



## MILTON KEYNES STOMA SUPPORT GROUP (MKSSG)

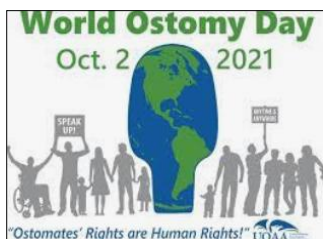
**Newsletter number 21  
September 2021**

Dear Member

When we were preparing material for this newsletter, we suddenly realised that these extended newsletters have been going now for a year. Little did we think, as we sat out in the sunshine last summer discussing how we could keep in touch with you all until meetings resumed, that these newsletters would still be coming to you a year later! We hope you have enjoyed reading them and are reassured that you are not forgotten and the group is alive and kicking despite all the restrictions.

As usual this newsletter is packed with a variety of topics. Included is information on a research study specifically related to those with a stoma (introduced in 'Ostomy research news'). Remember how you felt when you first had your stoma? Well, this research offers us a way to contribute personally to the future support of those still to go through such an experience. Do take part if you can.

On a global level, every three years in October there is a World Ostomy Day, and its 10th observance is this year on 2 October (the date of the first Saturday in October, and coinciding with the annual Ostomy Awareness Day). World Ostomy Day, sponsored by the International Ostomy Association, aims to raise awareness, highlighting health care disparities around the world regarding surgery and after care, suitable supplies, emotional support and the right to lead a normal life without being stigmatised. You may have heard about various awareness raising campaigns (encouraging you to take part) if you are a member of one of our national ostomy



organisations (Colostomy UK, IA or UA) or through information from your supplier. We are fortunate that we are able to get free surgery, supplies, and professional support, have the right to do what we want to do our stomas permitting (there is even an Ostomy and Continent Diversion Bill of Rights in the United States, advertised in the photo left), and have emotional support from our ostomy groups.

Talking of which, we had a good turnout to our second Dobbies get-together on 20 September. It was a lively morning with plenty of chattering and banter. Some of you got in touch to say for one reason or another you couldn't make it so we hope to catch up with you all at Dobbies on 18 October.

\* \* \* \* \*

### **Stoma care team**

Should you need help at any time, remember that our stoma care team are always available (in the photo from left to right Karen, Grainne, Helen and Elena).

Their contact details are:

**Stoma Care Direct Line: 01908 996951** (an answer machine which is checked very regularly and your call will be returned, but please ensure you leave your name and contact number)

**email: stomateammkuh@mkuh.nhs.uk**



## Transformation

In previous newsletters we have included Jenny's notes from her garden. For our September issue, things are on a much bigger scale as Morag guides us through the transformation that her whole garden has undergone over some years.

Quite an undertaking and not one for the faint-hearted!

*We used to have a beautiful garden with a fern and heather area, a shrubbery and a large rockery with two pools and a waterfall between them. However we decided to have a conservatory built and that meant losing a lot of the garden area.*

*My husband, Graham, took the opportunity to completely redesign the garden space and did all the work himself, despite being in his seventies!*



*In the beginning, it looked like a building site full of rubble and piles of dirt. He divided the garden into two levels – back-breaking work!*

*Then he built lovely, curving walls to hold raised beds.*



*I couldn't wait until he'd finished the garden before putting flowers in. I'm not a great gardener, I just pick plants that I like, dig them in and hope for the best.*



*The next job to tackle was the steps up each side of the garden. Graham built them extra wide so that I'd have room for all my pots and containers (52 to date!).*



*He then laid a patio, giving me full rein to pick the furniture and accessories.*





*He built a log cabin ...*



*and put down decking.*



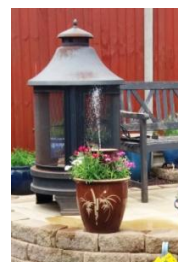
*The final job was to finish levelling the bottom part of the garden so that artificial grass could be laid.*



*Our dog Fudge loves the garden now. No more muddy paws in the bad weather.*



*I added a few more features:*



*I am delighted with the job that Graham did; he worked so hard. Although it took several years, it was well worth the wait. Here are some of my favourite flowers in the garden.*



*Dahlia Purple Gem*



*Fuchsia*



*Verbena with Geraniums and Dwarf Sweet Willam.*



*Dahlia Firepot*



*My last photo is the current view of the garden, including log cabin, patio, raised beds and lawn.*

*Graham has now started on the front garden so I'm looking forward to that being completed.*

## Ostomy research news

William Goodman, a PhD student in the University of Leeds, has contacted us. He is researching into 'well being and confidence in people with a stoma', in particular into what support those with a stoma received, or would like to have received, at the time of their stoma operation. He is looking for volunteers, colostomates and ileostomates (not urostomates, sorry!), to take part in the research. We did ask him why not include urostomates. He says it is related to 'the population we can look at. There is more research amongst colostomates and ileostomates and ... from a research standpoint they are more similar to each other than to urostomates'. He does accept though 'the need for more research amongst urostomates as they are often overlooked'.

In the supplement to this newsletter you will find the details he has supplied, including information on who is eligible and what is involved, what a participant may be asked to do and how your privacy is protected. Please have a read through the material and think about whether you are able and willing to take part. In so far as we can tell the research is ethical and supported by reputable bodies and we ourselves on the committee are happy to participate. For further information or to get involved you can contact the research team direct from the details provided.

We would be interested to hear if any of you do participate so please let us know.

## Brain teasers

- 1 In a year, there are 12 months. Seven months have 31 days. How many months have 28 days?
- 2 What is unusual about the following words: revive, banana, grammar, voodoo, assess, potato, dresser, uneven?
- 3 You are travelling to a village and reach a fork in the road. You can go either way but only one way leads to the village and you don't know which one. You happen to see two men standing at the fork and you can ask them. Unfortunately one of the two men always lies; the other one always tells the truth. But you do not know who is a liar and who is not. You are allowed to ask only the same one question to each of the men. What question should you ask to know the right way to take?

## Book review:

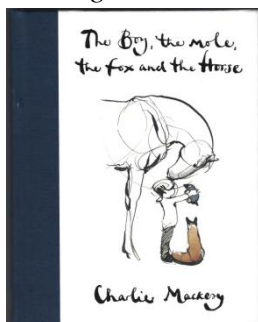
Jenny reviews the book *The Boy, the Mole, the Fox and the Horse* by Charlie Mackesy. Her review and a few images of the pages of the book say it all.

*I was given this book recently by a friend and, as the author recounts in the introduction: 'this book is for everyone, whether you are eighty or eight'. I have heard it described as a 'Marmite' book, in that you either love it or hate it. I am in the former, as are all those that made it a Waterstone's best seller.*

*It is a book that fills the heart and soul with the importance of friendship and kindness, both for others and yourself, as it charts the unlikely friendship forged by the characters in the title. Some critics have described the book as being a collection of motivational quotes held together with illustrations, but it is so well presented and the book's strength lies in its ability to subtly surprise and delight the reader at each turn of the page.*

*The text is hand written in bold black ink, and beautifully illustrated with simplistic pen and ink drawings that encapsulate and enhance the theme of the book. It is a very easy read, especially as there is something to touch the heart on every page.*

**Available:** Kindle edn £8.49; Hardback £16.99, Amazon £9.



'I'm so small,' said the mole.  
'Yes,' said the boy,  
'but you make a huge difference.'



'Sometimes I think you believe in me more than I do,' said the boy.  
'You'll soon catch up,' said the horse.



'Asking for help isn't giving up,' said the horse.  
'It's refusing to give up.'



## Day trips: Canons Ashby, Daventry, Northamptonshire, NN11 3SD



In our August newsletter, we mentioned providing suggestions of places to go within an hour's drive of Milton Keynes and Jenny gave us one suggestion. Lynne takes up the topic now with a different venue, Canons Ashby, and adds a recommended place to end your trip. It is approximately 22-25 miles depending on your route, travelling westwards from Towcester.

*One morning recently a friend and I set off to visit Canons Ashby run by the National Trust. Like me, you may have visited it in the past, but my friend was keen to see the gardens which she knew had had a 'make over'. The previous years of what some may have felt a below-par NT garden had been replaced by beautifully manicured lawns graced with topiary trees, various flower beds of which some seemed almost luminous yellow (calendula I think) surrounded by purple lobelia, not to mention fruit and vegetable terraces.*



*The impressive lion gates and other historical garden adornments were still in place of course and we were particularly entranced by the statue (which I had forgotten about) from 1713 of the young shepherd boy, honoured for his brave actions at the house during the Civil War. Going round the house itself, originally a Tudor farmhouse, we enjoyed viewing its grand halls, servants quarters, tapestries and other artefacts, and because it is not very large we could fit the house into our morning visit together with a browse in the secondhand bookshop. We also visited the church nearby, much of it lost through the dissolution of the monasteries but still with its bell tower intact. Canons Ashby is open every day and there is no advance booking required.*

*After a very enjoyable morning it was time for lunch. Rather than stay at Canons Ashby, we took a short drive through the nearby villages and pretty country roads just a few miles to the west and south-west and chanced to stop at The Red Lion at Culworth.*



*What a delightful place: no booking, great atmosphere, an attractive farm shop ('Barn') with excellent produce and gift items, and most of all wonderful food. I can't recommend it too highly; it was a perfect way to end our day. Check out their opening hours and do go there some time if you can!*

### Humour

The Grim Reaper came for me last night, and I beat him off with a vacuum cleaner.

Talk about Dyson with death.

I was at a cash point yesterday when a little old lady asked if I could check her balance, so I pushed her over.

I went to the cemetery yesterday to lay some flowers on a grave. As I was standing there I noticed 4 grave diggers walking about with a coffin. 3 hours later and they're still walking about with it.

I thought to myself, they've lost the plot!

Statistically, 6 out of 7 dwarves are not happy.

\* \* \* \* \*

If you have any stories, no matter what the topic or the length, or jokes to tell, preferably clean enough for us print, we'd love to receive them. For our October newsletter we need all contributions by/on Tuesday, 19 October latest please. Email or text is easy for us if you can, or please don't hesitate to phone. We are always happy to work with you on any wording and find pictures if that will help.

Best wishes

Jenny, Lynne, Morag, Tim, Tony

MKSSG Committee

**Contact details:** [www.mkssg.org.uk](http://www.mkssg.org.uk) • [mkssg.sec@gmail.com](mailto:mkssg.sec@gmail.com) • 07843-768386 (leave a number for us to call you back) • a closed Face book page (search for the group and request to join)

## **Supplement to September newsletter**

### **Answers to brain teasers in our August newsletter**

- 1 Each of the following words can be rearranged to give a name. What are the four names?  
HURT LONE EVENLY ROMANCE

**Answer:** Ruth, Noel, Evelyn and Cameron.

- 2 Paper plates can be recycled to make new plates. Nine used plates are required to make each new plate. There are 145 used plates.  
How many new plates can possibly be made in total?

**Answer:** 18. Continue using and recycling the plates until you cannot make any more.

- 3 If Sally gives Thomas £3 they will both have the same amount of money. If Thomas gives Sally £3, Sally will have four times as much money as Thomas.  
Who has what?

**Answer:** Sally has £13 and Thomas has £7.

### **University of Leeds Stoma Research Study**

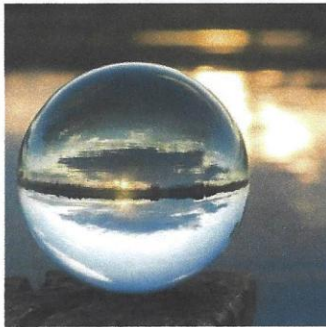
All the pages that follow comprise the information supplied to us by William Goodman.



**UNIVERSITY OF LEEDS**



## **Take part in unique new research for people with a stoma!**



### **Am I eligible\*?**

- Do you have a bowel stoma (ileostomy or colostomy)?
- Are you over the age of 18?
- Do you live in the UK?
- Do you have a smartphone?

Get in touch with our research team below!

### **Our aim**

We want to understand the day-to-day experiences of people living with a stoma.

This is a new approach to research for people with a stoma. Your involvement could feed into the development of support services.



### **What will it involve?**



You will be asked to complete some short surveys on your smartphone over the course of a week and may be invited to an interview afterwards. You will be asked about how you are feeling, your confidence, and if you are having any problems with your stoma.

For completing the surveys, you will be offered a £10 Amazon gift voucher.

## **This is your chance to have your voice heard**

If you would like to take part, or wish to find out more, please contact a member of the research team:

William Goodman – [umwdg@leeds.ac.uk](mailto:umwdg@leeds.ac.uk)



Please feel free to contact us on Twitter for further information: @WillGoodman23

\*If you are due to have surgery soon you MIGHT not be eligible. Please contact the research team to discuss.

## ***Participant Information Sheet***

### **Understanding day-to-day well-being and self-management practices in people with a stoma**

You are being invited to take part in a research project for people with a stoma. This study is being carried out in part fulfilment of the PhD for William Goodman. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the project?**

We do not currently understand how people with a stoma manage their stoma on a daily basis, and if this affects their well-being. Therefore, over the course of 7 days we aim to find how individuals manage their stomas day-to-day, and how their well-being and confidence changes throughout the day. This study will provide us with a better understanding of people's real-life experiences, which may help to improve the care for people with a stoma in the future.

#### **Why can I take part?**

You can take part in this research because you currently have a bowel stoma, are over the age of 18, are not having any surgery within the next two weeks and have a smartphone. We are recruiting 100 people to take part in this research and will invite 30 of these to take part in a feedback interview to give more detail on their responses over the course of the 7 days.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time. You do not have to give a reason.

If you are asked to take part in an interview, you do not have to take part and you can stop the interview at any point, for any reason.

#### **What do I have to do?**

You will be asked to complete a short questionnaire to gather data on your demographic and clinical characteristics (e.g. age, gender, type of stoma). You will then be asked to download an app (Ethica Data) to your phone. Once you have signed up to this app then it will prompt you 3 times a day, for 7 days to complete a short survey on what you are currently doing and how you are currently feeling. We would also ask that if you have any problems with your stoma (leakages, pain, ballooning, pancaking, skin irritation, dehydration, or anything else) then you complete a quick self-report survey at a convenient time for you within the app. You can complete this as many times as are needed. There will also be a brief exit survey at the end of the 7 days. Apart from completing the surveys you should just go about your normal life.

At the end of the 7 days you may be asked to take part in an interview with the lead researcher over the phone or online via Microsoft Teams. This will be to get a more detailed understanding of why the data you provided over the 7 days may have changed in different situations. Also, we would like to get a sense of the support you would have liked to have received post-surgery and if there is any support you would like to receive at this point and in what form this would come in. You are also free to delete the app after the 7 days.

#### **What are the possible disadvantages and risks of taking part?**

There are minimal risks involved in taking part in this study. Taking part may raise some questions about your stoma. If this is the case then we recommend that you contact either your stoma care nurse or your GP, otherwise you can use the links below to the Bowel Research UK, Colostomy UK or the Ileostomy and Internal Pouch Association websites for more information [for MKSSG members contact MKSSG].

#### **What are the possible benefits of taking part?**

If you take part in this research and complete 80% of the prompted surveys, then we will provide you with a £10 Amazon gift voucher for taking the time to complete these.

Furthermore, it is hoped that this work will provide researchers with a better understanding of people's real-life experiences, how we might improve these in the future and feed these findings into the development of support services.



## **Use, dissemination and storage of research data**

All the contact information that we collect about you during the course of the research will be kept strictly confidential and will be stored separately from the research data. This will be retained until the end of the study in case we contact you to take part in an interview after the surveys, after which it will be deleted. We will anonymise the research data so that you will not be identified in any reports or publications. The data is likely to be published in peer reviewed journals and used in conference presentations.

Once the study is completed anonymised survey data will also be uploaded to an open science database for use by other researchers in the future.

If you decide to withdraw from the study then your personal, identifiable information will be deleted immediately. Any survey responses you have provided, or the interview transcript will be retained completely anonymous under the principle of 'public task', whereby the data is retained in the public interest as scientific research.

## **What will happen to my personal information?**

Your personal information will be kept entirely confidential in a password protected folder on University of Leeds servers. While the study is ongoing you will be pseudonymised, which means that you will be given a study ID number which will link your personal information to the survey data and interview recording you provide. Once the study is completed all of your personal information will be deleted and your data will be completely anonymised.

For more information on what will happen with your data please see the "Research Participant Privacy Notice": <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>

## **What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?**

In the surveys we will ask questions related to your (age, sex, type of stoma, how long you have had this), your current context (where you are and who you are with), how you are feeling at the moment, how confident you feel in managing your stoma at the moment, if you are having any problems with your stoma, and how you are managing these. In the interview we will ask questions related to the data you provide in the surveys, and what your thoughts are around different types of support to help you manage your stoma.

## **Will I be recorded, and how will the recorded media be used?**

If you are invited to take part in the interview, then you will be recorded. This audio recording will be saved in a password protected folder on the University of Leeds servers. The recording will be sent to an approved transcription company to be transcribed, upon receiving this back the recording will be deleted. Quotes may be used in published papers or for conference presentations, but every measure will be taken to ensure that these cannot be attributed to you.

## **Who is funding the research?**

This research is funded by an Economic & Social Research Council White Rose Doctoral Training Partnership Studentship.

## **Contact for further information**

For advice or any problems regarding the study contact:

William Goodman Email: [umwdg@leeds.ac.uk](mailto:umwdg@leeds.ac.uk); Telephone: 0113 343 2223

If you have any problems or complications with your stoma during the study, then seek advice from your GP or your stoma care nurse.

If you have other questions raised about the functioning of your stoma [for MKSSG members again seek advice in the first instance from your GP or your stoma care nurse] or for additional support [for MKSSG members contact MKSSG] contact one of the following charities:

Bowel Research UK

<https://www.bowelresearchuk.org/>

Colostomy UK

<http://www.colostomyassociation.org.uk/>

Ileostomy & Internal Pouch Association

<http://www.iasupport.org/>

Thank you for taking your time to read through this information sheet and considering taking part in our research.