Spring 2019 | Issue 53

Supporting and empowering you

Tidings

Colostomy UK

A picture is worth a thousand words…

Inside

Monty remembered

Supporting you *every step of the way*

At Coloplast we have the teams in place to find the right solution for you – whether that is a new product or advice about your stoma care routine.

Find out more >> >>

Coloplast

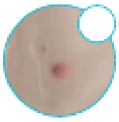
Coloplast® Charter

The Ostomy Check

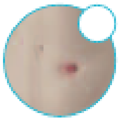
We understand over time your body shape and lifestyle can change, so it's important that you regularly check your stoma care routine, as well as ensuring that you are still on the best baseplate solution to fit your body shape. Why not take the Ostomy Check today to help you identify common issues such as sore skin, problems with adhesion and leakage? **Based on your answers we will make sure the information and support you get from Coloplast Charter meets your needs.**

Which best describes the area around your stoma?

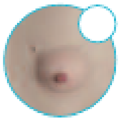
Please tick in circles where appropriate



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



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



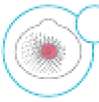
○ *Outwards*
The stoma opening is on curved body shape or outward area (e.g. a diagnosed hernia)

Do you have any adhesion issues?

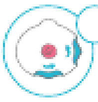
Ensuring your product sticks securely to your body helps you feel secure, and prevents complications.
You can tick one or more issues.

○ *None*

○ *Insufficient adhesion when applying*



○ *Adhesive dissolves during wear*

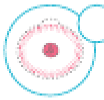


○ *Adhesive edges roll*

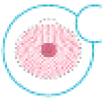
Do you have any skin irritation issues?

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

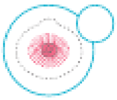
○ *None*



○ *At the outer edge of the baseplate*



○ *Under the baseplate*

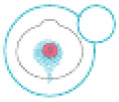


○ *Around the stoma*

Do you have any pouch issues?

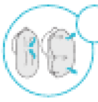
It is important that your pouch works for you and that you feel confident wearing it.
You can tick one or more issues.

○ *None*



○ *Leakage*

○ *Odour*

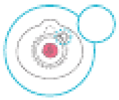


○ *Ballooning or pancaking*

For two-piece appliance users only

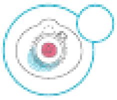
It is important your two-piece works for you. Tick on any coupling issues you might have.
You can tick one or more issues.

○ *None*



○ *Coupling difficult to close or open*

○ *Pouch falls off*



○ *Leakage at coupling*

*Would you like a member of the Telehealth team to call you to discuss the answers you have given above?**

Yes, please call me (tick as appropriate) ○

First Name		Surname	
Address			
Post Code		Date of birth (DD/MM/YYYY)	D D M M Y Y Y Y
Email			
Date of Stoma Surgery	D D M M Y Y Y Y	Telephone Number	
Signature		Register me to Coloplast Charter	☐

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 not like to be kept informed by: Post ☐ Email ☐ Phone ☐

Coloplast

Return your response to FREEPOST COLOPLAST (no stamp required)

Coloplast® Charter

Did you know we're ***more than just a delivery service?***

As we recognise that things change over time, the all NEW **Coloplast Charter** service is here to provide you with the ongoing support and advice you need to help guide you along the way, as well as deliver your products free to your home.

Wherever you currently get your products, **Coloplast Charter** *offers so much more.*

- Experienced and qualified specialists*
- Ongoing support programme
- Order updates via text/email
- Free cutting service
- Simple ordering
- Prescription collection service
- Free home delivery
- Complimentary items with every order

Regulated by Care Quality Commission

*Our Telehealth team is registered with the CQC (Care Quality Commission) who independently monitor the care we provide.

NHS
Providing NHS Services

So you can be you - ***we're always there...***

To find out more or to register to Coloplast Charter call today on:

☎ 0800 783 1434 option 2

Opening times
Monday to Friday: 09:00 - 17:00

Dear readers

Cover picture:
Jessica Logan

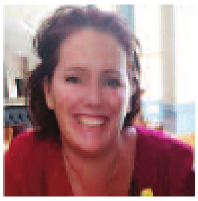
Cover photograph by
Stuart Randle
stuartrandle@outlook.com

Colin Allum: Greys Court, Henley–on–Thames, Oxfordshire

Welcome to the Spring 2019 edition of *Tidings*. Before we tell you about what we have in store for you, we must start by relaying some sad news. As you may already know if you have visited our website or follow us on social media, Monty Taylor, our chairman passed away in December last year. You can read our tribute to this special man on page 10. Although it seems wrong to be talking about 'replacing' Monty, we're sure you will forgive us for using this turn of phrase, as obviously we need someone at the helm to keep **Colostomy UK** on its current trajectory. Monty is certainly going to be a hard act to follow, which is why, at the time of writing, we are still searching for the right person. We will make an announcement as soon as we have some news.

Let's talk about *Tidings* now…we both think it's another great edition, with something in it for everyone. We have some fantastic Real Lives stories. Jessica, who is featured on our front cover, hopes sharing her story will raise awareness of the challenges of life with a stoma and also encourage a little more understanding from those on the 'outside'. Ann Inglis' experiences touch on two themes that we are sure will be relevant to many readers: taking control of your health and also the difficult task of explaining what you are going through to teenage children. Shirley Jones, herself a retired healthcare professional, talks about the support she has received from the closed Facebook support group since having her surgery. Brian Chapman tells us how he came to have two stomas. Ken Jones reports on how, despite undergoing stoma surgery, he has managed to stay involved (even into retirement) with the Duke of Edinburgh's Award and other outdoor activities. Finally, we have a short fictional piece, submitted by Barbara Harrison. You may be wondering how this made it to our Real Lives section, but when you read it you will see. The issues that Barbara tackles are very 'real'.

Complementing the above we have all the usual features. There is a round–up of **Colostomy UK** news. Giovanni gives an update on our Active Ostomates project. He also reports on a gift we received last year explaining how, in accordance with the donor's wishes, we are using this to support ostomates in the North East. Gifts left in wills are vital to any charity, so we were keen to give people an idea of the lasting impact they can have. We were also pleased that Bolt Burdon, a law firm based in Islington, were able to contribute a 'jargon–busting' article to explain how you can make provision in your will, should you wish to do so. Then, to round everything off we have Readers letters and e–mails, news from support groups across the country and Sarah's regular irrigation slot, which this time round has a piece from Pamela, an irrigator of 14 years who, Sarah admits, has taught her a thing or two!



Libby

Libby Herbert
General Manager

Sarah

Sarah Squire
Colostomate and Volunteer

Contents

We are **Colostomy UK.** Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

How to contact us

Helpline for:
Emotional support, experience based advice and guidance from a volunteer.
0800 328 4257
24 hours a day and completely free.

Adminline for:
Information packs, ID cards, RADAR keys, travel certificates and literature.
0118 939 1537
If we're not in, just leave a message.

info@ColostomyUK.org

To request (or cancel) your quarterly copy of *Tidings*
0118 939 1537

info@ColostomyUK.org

Editorial Enquiries
Letters, articles or other submissions

Colostomy UK
Enterprise House, 95 London Street
Reading, Berkshire, RG1 4QA

info@ColostomyUK.org

Advertising enquiries
For a media pack
and advertising rates
0118 918 0500

Arvind.Anand@ColostomyUK.org

Social media:

Find us on Facebook

Join our 'closed' support group today simply put 'Colostomy UK support group' into your FACEBOOK search bar, click on Group and click on 'Ask to join' you will be assured of a warm welcome!

Cover story

Colostomy UK news

Real lives

Wellbeing

Fundraising

Support

New products

Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 45 for donation form.

You can also donate via our website **www.ColostomyUK.org/donate** or by calling us on **0118 939 1537**

Colostomy UK: news

A big Thank you!

Everyone at **Colostomy UK** wants to say a big thank you to Janet Bradley who retired as a volunteer in January, after being with us for nearly 12 years. If you have ever called our Helpline, or got in touch with us with a query on irrigation, then there's a good chance you will have spoken to Janet. If not, then you might have bumped into her at an Open Day, as she attended many on our behalf in the Berkshire area. We wish Janet all the best and hope she likes the flowers and gift we sent.

A new member of the team

We were pleased to welcome Emma Howell to the team at the beginning of March. Emma joined us from the British Red Cross to take on the role of our part–time Volunteers Manager. As the job title suggests, Emma is going to be working closely with our volunteers. She will be ensuring that they are supported in all they do for us and receive all the training and development that they need. She will also be in charge of safeguarding issues and recruiting new volunteers. As she has already discovered, it's a busy job…but with well over a decade's experience in the charity sector at least she was able to hit the ground running!

Caring for a person with a stoma

Association of Stoma Care Nurses UK

We started to run our Care Workshops back in 2015 and they have proved popular with local authority reablement teams, nursing and care home staff and specialist dementia carers ever since. So far this year workshops have been delivered in Berkshire, Bristol, Buckinghamshire and Shropshire. In March, we were pleased to be able to talk about their impact at a meeting of the Association of Stoma Care Nurses (ASCN) held in Birmingham.

The two–hour workshops are free of charge and provide both professional and unpaid carers advice in practical stoma care management. To find out more email **Giovanni.cinque@ColostomyUK.org** or call **0118 939 1537.**

Stoma care nurse engagement

Last year we embarked on an ambitious plan to increase the direct engagement we have with stoma care teams across the country. The idea was to update them on everything **Colostomy UK** can offer stoma patients both pre and post op, and to explore even more ways that we can work together for the benefit of ostomates. As you can imagine, there are lots of stoma care departments across the country and so visiting them all is going to take time. So far this year we have met with nurses from: Wycombe General, North Middlesex University Hospital, Newham General, John Radcliffe and the Churchill Hospitals in Oxford, and the Queen Elizabeth and Heartlands in Birmingham.

We are looking for a finance/treasurer trustee

We are currently looking for a finance/treasurer trustee to join the team as our current trustee, Alfred Levy, would like to retire from the board.

The role: Finance/Treasurer Trustee

The overall role is to maintain an overview of the charity's financial affairs, ensure its financial viability and ensure that proper financial records and procedures are maintained. We are looking for someone who has a recognised accounting qualification, bringing with them a wealth of experience. As a trustee you will give direction to our charity and along with other trustees are ultimately responsible for its activities.

Please be aware this is an unpaid role, however expenses will be covered.

If you would like to discuss the role further or receive a full Job description please contact

Libby Herbert by e–mail **libby.herbert@ColostomyUK.org** or call her on **0118 939 1537.**

Interviewing process: Initial phone interview followed by face to face interviews.


freedom to be...
...transported to another world
Norman, 67
Aura

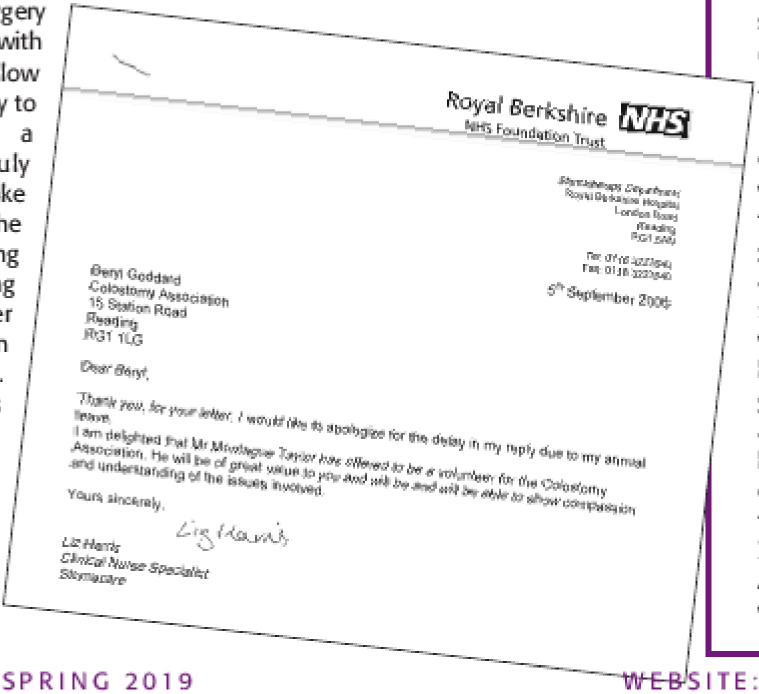
A tribute to Monty Taylor

It is with great sadness that we must report the death of our chairman, Monty Taylor. Monty died at home on 2 December 2018, surrounded by his family. He was 79 years old. We said a final farewell at his memorial service in early January and, as a charity, drew solace from sharing our many fond memories of this remarkable man.

Monty had a colostomy formed in 2002 as a result of diverticulitis and came across our charity shortly afterwards. At the time we were known as the British Colostomy Association. As those who knew him will attest, Monty had a positive 'can–do' attitude. This served him well in those early post–op days when it is all too easy to feel like throwing in the towel. His characteristic determination and resilience was perhaps never more on show than when, just three weeks after surgery and still wheelchair bound, he made a trip to Italy in order to celebrate his youngest daughter's 30th birthday.

It didn't take Monty long to get his life back on track. But the experience of stoma surgery left its mark on him, and with it the desire to help fellow ostomates. This led Monty to enquire about being a volunteer with us in July 2006. In his letter, he spoke about the comfort he derived from reading *Tidings* and how reassuring he had found it to discover that other people were in a similar position to him. By the Autumn Monty's application was complete and all his references were in, the last of which you can see pictured right. Looking back at his original application form raised a smile amongst the office team, as 'travel and holidays' was one the things he indicated he was happy to talk about on the helpline. As those who knew Monty will confirm, he was something of a globetrotter. When Libby our general manager visited him at home late last year, he was proud to show her his map of the world, suitably marked with all the places he had visited; Libby recalls there being very few blank spaces. In fact, in the four–year period between having his colostomy and becoming a volunteer, he visited Sri Lanka, went on two Mediterranean cruises, toured Australia and New Zealand and walked along the Great Wall of China!

Monty's in–depth knowledge and passion for foreign travel was undoubtedly an inspiration for people he spoke to, especially those worried about travelling abroad after their surgery. But when it came to helping ostomates, Monty's contribution went much wider than this. Monty took over as our chairman in 2008 and successfully led the charity as it changed premises a number of times, and developed from the British Colostomy Association to the Colostomy Association before becoming **Colostomy UK** in September 2017. As a charity we will always be thankful that we had him at the helm during what has probably been one of the most challenging periods in our history. His calm confident demeanour, coupled with drive, vision and extensive commercial experience helped to imbue everyone from patrons and trustees to staff and volunteers, with a sense of community and shared purpose. He was the team captain you wanted to play for and he will be sorely missed. ■



Royal Berkshire NHS
NHS Foundation Trust

5th September 2006

Beryl Goddard
Colostomy Association
15 Station Road
Reading
RG1 1LG

Dear Beryl,

Thank you, for your letter. I would like to apologize for the delay in my reply due to my annual leave.

I am delighted that Mr Montague Taylor has offered to be a volunteer for the Colostomy Association. He will be of great value to you and will be and will be able to show compassion and understanding of the issues involved.

Yours sincerely,

Liz Harris

Liz Harris
Clinical Nurse Specialist
Stomacare

Two of our longstanding volunteers, Jackie Dudley and Sue Hatton, had this to say about Monty:

> "Monty will be greatly missed and will be remembered always for his determination to take **Colostomy UK** to everyone who needs help, advice and support… there have been chairmen before and there will be chairmen in the future, but none will hold that special place in our hearts as Monty does." **JD**

> "Monty was born in 1939 in Nottingham. He became a chartered surveyor and in 1964 wed Sue. Monty and Sue have three children and seven grandchildren. Monty absolutely adored them all and his family meant everything to him. Monty was always a very genial host and loved his wines, his jokes and good conversation. He was always ready to give advice and help and always made time for others. He was such a breath of fresh air to those of us who were building up the Colostomy Association after Macmillan withdrew its funding." **SH**

Colostomy UK

Colostomy UK's BIG open day

SATURDAY 22ND JUNE 2019
TELFORD INTERNATIONAL CENTRE

meet the team . ask a nurse . nutritionist . fashion show .
chair yoga . art session . raffle . live entertainment . evening meal .

Telford International Centre
St Quentin Gate,
Telford, Shropshire,
TF3 4JH

FROM BIRMINGHAM CITY CENTRE TELFORD IS:
45 minutes by car
45 minutes by train
1 hour by coach

DIRECTIONS
For full directions call the venue on: 01952 281 500

The venue is 2 minutes by taxi from the train station, but is also serviced by a direct bus which drops you outside.

Free car park onsite.

We hope you can join us for our open day on Saturday 22nd June at the International Centre in Telford. It promises to be a great event!

There will be topical talks and presentations. You can book to see a stoma care nurse. Stoma care companies will be exhibiting their products. We will also be running chair yoga and art sessions, so you can see what these are all about. It's a great chance to catch up with other ostomates and perhaps make some new friends too. You can also say "hello" to the Colostomy UK team and volunteers! The countdown has started...

Hotels near the venue:
The International Centre: 01952 521 600
Holiday Inn Telford - Ironbridge: 01952 527 000
Ramada Telford: 01952 425 000

For more details please call: 0118 939 1537
Or email us on: info@ColostomyUK.org
Updates: www.ColostomyUK.org
Venue Website: www.theinternationalcentretelford.com

DAY TICKET - FREE - 9:30AM

Tickets for our open day are completely free, but if you'd like a lunch at the venue the cost is £10. This needs to be reserved in advance. Alternatively the venue is just a short walk from the town centre.

RESERVE LUNCH £10

EVENING MEAL - £30 - 7:30PM

Enjoy a three course meal and live entertainment. If you have any special dietary requirements, please let us know on the form below. We will also send out the menu with the tickets.

how many tickets?

☐ **DAY TICKET** ☐ **RESERVE LUNCH** ☐ **EVENING MEAL**

Names:

Address:

Postcode: Telephone:

Mobile: Email:

Dietary Requirements:

buy your tickets

online
www.ColostomyUK.org

by phone
0118 939 1537

by cheque
Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

Colostomy UK Purple Iris Stoma Care Award – Nomination Form

The Purple Iris Award recognises outstanding stoma care in community and clinical settings and will be awarded at our Big Open Day 22 June 2019.

Your details

First Name: ______________________ **Surname:** ______________________

Address: ______________________

______________________ **Post code:** ______________________

Telephone Number: ______________________ **Email:** ______________________

Nomination details

Name of team/department: ______________________

Name of hospital/community setting: ______________________

Reasons for nomination: In two brief sentences, please describe what impact this team's support has had on your life or that of a family member (maximum 50 words) here:

____

____

____

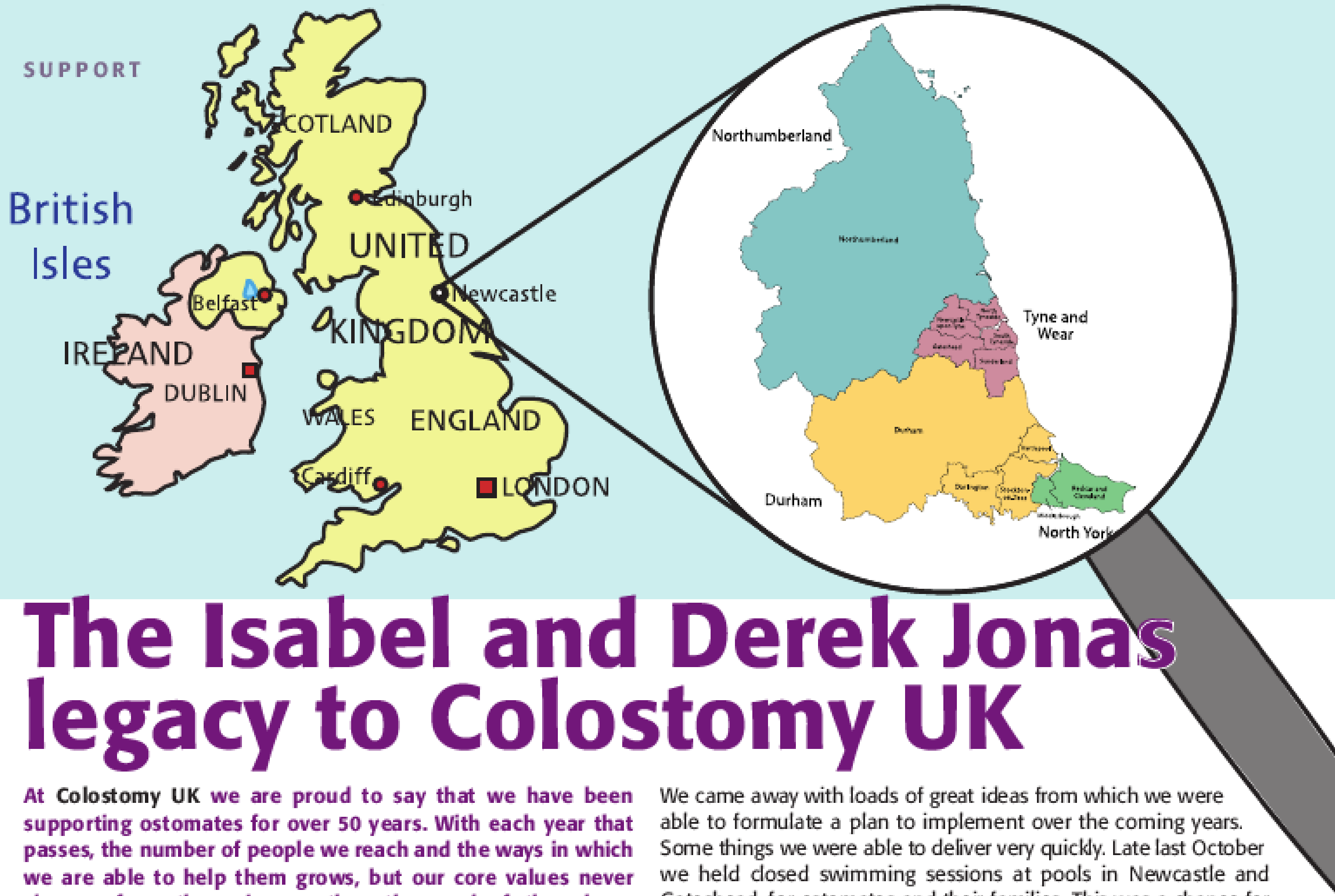
Additional Information

On a separate sheet please explain why your stoma care team/department deserve this accolade (maximum 500 words). Please remember to head this up with your name and that of your nominee.

I give my permission for **Colostomy UK** to inform the stoma care team about this nomination including what has been written on this form.

Signed: ______________ **Name:** ______________ **Date:** ______________

Please return this nomination form to: **Giovanni Cinque, Colostomy UK, Enterprise House, 95 London Street, Reading, RG1 4QA by 30 April 2019.**



The Isabel and Derek Jonas legacy to Colostomy UK

At Colostomy UK we are proud to say that we have been supporting ostomates for over 50 years. With each year that passes, the number of people we reach and the ways in which we are able to help them grows, but our core values never change: from the voice on the other end of the phone reassuring you that you aren't alone, to the projects encouraging you to express yourself through art or be more active, our focus remains on supporting you to live your life.

However, we couldn't do any of this without the kindness of people like you. As a self–funding charity, we rely on donations to help fund every area of support we offer. This includes everything from training our volunteers to answer the helpline and attend open days, to publishing and distributing *Tidings* each quarter and producing all our advice literature. Donations enable us to campaign for stoma–friendly toilets and work with the Civil Aviation Authority and UK airports to raise awareness of the needs of travellers with hidden conditions. They also make possible things like the ostomate–only swimming sessions that we ran last year, which saw many people with stomas get in the pool again for the first time in many years.

Regular and one–off donations are always gratefully received, no matter how big or small they are. You can also leave **Colostomy UK** a gift in your will. Many people are put off doing this as they think they need to give a substantial amount. This isn't the case. Every penny left to us is put to good use helping ostomates of today and tomorrow. If you leave us a gift, we will use it where we feel the need is greatest. Alternatively, you can request that it is used to support one of our campaigns or projects. You can even specify that you would like it to help ostomates in a particular part of the country.

A great example of this is our 'Isabel and Derek Jonas' project. Towards the end of 2017 we were left a legacy with the request that the funds be used to support ostomates in the North East. Our first step in implementing the donor's wishes was to listen to the views of local people. For us to deliver something that is both sustainable and impactful, we know it is crucial that those affected are involved right from the outset. Hence, last spring we visited Durham, Gateshead and Newcastle, where we met with the stoma care teams from North Durham and Gateshead Hospitals, our local volunteers, a number of facilities run by Gateshead and Newcastle councils, and members of support groups in Newcastle and Gateshead.

We came away with loads of great ideas from which we were able to formulate a plan to implement over the coming years. Some things we were able to deliver very quickly. Late last October we held closed swimming sessions at pools in Newcastle and Gateshead, for ostomates and their families. This was a chance for people, often the first time after their surgery, to try swimming again in a closed and supportive environment. Amongst other things, we hoped that this would help give them back the confidence to attend public swimming sessions and generally encourage them to be active. The response was very positive. One of the success stories was Martin, who said afterwards: "I've had my stoma for 40 years and this is the first time I've been swimming since my surgery. I wish I'd done it years ago". Of course, swimming isn't for everyone, so around the same time we also started to deliver the first Chair Yoga and Creative Minds arts sessions at support groups in Newcastle. We hope to extend these to other groups in North East this year. Other parts of the plan will take longer to implement and the results won't be felt quite so quickly. Part of gift we were left is being used to offer better one–to–one and group support to ostomates in the immediate post–surgery period. We are also aiming to strengthen our volunteer base in the North East and want to help make the area's support groups more sustainable.

So, as you can see, from the gift of a single generous donor, many ostomates have and will benefit. We are looking forward to updating you as our plans develop further. ■

If you'd like to talk to us about how a gift from you could help us make a difference or would like a copy of our *Legacy* leaflet (pictured opposite) please just call us on:

0118 939 1537 or email at **fundraising@ColostomyUK.org**

Remember, to leave us a legacy:

- State in your Will that you would like to leave a gift for **Colostomy UK.** We recommend contacting a solicitor to make sure your will is valid.
- Include our full details to make sure that your gift goes to the right place:

Colostomy UK
Registered Charity Number: **1113471**
Registered Address: **Enterprise House**
95 London Street
Reading, RG1 4QA

As you can see from our report on our work in Durham, Gateshead and Newcastle, leaving a gift to Colostomy UK in your Will is a truly special way to make a lasting difference to the lives of people with stomas – both ostomates of today and of tomorrow!

But, to leave a gift, you need a Will. This is a stumbling block for many people, as they aren't sure what is required or are worried that it is a long and expensive process. Gifts aside, we all know that there are plenty of other important reasons why you should have a Will, and yet we still put off doing one. We were therefore thrilled when Bolt Burdon Solicitors offered to 'demystify' Wills for us, by contributing a short, jargon–busting article to *Tidings*.

Richard Woods *of* Bolt Burdon Solicitors talks about Wills

Colostomy UK

YOUR WILL, YOUR LEGACY

USING YOUR WILL TO HELP OSTOMATES OF TODAY AND TOMORROW

Jargon buster

Beneficiaries: those who inherit under your Will or Intestacy.

Intestacy: where you die without a Will, or where your Will does not dispose of your entire Estate (for example you leave a gift to someone who dies before you, without making provision for who will inherit it otherwise).

Codicil: a legal document that amends an existing Will and/or previous codicil.

Estate: your property, after all your debts/liabilities have been paid.

Assets: means the property in your estate, including your home, possessions, and cash.

Liabilities: things that you owe money on, such as your mortgage, a bank loan or credit cards.

Executor: This is the person(s) you name in the Will who will then ensure that the terms of your Will are carried out.

Inheritance Tax (or 'IHT'): this is the tax which is charged after death but only on the value of your assets in excess of the NRB.

Nil–rate Band (or 'NRB'): this is the part of your Estate to which IHT applies at 0%. The general threshold is £325k per person, although further exemptions apply.

Legacy: a gift under the Will, whether a set amount or a proportion of the Estate, or a particular item.

Rules of Intestacy: standard rules that apply, that determine who inherits what, if you do not have a Will or part of your Estate is not covered by a Will.

What happens to my Assets when I die?

If you do not leave a Will, or your Will does not account for all your Assets, your Estate is distributed under the rules of Intestacy. This risks your Assets not going to those you intended, for example to a distant relative.

If you don't have a Will you need to be particularly aware when:

- **You are married with children**
  Your assets might be shared between your spouse and your children, and not go to your spouse outright as assumed.
- **Where you are co–habiting and not married**
  Depending on whether and how you own the property your partner might have no automatic right to your Estate.

CONTINUED ON PAGE 17, COLUMN 1


SOS

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SOLICITORS

CONTINUED FROM PAGE 15, COLUMN 3

Gifts to the Charity

Charities have no right to benefit from your Estate under the rules of Intestacy; therefore if you would like to leave a gift to a charity, you must make a Will.

Where you have a Will already you could make a Codicil (which essentially amends your Will) to include a gift to charity.

What can I leave to Charity?

A gift can be of:

- money, expressed as a set amount or a percentage of your Estate; or
- any (other) Assets you own outright (such as company shares, land, or an art collection).

Are there any benefits in leaving gifts to a charity?

Inheritance Tax at 40% is generally payable where the deceased's Estate exceeds the Nil–Rate Band (subject to various exceptions and exemptions).

Where you leave a gift to a qualifying charity, like **Colostomy UK**, no IHT will be payable on the gifted amount and if you leave 10% of your estate, IHT may be reduced from 40% to 36%.

Why not leave something to a charity as a "backstop"?

Including a provision in your Will that your Assets are left to charity, in the unlikely event that none of your family survives you, is something to consider.

For example, in December 2017 the CEO of the catering giant, Compass, together with all his main beneficiaries, died in a plane crash. Oxfam received £41m as the Will included a provision naming Oxfam as a beneficiary, but only in circumstances where his main beneficiaries had already died.

Should I speak with a solicitor?

While you can make a Will yourself, or use an online Will–writing service, to be valid and to ensure that your Assets go to those you want to inherit, you need to ensure that certain formalities are properly undertaken.

A Solicitor will ensure this happens for you. Without this guidance there is a chance that your Will might not work at all or as you intended.

In addition, without legal help you might not have considered what you would like to happen in certain circumstances, and indeed you might not be using your Will in a way that could lessen the tax burden which your beneficiaries might have to pay.

Making provision for your loved ones, and charities you hold dear, on your death is important – do not therefore underestimate the importance of making a Will and ensuring it is properly drafted.

Bolt Burdon

We have considerable experience and expertise in Will drafting and other legal areas. We meet with you, discuss your intentions, advise on all the options available to you, and then draft your Will in a way that delivers on your requirements and provides you with peace of mind. You can then rest easy, knowing that everything has been done properly. ■

Your travel checklist

On top of all the normal precautions, like making sure your travel documents are in order, take copies of important documents with you in case the originals get lost or stolen.

The ostomate needs to remember to:

☐ Pack sufficient supplies for your stay. At least twice the normal usage at home.

☐ Take all supplies and travel stoma kit as hand luggage.

☐ Ask the airline in advance if you need extra hand baggage for your supplies.

☐ Avoid food and drink that are likely to cause upset or excessive wind the day before you travel.

☐ Pack all your normal medications and any that may help an upset stomach.

☐ Pack some form of electrolyte replacement solution in case you become dehydrated.

☐ Drink bottled water, avoid ice in drinks and use boiled or bottled water to clean around your stoma, and to irrigate in countries where water could be contaminated.

☐ Store your supplies in a cool place, out of direct sunlight.

☐ 'Check in' online 24 hours before departure to secure your preferred seat.

Remember:

- You can request **not** to go through a body scanner but if you do, you WILL be subjected to a full search.
- Most UK airports now operate a hidden conditions lanyard or bracelet scheme. These are available from assistance reception areas. Wearing them identifies you to staff as having additional needs.
- If you need assistance on your flight you should advise your airline at least 48 hours before your departure date.
- You should AVOID requesting the presence of a healthcare professional if you are searched. Airports do not generally have such staff on standby and the likelihood is that you will miss your flight.
- You can only take more than 100ml of liquids in your hand luggage if there is a prescription label on said item.
- You should expect to be treated the same as everyone else. Having a stoma does not exclude you from any security checks.

General Enquiries:
0118 939 1537

Monday to Thursday
9am – 5pm and
Friday 9am – 3pm

or

E-mail:
info@ColostomyUK.org

Website:
www. ColostomyUK.org


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NEW
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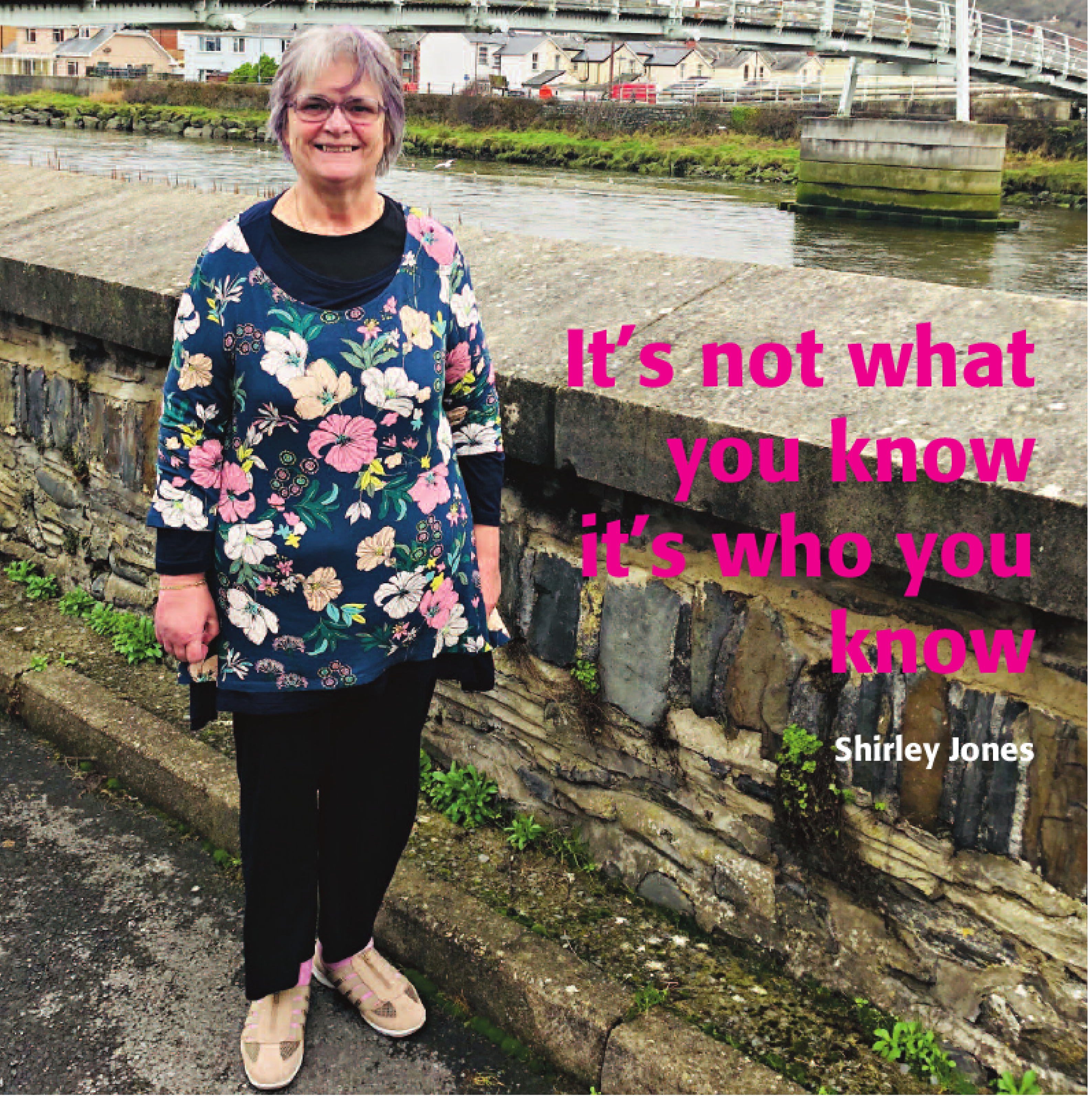
It’s not what you know it’s who you know

Shirley Jones



Shirley Jones is a retired staff nurse. During her forty–year service, she worked in every hospital ward and department, including over twenty years in theatre/recovery. During that time, she tended people pre, intra and post stoma surgery, but she says that her nursing knowledge was no help when she became an ostomate herself. It was the Colostomy UK closed Facebook support group that got her through a very troubled time.

Here is her story:

I had emergency surgery on the 4 October 2016 for an incisional hernia and a sub–acute bowel obstruction caused by adhesions from previous surgery in 1994. After the operation I was admitted to ICU and put on a ventilator. On the 6 October 2016 I was diagnosed with sepsis caused by a perforated bowel. I was taken back to theatre where my abdomen was opened and cleaned, the wound was left open so it could be washed out as necessary. A tracheostomy was also carried out. On the 18 October 2016 a permanent ileostomy was formed and the wound closed. This took over six hours, so Sebastian–Steffan, my stoma, was born and the long road to recovery began.

My family, friends, surgeon, stoma nurses, ward nurses and all ancillary staff of the hospital were very supportive. My beloved daughter joined the Colostomy UK closed Facebook support group before I was well enough, she wanted to understand and assist in my recovery. The group welcomed her and facilitated her awareness of what my recovery would entail. She is still encouraging, reassuring and sympathetic. I was eventually discharged after spending seven months in two different hospitals. With my daughter’s encouragement, I joined the closed group as soon as I could and started another phase of my extended recovery.

The closed group has been phenomenal for me. Any questions I’ve asked have always been answered with courtesy, empathy and kindness. One of the most far reaching

CONTINUED ON PAGE 20, COLUMN 1

CONTINUED FROM PAGE 19, COLUMN 3

questions I asked was regarding my deficiency in magnesium which had tormented me throughout because I could not tolerate magnesium orally or intravenously. I commented to the group and it was suggested I try magnesium oil spray. I checked with my GP and stoma nurses, they were not convinced about the results but they said to try it. The results were impressive as my magnesium levels returned to normal and have remained so. Magnesium oil spray is now being suggested to other ostomates. I also commented about passing mucus, and also the long–term exhaustion as no one had told me about it and I was panic stricken, but the group reassured me it was normal.

Psychologically I feel whatever problems I have had or acquired someone else can help and I do not feel alone. Loneliness with a stoma is very common but being part of the closed Facebook group I feel I am amongst friends who can empathise. I have met up with other ostomates who have become firm friends through **Colostomy UK.** I do say I have cried and laughed with the group. Cried because some situations are sad, grave and humourless. Laughed because the situations although at first sound dreadful become amusing, farcical and ludicrous. Soap and water usually gets rid of any evidence. Medically and psychologically, I would not have the positive outlook I've got if it was not for this formidable group.

Being a patient myself was a totally different experience. As a patient all my nursing knowledge was consigned to oblivion, it was no help because I was as fearful as anybody else and felt I could not ask various questions for fear of looking foolish amongst my peers. The staff could not empathise with that feeling of apprehension having never been in that position, so I felt very vulnerable not wanting to sound unintelligent in front of my colleagues.

I have set up the West Wales Stoma Support Group. We meet once a month. It is a very cheerful group where we have learnt much from each other. We also have guest speakers e.g. our stoma nurses, a retired stoma nurse, a dietician, Amy, the Macmillan cancer information and support coordinator, Ceredigion. We had a wonderful Christmas lunch and hope to have days out, more guest speakers and meals out in 2019. I thought I had finished saying how extraordinary this group is, but something has happened within this last few days that reinforces the spirit of this group.

This is not stoma related so all the more admirable for that reason. I commented that I had had a dreadful day which culminated in the loss of a ring which was of great sentimental value and how my lovely daughter had consoled me and put everything into perspective, that however valuable the ring is I've still got my family who love me unconditionally. I have received over 60 messages sympathising with me over the loss of the ring, and how my daughter's words were so kind, understanding and devoted. That is very true but also the comments from the group were so lovely, I cannot explain how important they were to me and how they have got me through a very troubled time. I feel very lucky to be a part of such a special group of people.

Without Colostomy UK's closed Facebook support group, I would not have the positive outlook I've got, the group has made me laugh and cry, I've gleaned so much information, I've never felt lonely, I've been in contact and met some wonderful people and made some lifelong friends, all because of **Colostomy UK.** I would like to thank my awesome family who have all had a part to play in my recovery all in their unique ways. My true friends who are all very special to me who have got me through so much. I am in debt to **Colostomy UK** and the administration of the Facebook group who provide a superb service. Thank you to all. ■

Photo ID Card

The **Colostomy UK** photo ID card can be useful if challenged when using accessible toilet facilities.

To apply for a Photo ID card, complete the form opposite and return it to the **Colostomy UK** for processing with the enclosures listed below:

- **A copy of your prescription or delivery note as proof of eligibility**
- **Passport photo x 1**
- **Payment – cheque or credit card***

***Note:** Credit card payments can be taken over the telephone if preferred, ensure the above are sent in the post in advance.

Alternatively, the form can be downloaded from our website: **www.ColostomyUK.org**

Allow maximum of 10–14 days for delivery.

Hafbs 3 | Issd no Photo ID Application | Date of Publication: July 2019 | Copyright © 2018–2019 Colostomy UK | Registered charity no. 1113471

National Key Scheme (NKS) Radar Key and Photo Identity Card

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to **Colostomy UK.** Return all required items to:
Colostomy UK, Enterprise House, 95 London Street,
Reading, Berkshire, RG1 4QA

(If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office: Telephone: **0118 939 1537** or Email: **info@ColostomyUK.org**)

National Key Scheme - Key and photo ID card purchase

Title: ________________

Name: ________________

Address: ________________

Postcode: ________________

Tel: ________________

Email: ________________

DECLARATION: I declare that the individual named above is chronically sick, has a disabling condition or has had a bowel or bladder diversion that necessitates the use of accessible toilet facilities. The key is for the personal use of the above named and their designated carer only.

Please **tick** as appropriate:

☐ I would like to receive a **key £3.50** (including postage and packing).

☐ I would like to receive a **photo ID** card for **£6.50** (including postage and packing) and enclose a passport photograph.

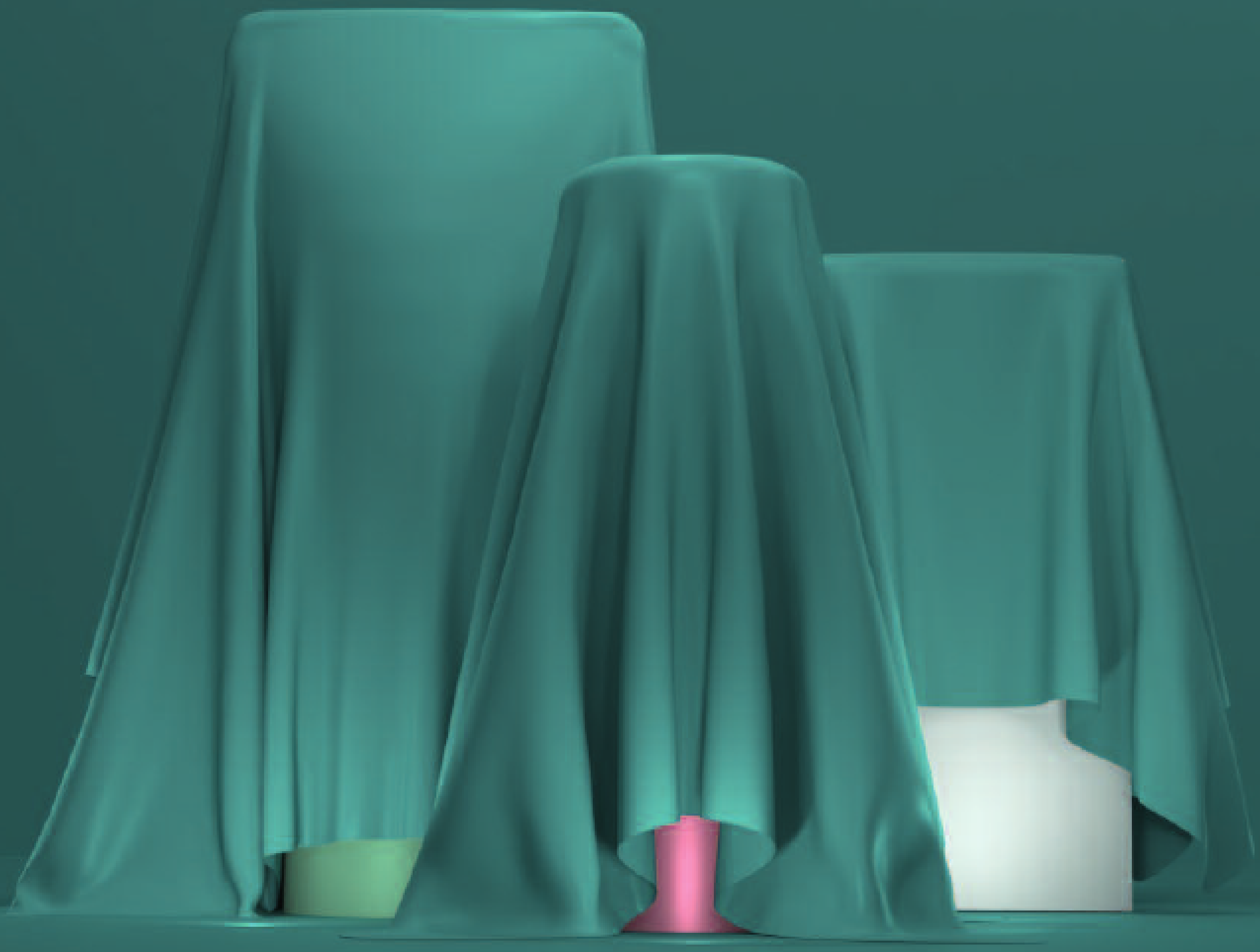
NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to: **Colostomy UK.**

For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received.

Signature of self or carer: ________________ Date: / /2019

T53

Please cut along the dotted line and return to the address on this form - thank you

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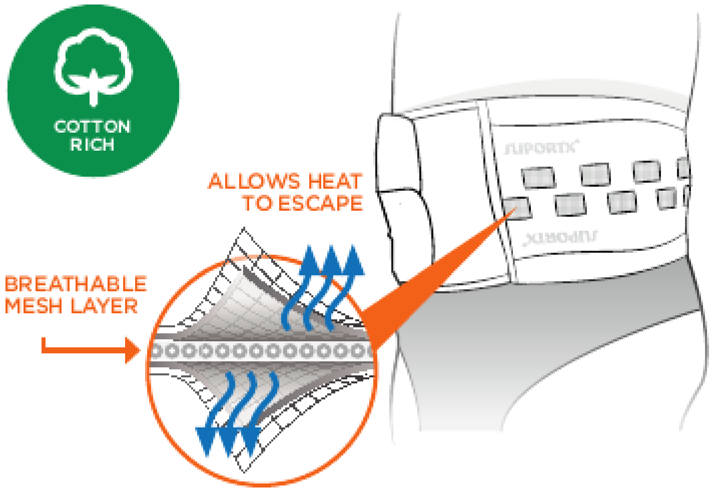

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When one bag just isn't enough

Brian Chapman

My problems started in early 2003, with continual constipation and a painful stomach throughout the day. In the months that followed, I tried several proprietary brands of laxative, rather than seek medical advice. But, as these weren't really successful, I grudgingly booked to see a GP at the local medical centre. Like many men of my age I avoid seeing doctors if I can, but in the next 18 months, I managed to see four of the practice's nine doctors! I was prescribed various medications, including enemas and, towards the end, taking eight Senacot all at once. Throughout this period my symptoms were intermittent. I would feel fine for a while and then become badly constipated again. There was one occasion when I had no bowel movement for three weeks. This lead to constant, very painful contractions. Eventually I went to A&E and was told (after much prodding and squeezing) that if nothing moved in the next few days I would have to go to hospital. Thankfully things slowly got going again and I seemed to recover. A few weeks later, I started to experience severe cramps in my lower abdomen. I also lost my appetite, started to feel very lethargic and began losing weight at an alarming rate. At this point I knew something was seriously wrong, and so reluctantly made an appointment with the senior practice partner. He gave me a thorough examination and was concerned to find some lumps in my stomach and so arranged for me to be seen by the cancer department at the Pilgrim Hospital Boston.

Here I had various tests, including an X–Ray, an MRI scan, Barium enema and endoscopy. From these, it was concluded that I probably had an obstruction in the colon. On 6 September 2005 I was admitted for an operation to remove the suspected blockage. I was told this would take no more than a couple of hours and advised that, although unlikely, I might need a temporary colostomy or urostomy to allow my insides time to heal and recover. Hence, pre–op, both sides of my abdomen were marked up, just in case this was necessary. My wife Julie was advised to go home and then call the hospital just after lunch, as it was anticipated I would be back from theatre by then. I remember walking along the ward with the nurses and joking about how the 'marking up' looked like a face.

When Julie called at 1:30pm she was told to call again at 4:30pm. When she called three hours later she was advised that I still wasn't back. Of course, Julie was getting very worried by this point and was climbing the walls by the time she was finally advised that I was out and in the high dependency unit. She immediately made the 25–mile journey to the hospital. On arrival she was intercepted by the surgeon who explained to her that what was expected to be a routine operation had turned out to be considerably more complicated. She was warned that I was attached to lots of monitoring equipment and told that, had I of been much older, then the safest option would have been not to proceed, but sew me back up again instead! As I'm sure you have already guessed, it was found necessary to form a stoma. But that's only part of the story… because when I came round, I was greeted with the news that it had been necessary to form not one, but two stomas: a colostomy and a urostomy! When the surgeons opened me up, they discovered that my problems had been caused by diverticulitis. This had affected the colon, parts of the intestine and also my bladder. Consequently, part of my colon had to be removed, as well as my bladder and rectum. Instead of the expected two hours, my operation took eight and a half and required two surgical teams to complete. Apparently, if diverticular disease is caught in time it can be managed with dietary changes, but in my case it was too late for this course of action.

My experience has given me the greatest respect and admiration for all who work in the field of medicine and especially all those who work for the NHS, from the specialist surgeons to the nursing staff who gave me all the care and attention I needed to recover. In spite of the odds, these dedicated people have given me a second chance of life. Since the surgery I have had several setbacks, including septicemia (to date five times). Subsequent scans have also revealed that the diverticular disease has damaged my kidneys, although thankfully (following a little trial and error) this situation is now being managed with medication. I have also had to give up my work as a plumber and gas fitter due to the physical and heavy exertion this at times requires. However I do lead a near normal life. I have several interests and am involved in the local community. I have been chairman of the town's Twinning Association for the last 15 years and, up until 2013, chairman of the town's Carnival too, with Julie sitting alongside me as secretary! For the past couple of years I have been chair of the fundraising committee for the local hospital's day centre. In 2011 I was proud to be made an honorary citizen of Skegness in recognition of my service to the town's inhabitants.

The journey I have described was a life–changing experience for both me and Julie. Neither of us had even heard of a stoma before the events of September 2005. Throughout it all, Julie was there for me giving, without hesitation, her support and devotion. I will never be able to thank her enough. On leaving hospital, we decided to be completely upfront about what had happened and not hide the fact that I had two 'bags'. As I'm sure you know, there remains a stigma attached to things like this and so we were worried that we might lose friends as a result. These fears proved completely unfounded, which just goes to show that if friends are real friends then it doesn't matter what happens to you, they still remain true. Like many other ostomates, I found the immediate post–op period overwhelming, as did Julie. There seemed so much to get your head around. We both learned 'on the job' as it were and, looking back, I think this might have been a little easier if we had had other ostomates to talk to. Likewise, it is important to remember that while only one person has the surgery, its effects are felt by family and friends. It is for this reason that I want to finish by encouraging anyone who is struggling or feeling alone and isolated to get in touch with **Colostomy UK**. You might feel that your world is collapsing around you, we certainly did at first. But, if you are patient and do your best to stay positive, you will come out the other side and, like us, get back on track. ■


Peace of Mind
Wind in your hair
time with friends
Jumping in Puddles
Laughing at bad jokes
Blowing Bubbles
feeling special

Ann took a different view

Ann Inglis

Back in April last year, Ann Inglis had an emergency colostomy. When I caught up with her in the summer she was well on the road to recovery and planning to return to work once the school holidays were over. As soon as we started talking, I knew her story would be of interest to readers. As you will see, it is about more than just staying determined and positive during trying times. It is about empowerment too, the empowerment that comes from taking control of your health, the difficult decisions that come with this responsibility and the challenge of talking to loved ones about what you have been through and what it will mean for the future.

Ann's bowel problems started as a child. Even now she can still remember rushing home from primary school because of a sudden urge to use the toilet. The problem was always the same: constipation. Right into adulthood, this was always thought to be Irritable Bowel Syndrome (IBS). When Ann fell pregnant in 1999 with her first child, Sophie, things took a turn for the worse. Ann developed haemorrhoids and was opening her bowels just once every 10 days. Perhaps understandably given her history, Ann's worsening problems were put down to her pregnancy aggravating her IBS. Ann feels that with hindsight she should have been less accepting of this diagnosis. But, as many of you will know, first pregnancies are something of an emotional rollercoaster and a step into the unknown. Perhaps more than at any other time, this makes us more compliant and dependent as patients.

In the years that followed, which included a second pregnancy (Ryan 2002), and a subsequent diagnosis of fibromyalgia in 2008, Ann's problems persisted. Each time she saw the doctor the explanation remained the same, as did the treatment, which centred around taking laxatives. Having been like this all her life, Ann started to become resigned to the idea that this was just the way she was. However, as 2016 drew to a close the constipation and accompanying bloating and pain got worse. By November 2016 it had become unmanageable, leading to a visit to see the emergency doctor and admission to hospital. Matters escalated from this point. A CT scan organised to check for kidney stones revealed instead diverticular disease. Antibiotics were prescribed, but when these made no difference and the pain continued to get worse, Ann's GP finally referred her to a colorectal surgeon.

The first half of 2017 was given over to tests and more tests, including another CT scan, a colonoscopy, ultrasound, defecating proctogram and finally a transit study test. The latter involved taking some pills whose progress through the bowel was then tracked through a series of x–rays. Despite being on a concoction of laxatives all through this period, Ann's condition worsened; she was in pain, constantly

CONTINUED ON PAGE 27, COLUMN 1

CONTINUED FROM PAGE 25, COLUMN 3

feeling sick and opening her bowels just once a month. Thankfully the tests established what was wrong. In June Ann was given the diagnosis of 'global slow transit'. In essence her bowel muscles were not strong enough to move waste along the bowel effectively. She also had a prolapse and stage 4 haemorrhoids, caused by years of straining. The initial approach was to try to manage things with peristeen irrigation and laxatives (seven sachets of movicol and 25ml of lactulose a day). But this didn't work and irrigation proved almost impossible because of the haemorrhoids.

Ann continued to suffer as attempts to manage her illness failed. She was admitted to hospital on seven occasions with blockages. Finally, after being rushed to hospital, her consultant said that medication alone was not going to be enough, but surgery might help. Ann was told she had two choices open to her: remove the haemorrhoids and repair the prolapse, or go down the colostomy route. The consultant discussed both options but, given the problem was to do with muscles, was concerned about stoma function if a colostomy was carried out. Ann took a different view. To her mind, while option one might provide a short–term fix, it seemed inevitable that with continued straining the prolapse and haemorrhoids would return. By this time, Ann had joined the Colostomy UK closed Facebook group. She found the information she amassed from talking with other members immensely helpful in making her decision to have a colostomy. Ann discussed her thoughts with her consultant. It was mutually agreed to progress with the colostomy and so in June 2017, Ann was added to the waiting list, expecting to have her surgery in around three months' time. As we know, NHS workloads are such that sometimes the wait for surgery can be longer than expected. Ann was still waiting in April, when she found herself back in A&E, where coincidentally her consultant happened to be working that night. After a scan revealed a dangerously enlarged bowel, it was decided to operate immediately. Within 30 minutes, Ann was on her way to theatre.

Ann's traumatic couple of years came shortly after the death of her mother and father and also the passing of her mother–in–law, who had bowel cancer and a colostomy. With this in mind, I was interested to hear how she had broached the topic of her own illness with her husband and children. I wondered in particular how Sophie and Ryan had coped with the knowledge that their Mum was going to have a 'bag' just like their late Grandmother. Although I'm no psychologist, it isn't much of leap to see how a young mind might start to make some worrying connections. Understandably the initial strategy was to shield the children as far as possible. This involved playing things down and talking in terms of: "Mum has a sore stomach". But, as we know, young people are very perceptive and, as Ann started to miss important family occasions (such a concert Ryan played in), this strategy quickly became unsustainable. Ann's husband David attended all appointments with the consultant, as she was keen to ensure that her decision was the best not only for her, but also for her family. They discussed the surgery in depth and both fully agreed that this approach was the best solution to improve Ann's quality of life. Hence, in July 2017, Ann and David sat the children down and gave a fuller explanation. Later, when the decision was taken to go for a colostomy, this was again explained to them. At this point, Ann offered to show them some bag samples, but says that this was met with a resounding "no"!

The key thing that Ann picked up from this episode was that Sophie and Ryan's central need was to same. Despite them being very different characters, different ages and, of course, different sexes, they both wanted to be reassured that she was going to be ok. What they didn't want, was the mechanics of how this was going to be made possible. To me, this speaks to a wider point, which is that there is no right or wrong approach when it comes to talking about having and living with a colostomy. Ann found the whole thing challenging, but she is absolutely convinced that being open with David, Sophie and Ryan was the right thing to do. Importantly it created a situation where the family could talk about what was happening and seek further information as and when they wanted it. Ann adopted a similarly open approach with her work colleagues and employers and has been rewarded with understanding and something a little more practical – a disposal bin has been ordered for the toilets.

At **Colostomy UK** we know just how difficult it can be to talk to others about having a colostomy and what it means to live with one. So we hope that if you are in this position, you will draw strength from reading about Ann's experience. I would like to thank Ann for sharing her story with me. By all accounts, life is starting to return to normal in the Inglis household. As Ann said, the children are back to asking her where things are and whether certain items of clothing have been washed etc. It doesn't get much more normal than that in a house with teenagers! ■

Written by
Richard Biddle

Since interviewing Ann there have been further developments. As members of the closed Facebook group will know, she has sadly seen the return of blockages and her colostomy is no longer functioning properly. She is now on the waiting list for surgery to convert her colostomy to an ileostomy. Ann remains positive as she feels that this will make a huge difference. Everyone at **Colostomy UK** sends her their best wishes.


Appeel.
Advance
No sting
Medical
Adhesive
Remover
Spray

I am Jessica

Jessica Logan

A picture is worth a thousand words…so take a look at the two above, and jot down the first five that spring to mind. When I did this, I came up with: young, healthy, sexy, bold and beautiful. Although neither reveal anything about the subject's life, it seems pretty clear this woman is doing well and is confident about herself. I mean, posing in that lacy number and dressing as 'Supergirl' speaks volumes doesn't it! If your thoughts were anything like mine, then I imagine that you would be surprised to learn that in the past 18 months she has undergone four separate bouts of surgery, has been wheelchair bound, verbally abused, harboured fears that she will never be able to have children, has been paralysed with pain and felt alone, isolated and judged. Not bad for someone just 26–years old. Let me introduce you to Jessica. In this article I'm going to tell you her story and explain why, on the front cover of this edition of *Tidings,* she has daubed her body with words and phrases that seem to contradict everything said by the pictures above.

Jessica first began to realise that something was wrong in the Spring of 2017, when she started to leak mucous when bending over. In the months that followed, this rather humiliating problem got steadily worse, forcing her to stay at home, rather than risk an accident. Abdominal cramps were next to make an appearance, along with blood. As Spring turned to Summer, Jessica's symptoms worsened, reaching the point where she would sit on the toilet crying with the pain and frightened by the amount of blood she was passing. In July, by which time she was going to toilet in excess of 30 times a day, Jessica was admitted to hospital following a visit to A&E. Things moved quickly from this point. She was immediately put on a high dose of prednisone (steroid) and Mesalazine, which, along with fluids, are standard medications for Inflammatory Bowel Disease (IBD). Investigations then began in earnest. Stool samples were taken, along with bloods to check for levels of inflammation. She was x–rayed, had CT and MRI scans, biopsies taken and, amongst other things, a flexo–sigmoidoscopy examination. Then came the diagnosis: IBD. The tests had revealed that the whole of Jessica's colon and rectum were severely inflamed and covered in ulcers.

Unfortunately, Jessica didn't respond to drug treatment and so, three days later, she was told that stoma surgery was necessary. Not only that, the surgeon wanted to operate as soon as possible. This was a dark time for Jessica. Having always been healthy, she had gone into hospital expecting the problem to be diagnosed and sorted. Instead, she found herself in uncharted waters. As she said to me: "To be told that you are at death's door is scary no matter how old you are and to hear these words at the age of 25 came as a shock…none of my loved ones really understood how unwell I was, not even myself". Despite the urgency with which surgery was necessary, Jessica managed to negotiate a couple of days delay with the surgeon, just so that she could have some time to take stock of what was happening and try to gain some understanding of what stoma surgery entailed. She had little idea of what to expect, but found the assurances that it would make the pain go away, encouraging. Hence, although naturally scared, Jessica went down to theatre with positive thoughts.

Jessica found the immediate post–op period upsetting. On seeing her stoma she was mortified: "It was swollen and looked like a foreskin hanging from my belly. I cried as soon as she [stoma care nurse] left because I didn't want to live like that. I felt disgusting and scared that no one would love me anymore". Like many others, Jessica also found things overwhelming at first. In quick succession, her stoma care nurse ran through supplies and bag changing and a dietitian visited, giving advice on what to eat during the recovery period and after. On the day Jessica was due to be discharged she had no output, just blood in her bag. She was advised this was normal, and so remained excited about going home. Unfortunately, it turned out to be anything but normal. Many people look back and see that first day at home as marking the start of their recovery. Jessica spent hers in terrible pain and ended up being re–admitted to hospital with a blockage.

In the weeks that followed, the same thing happened a further three times, culminating in emergency surgery, less than a month after her stoma was formed. This revealed that Jessica's bowel was twisted. Post–op she was in a lot of pain but this was put down to having two lots of abdominal surgery in such a short space of time. However, as her stomach started to swell and her surgical scar changed colour, Jessica became convinced that something wasn't right. On discharge day, her wound burst. The cause was a blood clot and abscess. Jessica still went home, but for the next two months had to make daily trips to her GP surgery to have the wound packed and dressed. The problem of blockages also persisted, leading to two more bouts of surgery. In April 2018 Jessica had her rectum removed and a J–pouch created, along with a loop ileostomy to allow the J–pouch to heal. In July 2018 Jessica's stoma was closed off and her J–pouch went 'live'. Despite everything, Jessica told me that she was sad to see her stoma go. This might seem strange, but it is in fact quite a common emotion, as the recent literature shows. When I interviewed Xenia Standbridge about her reversal surgery (*Tidings* Autumn 2018) she said exactly the same thing. For her, it was about saying goodbye to something that she knew had saved her life.

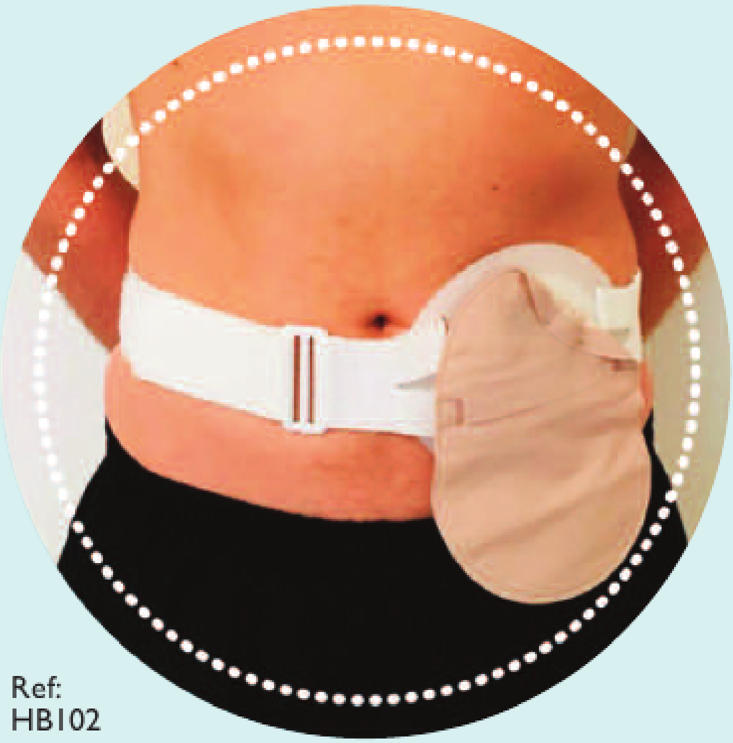
Regular readers will know from other stories in *Tidings* that new ostomates rarely manage to wrestle back control of their lives without some hiccups along the way. Along with the physical recovery, there are accidents and stoma management issues to cope with (sore skin, leaks etc). Mental wellbeing can also take a knock. However, even allowing for all this, few would argue that Jessica has had a very bumpy ride so far. As she said to me recently, she wishes that she could have lived her 25th year differently. Although she now feels more positive about the future, in her own words the experience of 2017/18 and the seemingly never–ending complications left her an 'emotional mess for a long time'. The toll was extensive. Constant pain and fatigue contributed to Jessica's feelings of isolation by placing severe limitations on what she could do. A much looked forward trip to the Birmingham Good Food Show ended up with Jessica needing a wheelchair. Ongoing problems with blockages led Jessica to develop irrational feelings that she was letting people down. This was never more so than on her wedding day, when she had to leave her guests long before the celebrations got underway. Jessica's body confidence, already dented by the stoma surgery, took a further blow when her initial drugs regime led to weight problems, along with the development of 'moon face'. And, to cap it all, Jessica has been challenged and verbally abused using accessible toilets – an issue that sadly ostomates all too often have to face. She has also encountered the IBD 'know–it–alls', who have given her unwanted advice about how, with a few dietary changes and a bit more resolve, she would be 'ok' again, ignorant of the fact that her condition is incurable.

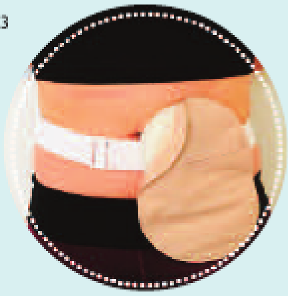
Although Jessica is still suffering from her illness and continues to worry about the effect the last couple of years has had on her fertility, she now feels the corner has been turned. During the course of her many hospital visits and stays she has made many close friends who, importantly, understand. Indeed one has Crohn's disease and a colostomy. She also draws much comfort from Colostomy UK's closed Facebook group. Time has also allowed her to reflect on her experience and recognise the importance of telling her story. Jessica's hope is that in doing so she can raise awareness and make the path for other young ostomates just a little less tangled than her own. We are often reminded not to judge a book by its cover. If ever you wanted proof of the wisdom of this advice, then look no further than Jessica. There is nothing strange about the words she chose to write on her body – they fully capture her experience. It's also no coincidence that she chose to dress as 'Supergirl'. Yes, she is bold and brave, but beneath that exterior lies something else. It's a salient message for us all. Jessica is right to urge people to remember that looks can be deceiving and through her pictures to remind them when you rely on looks alone 'you never truly know a person's battle'. ■

Written by
Richard Biddle

All photographs by
Stuart Randle
stuartrandle@outlook.com

Further information can also be found by visiting the Ileostomy and Internal Pouch Association **www.iasupport.org**





Do you irrigate? If not, are you interested in trying? If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the Colostomy UK website or purchase the Irrigation and you DVD using the form overleaf.

Irrigat

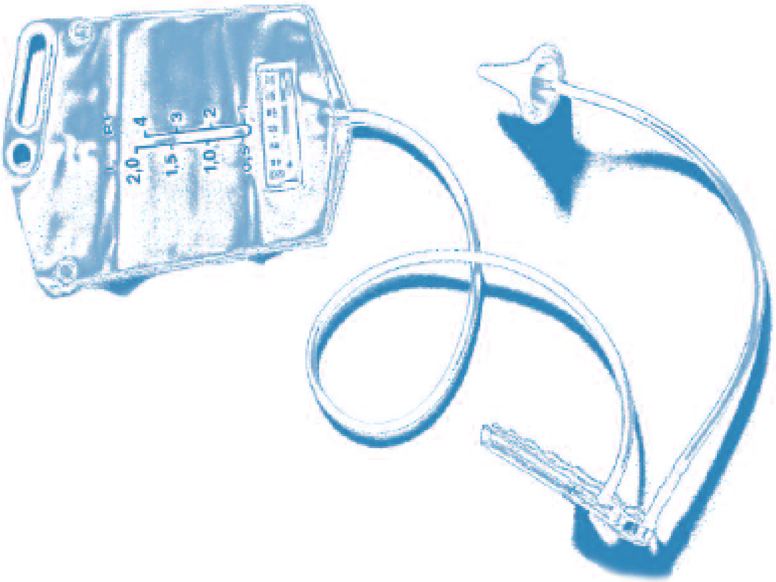
Sarah Squire
Co–Editor
E: Sarah.Squire@ColostomyUK.org

If you have any questions, comments or experiences of irrigation yo
sarah.squire@ColostomyUK.org or write to me at **Colostomy UK.**

I thought I had been irrigating for a fair while but here we hear from Pamela who has been irrigating for over 14 years. I genuinely learn something new every time I read the experiences of others so it's lovely to hear from readers with their stories.

I first realised I had bowel control problems back in 2004. After various tests, including a trial sacral nerve stimulator, it was concluded that I needed a permanent stoma. I have lived with a stoma now for 14 years but it was after the first three months I realised I could not wait to try irrigation

The irrigation kit consists of a water container, two plastic tubes with an adjustable clamp, a cone for inserting into the stoma and a long sleeve which I stick on in place of my normal bag. I use the Dansac water container which is in three parts. Their old system was very good, but they have recently changed the bag and you really need three hands to fill the water container (my husband helps). When the bag is filled with about one litre of warm water and everything is in place, I control the flow which takes about two minutes to run in. I then secure the top and bottom of the drain tube with pegs and let nature takes its course. I have a shower and do other things in the bathroom, while the process works. After about an hour, when all is complete, I attach a stoma cap (about two inches square) and I'm all set for the day. If I am going out during the day, I carry a normal size bag in case of emergency but have not had to use one yet.



ion and you

u'd like to share please send an e–mail to:

Whilst irrigation has been my success story, having a stoma has not been without its problems.

I had several hernias on the left–hand side over the first 10 years and always had them operated on, otherwise I had been advised not to travel on a plane long distances. After each repair I had to stop irrigating for a while. I also had several CT scans for problems with my tummy, but I did have mesh inserted for the hernias, which has caused many a problem. One CT scan in 2007 showed that I had an angiomyolipoma (benign tumour) about the size of a grapefruit on my right kidney which required removal of the whole kidney. I recovered well from that, then in 2015 I started having problems with irrigation which my consultant diagnosed as sub-acute small bowel obstruction which was very inconvenient as I did not know when this was going to occur. I had to lay down for several hours in chronic pain, so I returned to see the consultant to discuss my options. In July 2016 I had what proved to be a very big operation on my stomach and I was in hospital for a week with a convalescence period of six months. During this operation, I had the stoma put on the right–hand side and the left side stitched up. It was very hard coming to terms with it all, but I was positive and with the help of my husband came through the operation which lasted six hours. Within six weeks I started irrigating again.

I exercise every day and I have a very good stoma nurse who visits me about three times a year, this helps greatly. I've never looked back since I started irrigating, and would not choose to stop. I know it is time consuming, but it fits in with my morning routine very well, then I'm ready for the day. My days are busy, and no one would know I've got a stoma. I love cooking and entertaining people and attending the theatre, but I am very careful not to do things I should not.

I travel to Canada every year to see my family, which I love, and I irrigate there as well. I lead a busy life, I'm very active looking after grandchildren, organising big events for a society I belong to and an active committee member. I never even think about my stoma. A stoma should not run your life, it goes with you. It was not so easy for me for nine months when I felt so poorly, but all that's behind me now.

It's so easy to give in, as I've had a lot of operations, but I bounce back. I'm careful what I eat, but I do cook from scratch every day, as there are things I need to avoid. Before I had my colostomy I could not leave the house, as I was too nervous in case of an accident, so the transformation is good and I have a life back again. Irrigation to me means security and peace of mind. I've not had a hernia on the right side but I'm careful about lifting. Life is what you make it and I would recommend anyone to irrigate if they possibly can. So much better and you feel more confident.

I'm very pleased to be able to share my experience with others, and hope you enjoy reading my story. ■

Please remember these experiences are personal to Pamela. Before acting on suggestions from other ostomates you are advised to check with your stoma care nurse.


VENTURE CASE

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Unity is a lottery with a difference. We receive income directly from the number of lottery players we recruit, so we need your support. For every £1 entry – 50p comes directly to **Colostomy UK**.

How it works

For just £1 per week you will be allocated a six digit **Unity** lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques posted directly to you, so there is no need for you to claim. You must be 16 or over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

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Address:
Postcode:
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If you would like to receive correspondence via email, please tick here ☐
Email:
☐ If you do not wish your name to be publicised if you win, please tick here

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How many entries would you like each week? ☐

x

How often do you want to pay?
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☐	Every 13 wks	£13
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☐	Every 52 wks	£52

→ ☐

=

Total Payable ☐

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☐ Payment by Cheque

☐ I enclose a Cheque made payable to Unity
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Service User Number: 4 2 1 1 0 2
Reference: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

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Please pay Unity from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with Unity and, if so, details will be passed electronically to my Bank/Building Society.

Signature:
Date:

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16

Signature:
Date:

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Your letters and e–mails

Dear Editor

My experience started in 2003 when I suffered severe abdominal pains and was diagnosed with diverticulitis. At that time, I believe little was known in regard to the longer–term effects of this condition and whilst the appropriate treatment was given to relieve the pain and acute discomfort it became apparent later that the condition was worsening but it would not reveal the full consequences until many years later.

From 2014 I encountered continuous urinary infections and underwent numerous tests including a prostate biopsy, flexible and rigid cystoscopies, endoscopy/sigmoidoscopy and ultrasound procedures in order to identify the causes. The eventual diagnosis was a colovesical fistula, i.e. a communication between the bowel and bladder.

In November 2015 I was admitted to the QMC Hospital, Nottingham for a fistula procedure with the knowledge that this may result in my having a colostomy/stoma, and in fact it did. I was advised shortly thereafter that it may be possible to consider a stoma reversal some 6–9 months after the surgery, but that I need not make any decision in this respect in the short term.

I quickly adapted my lifestyle and diet to accommodate the stoma, and having a drainable pouch I encountered very little inconvenience. When the time came to opt for the reversal, I initially declined, as I had adjusted to living with a stoma (I named it Herbert) as I had heard mixed outcomes from acquaintances who had taken the reversal.

Over the course of the next 18 months I suffered two prolapses of the stoma and underwent the necessary procedures to rectify them. I became more conscious of the prolapsed stoma inasmuch as the bulkiness of it became more and more aesthetically unacceptable to me.

After a further prolapse my consultant again asked me to consider having a reversal and after fully considering and discussing both the benefits and risks, plus seeking experiences of others who had undergone this procedure, I decided to go ahead with surgery.

The procedure was performed in August 2018 and I can honestly say that I endured little pain and discomfort. Being in a high–dependency ward for 10 days on a diet of 'nil by mouth' and water only for the first seven days, I lost a stone in weight, but this was a very welcome outcome as I had been having little success with my own dietary attempts to lose some weight.

The surgical procedure was an 'open anterior resection' and this healed up fully over two weeks. The removal of the stoma left a 30mm diameter opening in my abdomen. For the first 2–3 weeks this was dressed daily then slowing down to every 3–4 days. The wound was fully healed within eight weeks of surgery.

Initially my bowel movements were somewhat loose and frequent, this being due to the bowel resection and colon reduction, but now I take one tablet a day (Imodium or similar) and this has overcome the problem.

This was undoubtedly one of the best decisions I have made during my lifetime. I now go about my daily life in a normal manner, eat almost the same type of food as I consumed prior to the fistula procedure, albeit I do have to be aware of certain products such as onions, brassicas and spicy sauces as these can have short–term effects. I understand that with passing of time, say 6–9 months, when everything has fully settled down, I should be able to take on these finer delicacies.

If anyone is considering a reversal, my advice is to keep your body healthy by taking regular exercise and maintaining a proportionate weight. If there is a 'Stoma Support Group' in your locality, they usually hold meetings on a monthly cycle, go along and talk to others who are considering or have undertaken the procedure, as you will find them most helpful and welcoming, and this will allow you to secure a far wider perspective of knowledge and experience.

I am now planning in confidence, my European holidays for 2019 and looking forward to enjoying life to the full without fear or worry.

Robert (aged 77)
Nottingham

To Co–Editors

After having a colostomy in 2016, I joined my local support group run by Irene Constable and her friend Carol (in Oswestry, Shropshire). I have found this group very helpful.

The meetings are on the 2nd Thursday of each month. It gives you support and you meet people in the same boat. There are lots of speakers that come to the meetings so you get to see different products and are given good advice. I would recommend this support group. Irene also arranged for me to receive the *Tidings* magazine. I look forward to this which is also very helpful.

Kath Campbell

Dear Co–Editors

I am enclosing a sponge ring and you will tell from its crude cutting that I made it. I have had a colostomy since 1992 and at one time I found the flange became very damp, at times damaging the skin and affecting adhesion. I was given some small cloth bags to put over the pouch and they worked to some extent.

I was, however, dissatisfied with their performance and so I bought a thin sheet of rubber foam for a few pence from an upholsterer. The enclosed ring was the result. I have used them for several years now and have suffered no more dampness, as the ring creates an air pocket between the bag and the flange. The ring is flexible and lasts a long time, is easily washable and has a low profile.

I have never seen anything comparable at displays of stoma equipment, and if a firm were to start to produce them, they could no doubt improve on the design or material.

It was at a recent event that I came across *Tidings* for the first time, and it struck me that your correspondence page may be a useful way of drawing the ring to the attention of others who have experienced the same problem.

With Best Wishes
Yours sincerely
David Lane

Dear Editor

In the recent *Tidings* magazine I read an article regarding help with leakage.

It mentioned using a simple method of protecting clothing from the output of a leakage by wearing a layer of “a puppy training pad”.

As I suffer from leakage – which is upsetting, distressing and embarrassing I thought I would follow the advice.

I was able to purchase a package of these puppy training pads (at the cost of £1.00 from the shop of that name) and cut one to the size I needed – lapping over my pouch and flange – protecting my clothing and tucked neatly against my underwear.

What a wonderful idea. Since I have been wearing these protective sheets I have continued to experience leakages but not once has it reached my clothing. I am able to change my pouch and flange and not one spot of faeces has reached or spoilt my underwear. Night–time leakages are also managed – and at last I do not have to get up, clean up the whole stoma area and then worry about the dirty clothing. I merely remove the soiled wrap, change the pouch and after replacing the new wrap go back to bed!

No more having to find the change of nightwear! No soiled garment to soak ready for the washing machine next day.

I have full confidence in going out and about every day. I have full confidence in knowing that my bed will not become soiled as the leakage escapes the nightwear!

I know that the articles – also in the magazine – showed how distressing leakages can be and the writers wrote of their own experiences and I am sure that they managed their problem. I have spoken to my stoma nurse and we have tried various flanges, wafers (rings) and different pouches to trying to combat the problem. However the only one not listening to the problem is the stoma itself. It changes shape and size whenever it wishes. It can be to do with what I eat, drink or just do too much. Perhaps I sit at the computer too long, perhaps I walk too far, perhaps I eat too many chocolates – whatever the reason the problem of a leak remains. Now – however – I have the solution to my taking control again.

Well done to SH for giving the advice – it works! Thank you.

Yours sincerely
Jackie Dudley

Please note:
Before acting on suggestions from other ostomates regarding medication or treatment you must check with your doctor or stoma care nurse that this course of action is suitable for you.

We look forward to hearing from you, our readers:

Send an e–mail to: **info@ColostomyUK**

Write a letter to: **The Editor, Colostomy UK,**
Enterprise House, 95 London Street,
Reading, RG1 4QA

Please make sure you include your full name and contact details, and confirm that **Colostomy UK** has permission to publish your letter. Also indicate whether you would like us to use your full name or just your first name. If you do not give us permission to use your name we will publish only your initials.

Colostomy UK: active ostomates

Giovanni Cinque
Fundraising and Development Manager
E: Giovanni.Cinque@ColostomyUK.org

Welcome to the regular update page dedicated to our 'Active Ostomates' project.

'Active Ostomates' supports your wellbeing with a range of programmes. Some are delivered through support groups, some can be done in your own home, others you need to sign up for. We will also be promoting activities and events that can help everyone work towards having a more active body and mind.

Get Creative!

Our new 'Creative Minds' art project is proving really popular with support groups. Here's some feedback from a session we did in Guildford:

> *"I have to say it was FANTASTIC! The patients really enjoyed themselves. It was a real change from the usual medical tone to the support groups and allowed them to find other things to talk about and be themselves not patients."*

To find out if we are running a session near you or if you run a support group and are interested in hosting us just call **0118 939 1537** or e–mail: **Giovanni.cinque@ColostomyUK.org**

Chair Yoga expanding in 2019

Our free chair yoga is proving ever more popular. This year support groups from across the country including Harrogate, Bradford, Chester, Newcastle, York, Salisbury, Bristol, and Kings Lynn to name but a few, will be hosting sessions. To get involved or find your nearest session e–mail **Giovanni.cinque@ColostomyUK.org** or call **0118 939 1537.**

Revised booklet available

Revised and updated *Sport and Fitness after stoma surgery* booklet available

We have distributed over 6,000 copies of our *Active ostomates: sport and fitness after stoma surgery* booklet since its initial launch in 2016.

The newly revised and updated version is now available which includes new sections on modified sports and updated advice and links to numerous activities you can try.

To get hold of your copy either download it for free on our website, call us on **0118 939 1537** or e–mail **info@ColostomyUK.org**

Why not also grab a copy of our *Healthy eating* booklet too? This gives useful guidance on how to achieve and maintain a healthy diet.

New swimming date announced

Our first ostomates and family member only swimming event will take place on 10 April between 3pm and 5pm at Sport Liverpool, Liverpool University. It's free to attend but you need to book your place in advance.

If you'd like to attend or want more details please call us on: **0118 939 1537** or e–mail: **Giovanni.cinque@ColostomyUK.org**

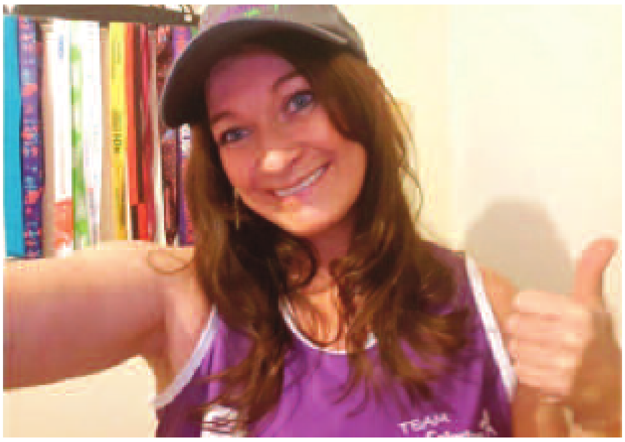
#ActiveOstomates

Rugby League Update

After the success of 2018 we're pleased to be able to announce three further fixtures for our Team Colostomy UK Rugby league team. On 20 April we play Medway Dragons at Medway Park Sports Centre with a 1pm kick off. On 01 June we travel to Lancashire to take on a team from Chorley Panthers as a curtain raiser to their open age game against Manchester Rangers, and on 18 August we face the 'Rugby League All–stars' as a curtain raiser to the Championship fixture between Swinton Lions and Halifax.

We'd love your support!! For more information on any of the games check out ColostomyUK.org, call **0118 939 1537** or e–mail **Giovanni.cinque@ColostomyUK.org**

Emma's Everest Challenge



"My name is Emma. I'm 43 years old and have two grown–up children. I was diagnosed with Crohn's disease when I was 26, soon after the birth of my second child.

"Since then, I've had a great many trips to the theatre…and that's not to see shows! I reckon the current total to be around 19. These have included: a subtotal colectomy for the removal of abscesses; closure of hernia; many colonoscopies. Ongoing problems with adhesions and fistulas make me a complex case.

"I took up running three years ago. I did this not just because I wanted to show Crohn's who was boss, but also because in the past I have suffered from PTSD. Exercise is so good for the mind; it's allowed me to heal and grow. Since then I have taken on many challenges running 5k, 10k and half marathons. I am extremely resilient, and this is my major strength. I have pushed myself regardless of the disease I am living with so I can get to the finish lines and to complete other challenges such as mountain walks.

"I had stoma surgery on 10 October 2018. This has been the best thing ever. Now I can go and live my dreams and make them come true. I ran the Wrexham Half Marathon in March, and will be competing in the Liverpool Rock and Roll marathon in May and The Race to the Stones 100k weekend challenge in July. I have also booked to walk to Mount Everest Basecamp in 2020. This is the dream I am looking forward to most."

You can follow Emma's journey in *Tidings* and through our website where she's writing a monthly blog as her journey to Everest gets closer.

Julian Whitehouse

We were sad to hear that Julian Whitehouse passed away just after Christmas. Julian was a great supporter of our charity and our first Team Colostomy UK Darts player. Originally from West Bromwich, Julian took up Darts in 2005 when he moved to Hampshire.

When competing he adopted the name 'The President' (due to his surname) and his walk on music (The Stars & Stripes, American Idiot, then finishing off with United States of Whatever). We feel this really reflected his outgoing, infectious, personality.

After being diagnosed with rectal cancer Julian had a colostomy in June 2017. Two weeks after surgery he was back playing Darts and soon after became part of Team Colostomy UK.

Although post–op we know Julian occasionally felt frustrated about not being able to play darts to the standard he knew he was capable of, 2018 did bring some great achievements. This included playing former World Match play champion and World number one Colin 'Jaws' Lloyd, and being crowned Sutton Bridge Singles League winner.

Julian was also a great fan of our Team Colostomy UK Rugby League team and it was an ambition of his to play in a match one day. He even went as far as dying his hair purple to show his support for our last game of 2018.

Ostomy Covers

A simple solution by Linda

My covers are made to fit every individual bag/pouch which ensures an exact fit. A flap on the reverse of the cover unfolds, which allows easy emptying if using a drainable bag. The covers are made from cool polyester cotton or lacy fronted polyester cotton and are made to suit Male, Female and Child Ostomates alike.

If you are fed up with the feel of plastic against your skin and the appearance of the bag, this is a great solution. They are available in plain, patterned, or lacy fronted with polyester beneath. They are soft, comfortable, long lasting and fully washable.

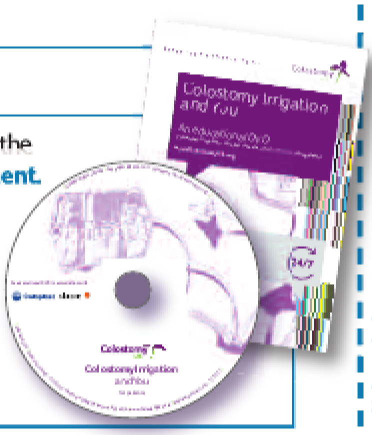
Should you have your own fabric which you would like me to use to make your Ostomy covers I am happy to do this at a reduced cost. Most of my customers come back to me for repeat orders with the most usual comment being 'How ever did I manage without them?'

So, whether you have an Ileostomy, Colostomy or Urostomy, resulting in a Stoma, I'm sure that my covers will help you to regain your confidence and help you to feel complete again.

www.ostomycoversbylinda.co.uk
01205 723327
lindabutler278@gmail.com

Colostomy Irrigation and You **DVD**

Order Form **Colostomy Irrigation** and You (Patients)



Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy UK** to raise awareness about ***colostomy Irrigation* as a method of bowel management.**

Note: Not all colostomates can irrigate. It is therefore essential in the first instance to consult your surgeon/stoma care nurse as they will advise as to your suitability.

To obtain your single copy of *Colostomy Irrigation and You* at the special price of £1.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **Colostomy UK**, to:

Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA

Title:

Name:

Address:

Postcode:

Tel:

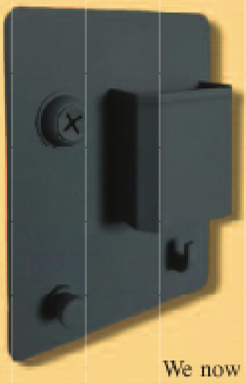
Email:

T53

Please allow 30 days for delivery.

Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA Charity No. 1113471 VAT No. 917079312

Please cut along the dotted line and return to the address on this form - thank you



My life has changed

from a time of worry and concern to one full of interest and positive thinking

Ken Jones

To go into hospital in August 2003 for a minor operation on a fistula and come out with nothing having been done was quite a shock especially as the consultant stated that he had found something "he did not like" but I had to await the result of further tests before he could confirm anything. A few weeks later I was transferred to another consultant who informed me I had cancer of the colon. Like most people I went to pieces and it took a couple of days to realise I could not change anything and just had to learn how to cope.

For many years I had been involved with lots of outdoor activities including the Scouts, Duke of Edinburgh's Award (DofE) and the Ten Tors event held on Dartmoor each year. I saw the future as bleak, having to face giving up all that I enjoyed. My employers gave me a lot of help and support and allowed me to come and go as and when I felt well enough. I was running an Industrial DofE Group at my work place at the shipyard in Falmouth and decided that if I was unable to walk across the moors I could at least plan and direct the expeditions. For this reason I took my maps and navigational gear into hospital with me and worked on them until my operation. I spent 17 days in hospital over Christmas and hated every minute of it as I wasn't used to lying in bed doing nothing. The hospital staff were great, but I was not the best of patients by a long way and it was a struggle to get home. Finally on New Year's Eve I made it, determined the New Year would be a fresh start!

The next few weeks were hard on everyone as, despite their efforts, it took a long time to heal the operation scars and it was several weeks before I could eat anything. Food always smelled good but once I tasted it I could not eat it. A small gammon steak the size of a tea cake changed everything and once I started to get my appetite back I started enjoying food again.

The colostomy bag never proved to be a problem as for me I had no choice but to cope, so I did.

After six months at I home I returned to work again with a lot of help from my employers and with help from the workforce managed to lead the expedition to Dartmoor I had planned for the DofE group. I spent most of the time in the mini–bus and let others do the work, but it felt good to do something constructive. This effort was worth it as it resulted in 10 young people going to St James's Palace to receive their award from the Duke of Edinburgh.

Being unable to do any heavy lifting, but thinking I knew better, resulted in a parastomal hernia which I had repaired a few years later. I took on an office role at work and found this hard to cope with after so many years working outdoors. After three years of trying different roles, the company nurse advised me that I shouldn't be working. I consulted my doctor who also felt the same way. I was offered early retirement and took it, looking forward to enjoying what life had to offer.

Over the previous two years I had begun to get more involved in Scouting and DofE again and now had the time to take on an administrative role, running groups on expeditions. I had to balance what walking I was able to do by making sure that I walked only when I felt up to it and only reasonable distances.

My friends often walked with me enabling me to start to fill in the "spare" time I had with some constructive training for lots of young people. Since my retirement in 2007 I have managed to get involved in the Ten Tors event on Dartmoor again, but decided in 2013 (my 20th year) that it was time to back off as a leader, as the training takes place during the winter months. However I have also trained and been an assessor for DofE for over 25 years and this has become a major part of my life. In this role I have completed hundreds of assessments on many expeditions on Dartmoor, Exmoor and all over Cornwall. I also undertook the role of County DofE Advisor for Cornwall with the Scout Association. After six years, I finally gave this up at the end of June 2018. It was a role I enjoyed. Like most things, DofE is now computerised and the change

CONTINUED ON PAGE 41, COLUMN 1

CONTINUED FROM PAGE 39, COLUMN 3

from being book based was challenging but the teething problems have been overcome and the system now works well. With this role I travelled all over Cornwall setting up groups and it was very rewarding. As with all things time moves on and in 2015 I became chairman of Cornwall Ostomy Support and have seen this group grow to 160 plus members and running around 30 events a year and also donating large sums to the stoma nurse and supporting young people with stomas. My wife and I both enjoy seeing the pleasure that young people get from overcoming the various problems that outdoor expeditions present. We derive great satisfaction from still being able to contribute something so valuable for young people to experience.

How do I cope with "my pouch" in the middle of Dartmoor and on expeditions? Good question! The answer is quite simple as it has proved to be no more difficult than at home. I change the pouch regularly and use a flushable bio degradable bag which I can bury or carry to the next suitable place for disposal. It sounds perfect but I have had my moments when things have gone wrong but, just as if I was at home, I have coped and got on with it. After all what choice do I have! The weight of the rucksack was a problem but this was overcome by taking a close look at the type of equipment I carried and the way things were done. I now stay at a base camp, thus reducing the need to carry a tent etc. I now carry an emergency shelter instead. I no longer walk long distances (20km a day max) and plan my route in advance so it consists of short walks with car rides in between. I have also looked at the clothing I use and reduced this by using Paramo clothing which is waterproof but has built in zips to keep you cool in hot weather. I also use lightweight food which isn't what I prefer, but it provides the energy I need until I find a suitable place to eat.

What with Scouting, running a DofE group, carrying out DofE assessments, leading expeditions, training people for expeditions and the Ten Tors event I wonder how I managed to find time to work. My life has changed from a time of worry and concern to one full of interest and positive thinking. It is a case of taking what you have and adapting it to make sure you use it to your full potential. From this you can find new interests and develop many of the things you did before and still perform a useful role in the community. I feel very grateful. As I watch my grandchildren grow I know how lucky I am to have had the support of my wife, friends and family. Life is good, make the best of it and enjoy every day. ■

New products and services

Tidings is always **interested to learn about new stoma care products and services** from **manufacturers and suppliers.** If you have found **a stoma care product** or **service beneficial to 'living with a colostomy' please let *Tidings* know. YOUR findings could make ALL the difference to others.**

Do something amazing!

Join Team Colostomy UK.
Together we can make a difference.

Whether you run 5K, complete a marathon, skydive or swim the channel. Do it as part of Team Colostomy UK!

fundraising@ColostomyUK.org
0118 939 1537

Colostomy UK: focus on fundraising

Giovanni Cinque
Fundraising and Development Manager
E: Giovanni.Cinque@ColostomyUK.org

Thank you!

Unfortunately we don't have the space to thank everybody who has donated to Colostomy UK, but we'd like to acknowledge a few people and organisations who have been busy raising funds for us:

- Elizabeth McCartney, pictured above, raised **£200.00** from her Christmas Craft sale in Clyde.
- The Goring Chamber Choir donated **£343.50** as result of their Christmas Concert.
- SecuriCare held a 'Wear Red' day and raised **£326.70** to help us support parents of children with a stoma.
- Julie Humphreys donated **£200.00.**
- Customers of Salts Healthcare chose us as their preferred charity and we received a donation of **£250.00**

Why should you fundraise for Colostomy UK?

Colostomy UK is a self–funding charity. We receive no statutory support and so rely on donations fund our activities. This means that every penny that you fundraise for us is precious. Without your help, we couldn't support and empower ostomates or be their voice on the bigger issues.

2018 Raffle

We're delighted to announce the winners of our 2018 raffle. Congratulations to all of them. Thank you to everyone who bought a ticket. Tickets for our 2019 draw will be enclosed in the next edition of *Tidings*.

Janice Peterson

£3,000.00	**Anonymous**
£500.00	**Ian Kennedy** and **Trevor Craven**
£250.00	**Janice Peterson** (pictured left), **Anonymous,** **Anonymous,** and **Anonymous**

Sammi's story

Samantha Nevey and her brother Mark are planning to raise funds for **Colostomy UK** by climbing Snowdon this August! This is her story:

My name is Sammi. I am 31 years old and have suffered from Crohn's Disease for 20 years, after being diagnosed on my 13th birthday, following lots of tests and the need for a blood transfusion.

It was a truly horrible age to be suffering with the numerous symptoms associated with Crohn's disease, including fatigue, loss of blood, loss of weight, sickness, incontinence, urgency to use the toilet and many more. All of these were experienced on a daily basis, whilst at the same time starting secondary school. It resulted in me becoming a victim of bullying. Other kids would notice how long I spent in the toilet during lesson times and ridicule me for it. I

Unity Lottery

It's now been over three years since the Unity Lottery replaced our 500 Club and we are glad to say that not only is its popularity growing with more supporters taking part on a weekly basis, they are also winning regularly as well!

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to **Colostomy UK**), as well as smaller prizes of five free draws, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 34 or online by visiting **www.unitylottery.co.uk** Just remember to link to **Colostomy UK**!

also missed a lot of school, as I was just too poorly to attend.

When I was 16 I developed a fistula, which tracked across my stomach and presented itself as an abscess under my stomach. I ended up doing my GCSE coursework from my hospital bed and only being allowed out to take my exams.

Once I had completed my exams I had my first surgery. This took place in the August after school, at Leicester hospital, an hour away from my family. This was because I needed both an adult and paediatric team present. I had my sigmoid colon removed which ended up being very successful and I was lucky that I didn't need a colostomy, which they had warned me about. The fistula had caused other damage though, to the veins running down my legs. I had a vein grafted from elsewhere, to replace the damaged vein, but unfortunately it clotted. I was put on to Warfarin tablets for many months after.

In 2012 my symptoms came back and were completely out of control. I was put on new medication, an immunosuppressant, but this unfortunately didn't work and made me extremely ill. I had had steroids on and off for years, but they soon caused me to develop steroid–induced diabetes, so were no longer an option. My final attempt to control it was in 2017 when I was put onto an infusion. I had to go to hospital every six weeks and have a three–hour course of treatment. After six months it became clear that this wasn't working either.

Finally, in 2018, I decided that having a permanent stoma was going to be the only way for me to have any kind of life again.

I am now engaged and will be getting married in May 2019. My family, friends and fiancé have been more supportive than I could have ever wished. Since having my surgery my life has completely changed for the better.

Now that I am able to lose weight and get fit, myself, my brother, and one of my best friends, are going to be raising money for the amazing charity **Colostomy UK**. You can donate to support Sammi online through this link:

www.justgiving.com/fundraising/samantha-nevey

Donate by SMS/Text message

You can donate to **Colostomy UK** by SMS/Text message:

To donate **£1**, text **ColUK001** to **70201**
To donate **£5**, text **ColUK001** to **70970**
To donate **£10**, text **ColUK001** to **70191**

There is no cost to you for sending the message and your free allowance or bundle will not be affected – the only charge will be the donation itself. The amount you donate will be added to your mobile phone bill, or deducted from your pay–as–you–go credit. You will receive a reply confirming your donation.

Fundraising, payments and donations will be processed and administered by the National Funding Scheme (Charity No: 1149800), operating as DONATE. Texts will be charged at your standard network rate. For Terms & Conditions, see www.easydonate.org

Grants and Trusts

Thanks to the following charitable trusts for supporting **Colostomy UK**: The Oakdale Trust, The Colefax Trust, The Cardy Beaver Foundation.

We want your stamps!

WANTED

POSTAGE STAMPS

- STAMPS TO BE CUT / TORN FROM RECENT MAIL
- BRITISH AND FOREIGN STAMPS – NO NEED TO SEPARATE
- NO MORE THEN 1CM OF ENVELOPE LEFT AROUND EACH STAMP
- DO NOT TRIM STAMPS TOO CLOSE SO THAT PERFORATIONS ARE DAMAGED

Send your stamps to -

COLOSTOMY UK
STAMP APPEAL
10 Chestnut Avenue
North Walsham
Norfolk
NR28 9XH

You can now donate your used and unwanted stamps to **Colostomy UK**. Please see the image for details.

Colostomy UK

Colostomy UK kit and merchandise

All profits raised from the following items help us to support and empower ostomates. Complete the order from below or order online at **www.colostomyuk.bigcartel.com**

Team Colostomy UK Beanie hat

£8.99

Shipping £1.99

100% soft touch acrylic. Features embroidered Team Colostomy UK logo on front.
One size fits all.

Qty required: ____________

Team Colostomy UK Training singlet

£24.99

Shipping £3.00

100% sublimated polyester features Team Colostomy UK logo on front and #ActiveOstomates on back

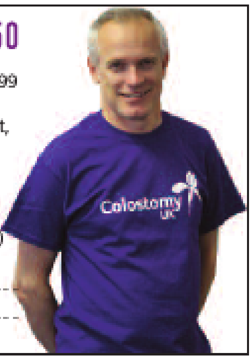
Sizes available (inches): Small (34"/36"), Medium (38"/40"), Large (42"/44"), XLarge (46"/48")

Qty required: Small ________ Medium ________
Large ________ XLarge ________

Colostomy UK Logo T–Shirt

£11.50

Shipping £2.99



100% heavy duty cotton. Colostomy UK logo on front, Colostomy UK.org on back

Sizes available (inches):
Small (34"/36"), Medium (38"/40"),
Large (42"/44"), XLarge (46"/48"), XXLarge (50"/52")

Qty required: Small ________ Medium ________
Large ________ XLarge ________
XXLarge ________

Team Colostomy UK RL hooded sweatshirt

£31.99

Shipping £2.99

45% acrylic, 30% cotton, 15% polyester, 10% mixed fibres.

Team Colostomy UK RL hooded sweatshirt. Features printed logo on front and #ActiveOstomates on back

Sizes available (inches):
Small (34"/36")
Medium (36"/38")
Large (42"/44")
XLarge (46"/48")
XX Large (50"/52")

Qty required:
Small ____________
Medium ____________
Large ____________
XX Large ____________
XX Large ____________

Team Colostomy UK Training T-shirt

£29.99

Shipping £3.00

100% sublimated polyester features Team Colostomy UK logo on front and #ActiveOstomates on back

Sizes available (inches): Small (34"/36"), Medium (38"/40"), Large (42"/44"), XLarge (46"/48"), XXLarge (50"/52")

Qty required: Small ________ Medium ________
Large ________ XLarge ________ XLarge ________

Anatomy aprons

£156.00

Shipping £4.95

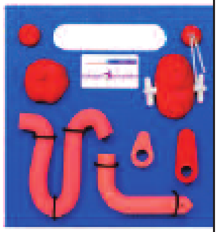
A fantastic teaching tool for educating people about the various kinds of stomas. Aprons can help explain a variety of different surgical procedures including colostomy, loop colostomy, transverse colostomy, ileostomy, colectomy and hemicolectomy.

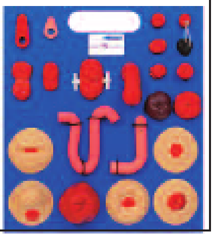
Qty required: ____________

Otto ostomy anatomy model

Standard £1,020.00
Advanced £1,260.00

Shipping £4.95





An excellent teaching resource. Using a simple colour–coding system for the various organs, Otto can help patients better understand the workings of their digestive system and urinary tract. An end or loop colostomy and ileostomy can be demonstrated, along with a urostomy and gastrostomy tube replacement.

Standard Model	Advanced Model as standard model plus:
Stomas:	**Stomas:**
7/8" Diameter stoma	3" Diameter stoma
2" Diameter stoma	Loop without rod
Loop with rod	Double barrel stoma
Urostomy with 3" stents	Oval stoma
	Granuloma stoma
	Necrotic stoma
	Mushroom stoma
	Prolapsed stoma
	Ischemic stoma
	Flush stoma
	In–skin fold stoma
	Parastomal hernia stoma
	Mucocutaneous separation stoma
	Recessed stoma

Additional parts included in both models:
small intestine segment, ileostomy loop adaptor, colostomy loop adaptor, ileal conduit.

Qty required: ________ Qty required: ____________

All products sold individually and prices are per item and inclusive of VAT & p+p to UK & NI only. Please allow 28 days for delivery.

Please send me the above marked items. I enclose a cheque for £ ________ made payable to: **Colostomy UK.**

Title:

Name:

Address:

Postcode:

Tel:

Email:

T53

Colostomy UK

Donate to help us support and empower.

www.ColostomyUK.org/donate
0118 939 1537

Make a donation

Colostomy UK

Without **donations** from people like you, **Colostomy UK** could not continue its vital work **supporting** and **empowering** ostomates. Thank you for supporting us.

My Details: Title: Forename: Surname:

Home address:

Postcode:

Telephone (home): Mobile:

Email:

Date of Birth: Month and year of operation:

Reason for your stoma: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Tick as appropriate: I would like to be kept informed by: ☐ Post ☐ Email ☐ Telephone. Please tick if you would like a receipt ☐

I would like to receive information about: ☐ Tidings magazine ☐ Bag and product manufacturers ☐ Colostomy UK, the work it does, including training, conferences, volunteer opportunities and fundraising.

We will never sell or swap your information with other organisations. You can change how we communicate with you at any time.

Call us on: **0118 939 1537** or email: **info@ColostomyUK.org**

I would like to make a donation of:

☐ £20 ☐ £30 or whatever you are able to give £

☐ I enclose a cheque or postal order made payable to **Colostomy UK**

☐ Please debit my Visa/Mastercard/Maestro Card with the amount specified

Card number (Maestro only)

Expiry date / Security code (Maestro only) Start date / (Maestro only) Issue No.

Signed Date D D M M Y Y

giftaid it Thank you for your gift

Thanks to the gift aid scheme – we can reclaim money on your donation from the government. For every pound you give us, we can claim an extra 25p. For example, a donation of £20 becomes £25 with gift aid, at no extra cost to you.

☐ I want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: Date: / / 2019

I would like to make a regular donation – Instruction to your Bank/Building Society to pay by Banker's Standing Order:

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

I would like to make a regular donation* of ☐ £20 ☐ £30 or other amount (please state) £

☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th ☐ 25th of month: year:

thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

*Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words:

Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP

Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS) T53

Signature: Date: / / 2019

To donate, please fill in the form, check your details are correct, then return this page to Colostomy UK – thank you.

Please fill in this form to make a donation. Check your details are correct, then return the completed form by post to: Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

Chloe's Day

Barbara Harrison

Chloe left the pool, swiftly grabbed her towel off the sun lounger and, after a quick dry, wrapped her brightly coloured sarong around her waist, hiding the lower half of her swimsuit. She sat for a little while but was fidgety. "Are you OK love?" asked her mum who, from the next lounger, had been discreetly watching her.

"Yes Mum, I'm fine. Just a bit tired. I think I'll go back to the room for a bit."

"Alright love, we'll all be up soon to get ready for dinner. See you in a little while."

Having showered, Chloe took a look at herself in the full length mirror, something she'd found difficult to do these last six months or so. She could still see the long scar that ran down the middle of her body, but she realised it wasn't as obvious as it had been. It wasn't as red and ridged as it used to be. She ran the fingers of her right hand up and down it as though to seek confirmation, whilst carefully holding her left hand over 'it'. How come she'd not noticed this change before, she thought to herself. Pulling on her shorts and tee shirt she decided she'd sit on the balcony and read for a little while. She opened her book but could not concentrate on it. She kept thinking about her day, and as days go, it hadn't been too bad.

She'd hated the first few days of this holiday. What was the point of being on a beach and pool holiday when you had to spend most of your time covered up in sundresses and sarongs, or wearing swimsuits if you dare go in the pool, and terrified everyone would see your bulge and think you were a freak. She had to admit to herself that yesterday had been a bit better when Anna and Jessie, two girls about her own age, had come over to talk to her and encouraged her to go for a dip with them. Today had been even better when twins Matilda and Matthew had arrived and joined them too. They'd all agreed to meet the following day, and if they could get their parents to agree, to go snorkelling. She was still very self–conscious about being seen without some covering over her swimsuit but if she was quick getting in and out of the pool it wasn't so bad. She had brought a tankini with her and wondered if she'd ever have the courage to wear it, but doubted she'd ever wear the bikini's that she used to wear on holiday.

As she sat there, going over everything in her head she heard the rest of the family return. "Mum, Dad, can I talk to you?"

"What's the matter Chloe?" asked her dad. "Is everything OK? You're not feeling ill are you?"

"No Dad, I'm fine thanks. I just want to say sorry to you and Mum."

"Sorry! What have you done love?" her mum asked.

"I want to say sorry that I've been such a pain to you both. I know I've whinged about this holiday. I really did want to come, even if I didn't always show it, and I know you both needed a holiday, even more than me. So I'm sorry if I've spoilt it for you."

"Oh sweetheart," her dad said, "we just want you to have a good time. You've been through so much this last year with your surgery and everything else you've had to deal with."

"But you've both been through it too. You've both given up so much for me. I just wanted to say sorry and that I love you both so much."

"We love you too Chloe." said her parents in unison.

"Now," said Dad, "who's hungry? Let's get ready for dinner and go and try out a restaurant in town."

As they waited by the lift Chloe caught a glimpse of her reflection in the window. "OK LoopyLoo, you'd better behave yourself tonight." she thought, but could be heard to say out loud as she looked at her sleek image in her fitted sundress "Bag! What bag?" This was the moment she knew that she was going to control her colostomy, not have it control her. ■

I've been an ostomate for just over three years. I've been dabbling in creative writing for much longer. Last year, whilst being part of a creative writing group facilitated by my local adult education centre, we were considering the genre of children/young people's literature, in particular tackling difficult subjects such as divorce, death, disability.

At first I didn't know where to begin, and then I thought about a young teenage girl and her mum that a mutual friend had put in touch with me. They were both trying to deal with the daughter's impending colostomy, and also worrying about a holiday abroad they were going on soon afterwards as a family. I was, or at least I think I was, able to help demystify some of the terms and issues surrounding having a colostomy, and give some practical advice on what and how to pack. Thinking about the piece I had to write, in a format not longer than one side of A4, I wanted to try to show that even for young folk, a colostomy should not stand in the way of anything they want to do.

As I write this, I am mindful of the young boy Seven Bridges who recently committed suicide as a result of bullying he received because of his colostomy. When I wrote my mini story, I wrote in the hope that in some small way it might help someone. It makes me sad and angry that Seven didn't get the help he clearly needed. I am even more aware that we need to make taboo subjects normal to talk and read about – no matter what our age.

Barbara Harrison

News from support groups across the UK

Ayrshire and Arran Stoma Support Group

Are you looking for a support group on the west coast of Scotland? The Ayrshire and Arran Stoma Support Group has been helping ostomates for the past 22 years. They meet five times a year at Biggart Hospital, Prestwick, Ayrshire, in the Ferguson Day Unit, starting with the first Saturday of the month and then every two months thereafter (except August) – so that's February, April, June, October and December. All they ask is that you make a small donation towards the tea/coffee and biscuits. You can also bring along your partner or a friend. Most meetings have a speaker or a rep from one of the manufacturers, but the main thing is just to meet and have a cuppa!

For more information phone **Jim Krasewitcz** on: **07729 771 350**

A Plea from Irene Constable, Bums on Tums Support Group (B.O.T.s)

Support groups are really needed. As we all know, having a stoma can be very traumatic. Shropshire B.O.T.s currently covers the whole of Shropshire and into North Wales. Unfortunately, this group is getting to the point where we may have to think about a waiting list, as it is getting rather big. I don't want it to come to this and would love it if someone would start a support group in another part of the county, perhaps to the south and/or into North Wales. There are people in both areas that need a group. All it needs is for someone to step up to the plate and get one off the ground. If there is someone out there who would like to start a new group, then I am more than happy to help get it off the ground and share information with them. I learned lots over the years I have been running B.O.T.s. You can contact me on **01691 238 357** or by e–mail: **ireneconstable@phonecoop.coop**

Colostomy UK can also help people to set up support groups, so if you are considering starting a group anywhere in the UK then don't hesitate to get in touch with us for advice. Tel: **0118 939 1537** or e–mail: **info@ColostomyUK.org**

If you would like to set up a support group in your community or if you're interested in volunteering please email **info@ColostomyUk.org** or call us **0118 939 1537** and speak to Giovanni or Libby.

Bristol Ostomy Self Support Group (BOSS)

BOSS are holding their annual open day on Saturday 1 June from 10:00am to 01:00pm. The venue is: The Future Inn, Bond St, Bristol BS1 3EN. The event is open to all ostomates, family members and carers.

Colostomy UK will be in attendance throughout the day and will be hosting a series of active ostomate 'chair yoga' taster sessions. These are open to all ostomates, whether they be 9 or 90!

For more information, including how to book your place on one of the free chair yoga taster sessions, contact **Janet Clark** on **01934 248 114** or email: **janet.clark@ostomy.org.uk**

Nuneaton Stoma Support Group

Thanks to Bob Burrell for sharing this photo of his support group's Christmas Party. As he says, it was well attended, the atmosphere was very friendly and everyone seems to be having a good time! If you are in the Nuneaton area then you can find full details of the group in the Support Group directory (pages 50–52).

Wessex Stoma Support Group

2019 is going to be another busy year for us. With the first half almost behind us, let me tell you what we have planned from June onwards:

Saturday 1 June	AGM
Saturday 13 July	Annual BBQ, 12noon
Saturday 3 August	Full Meeting
Wednesday 11 September	Annual seaside trip to the Isle of Wight
Saturday 20 September	Full Meeting
Saturday 5 October	Coffee & Chat
Saturday 2 November	Full Meeting
Saturday 23 November	Xmas Craft Fair
Saturday 7 December	Xmas Party
Friday 20 December	Annual Pantomime trip (Robin Hood) Salisbury Playhouse tbc

Further details can be obtained by e–mail **wessex.stoma@yahoo.co.uk** Tel: Secretary on mobile **0779 986 3766**, or visit our website: **www.wessex-stoma.co.uk**

Stoma care open days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available. It is also a chance to meet other people who have a stoma and visit the Colostomy UK, IA and Urostomy Association stands.

Colostomy UK volunteers, who all have stomas themselves, attend stoma care Open Days all over the country whenever possible. Do come along, call at our stand and have a chat.

Open Days that we are aware of at the time of going to press are listed below. An up to date list, including events in your area, can be viewed on the **Colostomy UK** website.

CliniMed Event
Burnham Park Hall, Windsor Lane,
Burnham, Buckinghamshire, SL1 7HR
3 April 2019 1:00pm–3:00pm
T: CliniMed: 0808 1596 017

Royal United Hospital
Stoma Open Day
Bath Racecourse & Conference Centre,
Lansdown, Bath, BA1 9BU
4 April 2019 10:00am–2:30pm
T: Stoma Care: 01225 824 056

Stoma Care Open Day
Ellesmere Port Masonic Hall,
Orchard Suite, 114 Chester Road,
Whitby, Ellesmere Port, CH65 6SD
24 April 1:00pm–5:00pm
T: Stoma Care: 01244 366 170

Oxford Stoma Care
Patient Open Day
Tingewick Hall, John Radcliffe Hospital,
Headley Way, Headington,
Oxford, OX3 9DU
4 May 2019 Time: TBC
T: Stoma Care: 01865 221 839

Queen Elizabeth Hospital
Stoma Care Open Day
Knights Hill Hotel & Spa,
Knights Hill Village,
Grimston Road,
Kings Lynn
10 May 2019 Time: TBC
T: Stoma Care

Royal Victoria Infirmary
Stoma Care Patient Open Day
Brunswick Methodist Church,
Brunswick Place,
Newcastle-upon-Tyne, NE1
19 June 2019 10:00am–2:00pm
T: Stoma Care: 0191 282 4116

Tell us of your open days to include them on our website and in the next issue of *Tidings*.

Contact **Colostomy UK**, e-mail your contact details to: **info@ColostomyUK.org**

National support organisations

IA The Ileostomy and Internal Pouch Support Group
www.iasupport.org
Telephone 0800 0184 724
e-mail info@iasupport.org

UA Urostomy Association
www.urostomyassociation.org.uk
Telephone 01386 430 140
e-mail
secretary@urostomyassociation.org.uk

Mitrofanoff Support
www.mitrofanoffsupport.org.uk
Telephone 07903 382 013
e-mail info@mitrofanoffsupport.org.uk

IOA International Ostomy Association
www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)
via the **Colostomy UK** 24-hour free helpline 0800 328 4257
e-mail info@ColostomyUK.org

Breakaway Foundation
www.breakawayfoundation.org.uk
Telephone 01283 240253
e-mail info@breakawayfoundation.org.uk

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone 020 7940 1760
e-mail: admin@bowelcanceruk.org.uk
Email Bowel Cancer UK nurses:
nurses@bowelcanceruk.org.uk

Macmillan Cancer Support
www.macmillan.org.uk
Telephone 0808 808 00 00
Monday-Friday, 9am-8pm

Crohn's and Colitis UK
www.crohnsandcolitis.org.uk
Telephone 0300 222 5700
e-mail info@crohnsandcolitis.org.uk

The IBS Network
www.theibsnetwork.org
Telephone 0114 272 3253
e-mail info@theibsnetwork.org

Support groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

If, you are thinking of starting a support group in your local area, or are perhaps about to take over the running of an existing one, then please don't hesitate to get in touch with us for advice, Tel: 0118 939 1537 or e–mail: info@ColostomyUK.org

Stoma support groups
in your county

Channel Islands

Guernsey
Guernsey Ostomates
Luci Deane 01481 236 077/
lucideane58@gmail.com

Jersey
Jersey Ostomy Society
Fiona Le Ber: 01534 445 076 or
jerseyostomysociety@gmail.com

England

Berkshire
E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 01344 426 652
Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297
or 07974 790 558
WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
If you are interested in joining then please e–mail Giovanni: info@ColostomyUK.org or call on 0118 939 1537

Bristol
Bristol Ostomy Self Support (BOSS)
Janet on 01934 248 114 or
Rob on 0117 966 8021

Buckinghamshire
High Wycombe Stoma Support Group
Clare Hall telephone 0800 318 965
Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
mkssg.sec@gmail.com 01908 567 091
You Are Not Alone Stoma Support Group
Carla 07846 354 918
e-mail: carla_wright@sky.com

Cambridgeshire
Peterborough Stoma Support Group - Ostomistics
Alan Wright 01354 653 290/07836 661 102 http://www.ostomistics.org/

Cheshire
Countess of Chester Hospital Stoma Support Group
Stoma Nurses 01244 366 170
East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071
Stockport Support Group
Marion Caulfield: 0161 320 9400/0800 652 6667
Warrington Ostomy Support Group
Louise or Joan on 01925 454 813

Cleveland
Oops Group
Julie Morrisroe/Carol Younger/
Alison Hall-O'Donnel: 01287 284 113

Co. Durham
Bishop Auckland Stoma Care Group
Mrs Maureen Davison tel: 01388 818 267 email: trebornosivad@tiscali.co.uk
Darlington Support Group
Sister Jacqui Atkinson: 01325 743 005
Durham Stoma Support Group
Sister Maxine Santana 0191 333 2184

Cornwall
Cornwall & Plymouth Bowel Cancer Support Group
The Secretary: 01872 241 145, cbcsginfo@gmail.com or website www.cornwall-bowel-cancer-support-group.co.uk
Cornwall Ostomy Support
Ken Jones: 01872 863 106 or
www.cornwallostomysupport.org.uk
Lanhydrock Ostomist Group
Mandy Rowe: 01726 832 642
E: murphy.rowe781@btopenworld.com;
Henry Kendall: 01208 850 986
E: h.kendall380@btinternet.com

Cumbria
Grange Cancer Support Drop in
Marie O'Connor 01539 533 279
Stoma Support Groups in North Cumbria
Stoma Care Nurses 01228 814 179

Derbyshire
Diverted Local Stoma Support Group
Diana Manning: 01283 541 311

Devon
Devon IA
Martin Hornby: 01458 251 095 or
email: devon@iasupport.org
Mid Devon Ostomy Support Group
Janice - janice234ford@gmail.com or
tel: 07923 975 051 or 01884 799 369
Plymouth & District Bowel Cancer Support Group
Wendy Wilson - Facebook: Plymouth Bowel Cancer

Dorset
Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Bournemouth)
Beryl Andrews 01202 483 303
Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Poole)
Jenny Pipe: 01202 740 440
Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Colin Clare - 01305 853 238

Essex
Connect
Lin Hart 01279 505 273 email:
comeconnectwithus@gmail.com
Mid Essex Stoma Support Group
Paul Foulger: 01245 224 374
N.E.S.S (North Essex Stoma Support)
Brian Waller- 01206 540 449
Optimistic Ostomates
Angela Taylor 01702 385 510
Redbridge Ostomists Club
Stoma Nurses - Chris/Lisa: 020 8970 8321
STEPS - Stoma Essex Patients Support
01268 451 937 or
e–mail: stepsessex@gmail.com

Hampshire
Replummed stoma support group
www.replummed.me
Solent Ostomates Support Group (S.O.S.)
For information 07527 707 069 or
solentostomates@hotmail.co.uk
Southern Ostomy Group
Caroline or Karen on: 07756 819 291
southernostomygroup@hotmail.com

The Hampshire Ostomates Support Group
Contact Nicki Beare on 07771 558 458 or Nichola0405@yahoo.co.uk

Waterside Stoma Support Group
Hazel Derham: 023 8089 1934 or hayjuder@sky.com

Wessex Urology Support Group
Mrs Jo Stacey: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 01432 880 656
or email: carolsteeleglo@gmail.com

Hertfordshire

Colonise
Anastasia 01727 760 981

Ostofriends Support Group
Peter Lannen ostofriends@gmail.com 07501 137 511

Stevenage Ostomistics
Judy Colston: 01438 354 018
neilcolston@btinternet.com

Isle of Man

IOM Bowel Cancer Patient and Carer Group
Heather Norman: 07624 480 973

Stoma Support Group
Carole Cringle stoma nurse: 01624 650 212

Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma 01983 534 009

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014 or Margaret Webb 01233 628 807

Atoms Support Group
Maria Culleton, SCN: 01227 769 679 or 07827 997 424

Dartford Ostomy Group Support (DOGS)
Tracey or John: 07779 155 846 or 07948 974 350 or dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Julie Bell/Ros Marshall: 01233 616 646 and Support Group Organiser June Golding: 01304 822 696

GOGS (Gravesend Ostomy Support Group)
Tracey: 07779 155 846 or
Helen: 07710 780 958

M.O.G.S (Medway Ostomy Group Support)
Tracey: 07779 155 846; Helen: 07710 780 958 or
e–mail mogs-uk@hotmail.co.uk

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

Tunbridge Wells Stoma Support Group
Cathy Chitty/Mags Donovan 01892 632 323

Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194
sogs-uk@hotmail.com

SWANS Stoma Support Group - Swanley
Heather - 07711 445 312
heather601@virginmedia.com

Thanet Stoma Buddies Support Group
Kathy 01843 291 825

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 07774 263 563

Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet: 01772 683 790,
www.phoenixgroupbvh.com
or eMail: sandrapeet7@aol.com

Kangaroo Klub, Blackpool stoma support group
For further details please contact the stoma department at Blackpool Teaching hospitals, Tel: 01253 956 620 or e-mail crc-stomanurses@bfwhospitals.nhs.uk

Leicestershire

Kirby Ostomy Support Group. Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper: 07464 957 982
kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group
Betty Williams - 01205 724 120
Sheila - 01205 364 493

Grantham Support Group
Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support Newham
020 8553 5366

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 020 8510 5318 or 020 8510 7599

Rectangle - Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

South Woodford Support Group
Nurse Christina and Lisa: 020 8535 6563

Surrey & South London Bowel Cancer Support Group .
Sue Berry: 01737 553 134 or
John Amos: 020 8668 0796

Time 2 Talk
Ifrah Mohamed - 07463 838 718 mybodysauthor@gmail.com, Viki Palmer - 07894 276 986

Newham Stoma support group
Contact Lauren King 020 7055 5576

Merseyside

I.C.U.P.S ,
Sue: 07742 237 013

St Helens Cancer Support Group
01744 218 31
Denys Floyd- 01744 884 097

Middlesex

Inside Out
Sarah Varma: 020 8235 4110
Bob (chairman): 020 8428 4242

Norfolk

Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698/01553 674 962/01553 768 271

STARS (STOma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733 448
sylvia.ruth.hughes@gmail.com

Norfolk Ostomates Support Group (on Facebook too)
Barbara Harris 01603 417 046
07789 581 312

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663 363

James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955

Northamptonshire

Northampton Ostomy Support Group
07801 316 403 (evenings) or
Trish 07703 188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman: 01773 715 460

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support
Jenny or Kate: 0115 962 7736
Mrs B Heath: 0115 966 3073

Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable on 0169 123 8357

Somerset

Stoma Heroes Support Group
Shane Green 07802 428 074
Shane@stomaheroes.com

Staffordshire

Outlook The North Staffs Ostomy Support Group
Moira Hammond 07788 402 195 or
e–mail: cm.hammond@ntlworld.com

County Stoma Group
Christine Bryden 07757 911 726 or
e–mail: countystoma@yahoo.com

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 01473 311 204

L.O.G.S (Lowestoft Ostomy Group Social)
Mandy O'Shea: 07899 913 617 or
Bruce Pollard: brucepollard@me.com

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse:
01638 515 525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena:
01372 735 925

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126 or 07852 554 049 or Jackie Sanders: jackie-sanders@hotmail.co.uk or 07815 603 742. Website: http://www.normandystomagroup.wordpress.com

Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 01273 554 407
Chichester Stoma support Group
The Stoma Care Team 01243 831 527
The Ostomy Friends Group
Jane Quigley: 01323 417 400 ext 4552
West Sussex Princess Royal Stoma Support
Tina Walker: 01444 441 881 ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com
NHS Molineaux Centre
John Burchell 0191 265 1047
Royal Victoria Infirmary Support Group
Stoma care nurse specialist: 0191 282 4116
Sunderland Support Group
Michele Downey 07704 949 30 email: micheledowney@outlook.com

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com or Bob: 07564 680 803

West Midlands

Coventry Stoma Support
Martin - 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Michael Slater: wessex.stoma@yahoo.co.uk or on 01722 741 233
www.wessex-stoma.co.uk

Worcestershire

Kidderminster & District Collossus Support Group
Brendon Drew: 01299 400 843

Yorkshire

Acorn Ostomy Support Group
07580 693 155 (After 6:00pm)
Airedale Stoma Support
Sue Hall: 01535 646 373
Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 01226 432 528 or Celia Utley (Chairman) 01226 284 262
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 01484 355 062
Bottoms Up (for urology and colorectal cancer patients)
John Whelpton 07974 657 146 email: midyorks.bottomsup@gmail.com
Bradford Stoma Support Group
Please get in touch with Lisa Hall on 07552 276 747
Dewsbury & District Stoma Support Group
Janet Edmond: 01924 512 041 or 01924 512 072
Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses - Judith Smith and Mary Hugil 01609 764 620/07736 295 131
Harrogate Stoma Support group
Stoma department office Nurse Gill Wilson/Fiona Holtham 01423 555 786
Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535
Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388
The Hull and East Riding Colostomy Support Group
Pete Smith: 07989 565 335 or Pete Rennard: 07939 518 642/01482 793 966 or Rosanna Grimsby: 01482 801 575. www.hercosg.org.uk

Northern Ireland

County Antrim

Colostomy UK Volunteers Northern Ireland
Chris Wright: 07720 717 771
Belfast City Hospital Stoma Nurses
Audrey Steele, Karen Boyd, Kirsty Niblock, Annette Lambert, Emma Dunn tel 028 9504 5941

County Armagh

Craigavon Area Hospital
Claire Young/ Lynn Berry/ Tanya Garvie 028 3756 1845 (Direct Line)
Daisy Hill Hospital Support Group
Bernie Trainor: 028 3756 2932 (Direct Line)

County Down

North Down Stoma Support Group
Adrian Ewing on 07850 741 511
Ulster Hospital
Hazel/Martina: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Republic Of Ireland

County Mayo

Mayo Stoma Support
Marion Martyn: +353 94 902 1733

Dublin

Bowel Cancer Support Group (ICS) Dublin
National Cancer Helpline: +353 1 800 200 700 or Olwyn Ryan: +353 1 231 0500

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 01292 220 945
Stoma Care And Recovery (SCAR)
Maggie: 01294 271 060/ 07817 736 147 maggie13@sky.com or Rhona: 01294 557 478

Fife

Fife Ostomy Support Group
Ishbel Barr: 01592 772 200

Lanarkshire

Glasgow Stoma Support group
Morag Sinclair 0141 779 1322 or Jackie McChesney 01505 324 052

Moray

Moray Ostomates Support Group
Meggie 01343 552 449
Kathleen 07789 684 285

Scottish Borders

Stoma Support Group
Nancy Fraser: nancyfraser@talktalk.net or 01450 374 012. Fiona Gentleman: r.gentleman@sky.com or 01450 371 063

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644
Bring Your Own Bag Stoma Support Group
Western General Stoma Team 0131 537 1000

Wales

Aberystwyth

West Wales Stoma Support Group
Shirley Jones: shirleyejones78@gmail.com

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 01656 645 602 or bridgend.ostomy@gmail.com

Carmarthenshire

W.O.W.S. Wales Ostomy West Support
Judi Hopkins 01267 237 847 or Julian Boswell 01554 772 877

Conwy

North Wales Ostomy Support Group
Hazel - 07976 817 246 or Lesley - 07828 837 325

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 01873 852 672 After 6pm
Cwmbran Ostomy Support Group (COSG)
Philippa Lewis: 01633 791 339 07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Chair person 01685 877 144

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Rosemarie Rees Paton: 01437 532 473

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823 646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 01792 418 245