

Signed **Date**

Please send this form to
Urostomy Association National Office, 2 Tyne Place, Mickleton, Chipping Campden, GUS 6UG
✆ 01386 430140 email: *info@urostomyassociation.org.uk*

COMPANY NUMBER 6918246 PRINT DATE MARCH 2019; REVIEW DATE DECEMBER 2021

UROSTOMY ASSOCIATION

Registered Charity Number:
England and Wales 1131072 Scotland SCO47740

Donations

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4 ways in which you can help.

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Account number 10226540 Sort code 161016

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The sum of (in words)
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Signature
Date

Please sign and send with the Gift Aid declaration if appropriate to:

Mrs H Pixley, CEO, Urostomy Association, 2 Tyne Place, Mickleton, Gloucestershire, GL55 6UG.

2 ONE-OFF DONATIONS

I enclose a cheque made payable to the Urostomy Association for £

Please sign the Gift Aid declaration if appropriate

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Address

Postcode

Please return form and cheque to
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Mickleton, Gloucestershire, GL55 6UG.

3 GIFT AID DECLARATION

If you are a taxpayer, we can reclaim tax on your donation, as long as you continue to pay an amount of tax equal to the tax we reclaim on your donations. This is a valuable source of income for the Association. If you are a UK taxpayer, please sign this declaration, which will enable us to reclaim tax.

I wish the Urostomy Association to treat my donation as a Gift Aid donation.

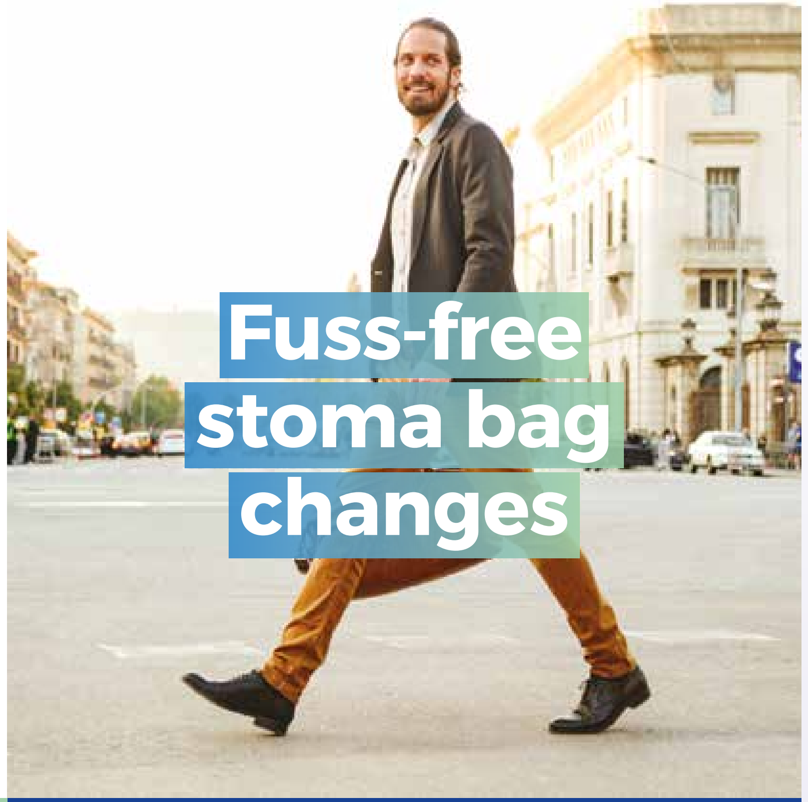
Signature
Date
Name
Address

Postcode

Please send this form to:
Mrs H Pixley, CEO, Urostomy Association, 2 Tyne Place,
Mickleton, Gloucestershire, GL55 6UG.

4 LEGACIES

If you would like to leave something to the Urostomy Association in your Will please read our Legacy leaflet available from Mrs H Pixley, CEO, Urostomy Association, 2 Tyne Place, Mickleton, Gloucestershire, GL55 6UG.
✆ 01386 430140 or email:
info@urostomyassociation.org.uk



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Our copy deadline for advertising in the **summer edition** of the magazine is **15 June**.

Please get in touch

We welcome your contributions to the Journal, so please get in touch with your stories, articles and letters. We can't promise to print them all, but they will certainly be considered.

Please send your contribution as a Word document to:
editor@urostomyassociation.org.uk

Wherever possible, your submission should include some good quality photos as jpeg attachments.

Thank you.

Deadlines are as follows:

Summer Journal	**June 15th**
Winter Journal	**October 15th**

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