Wessex Stoma Support Group
Supporting ostomists with Colostomy, Ileostomy, Urostomy & Mitrofanoff

Celebrating 10 Years
2006 - 2016

See inside for further details

www.wessex-stoma.co.uk

Supported By
Secretary’s Welcome

Hi readers and welcome to your first Newsletter of 2016 - the Spring Edition. We have a few of the membership who are unwell at this time, and our thoughts are with all of them as they recover. Of course, the Group is always around should anyone need our help, or just someone to talk to. We are happy to come and visit anyone who is unfortunate enough to need a hospital stay. Just get in touch.

Well, we have a very exciting few months ahead of us, starting with our Full Meeting on the 4th March with two guest speakers and seven companies with tables exhibiting their latest products. I look forward to seeing you there. This is closely followed by our Easter Fair, once more being held at the Wilton Community Centre, on the 19th March and always a popular date in the calendar. This is followed by, I think, our most exciting event of the year. It is, of course, our 10th Anniversary on Saturday 23rd April, when we are putting on a patient day with guest speakers, suppliers and the national organisations turning up to help us celebrate our first 10 years of helping and supporting our fellow Ostomates. Then on Wednesday 4th May we are heading across the border into Wales to visit our sponsors Pelican Healthcare and if it lives up to the previous visits we made to Fittleworth in Littlehampton and Salts Healthcare in Aston (Birmingham) we will have a great day.

Now just a quick look back to our Christmas meal on the 4th December which I am afraid to say on listening to the feedback was a bit of a disappointment compared to previous years with regards to the venue and service. Oh Well! This year we will try a different venue. And what can I say about the Pantomime at Salisbury Playhouse? Brilliant, Marvellous, Majestic!! The Pantomimes just keep getting better every year, long may it continue to do so.

Have a great Easter everyone and I hope to see you at our upcoming events this year. An awful lot of hard work and time is put into organising all of the events throughout the year so please do come along and enjoy and support the different events. We are always pleased to see you.

Michael Slater - Secretary

Chairman’s Message

Well, spring has sprung a little early this year and Easter is almost upon us. The flowers in the garden are lovely even though they are early.

I am currently working with the Colostomy Association to help promote Stoma Aid and going to give talks at Rotary and Round Table groups to create awareness of Stoma Aid in the hope of getting some funding and also promoting Wessex Stoma Support Group at the same time.

We have a lot of activities in the next few months with the Craft Fair, the 10th Anniversary Celebration Patient Day and a visit to Pelican, plus all our normal meetings. So there is plenty going on. I have made my piece short this time and ask you to note all these upcoming events and support us.

I wish you all a Happy Easter. And with the nights drawing out we can get out and get some much-needed spring air.

Ken Edwards - Chairman

Easter Craft Fair

19th March

Wilton Community Centre

10am – 3pm
Case Study Award

Winners of the Case Study Award, and a donation to their Department of £250, were a team from Salisbury NHS Foundation Trust. Stoma Care CNS nurses Sandra Bryan, Suzie Dukes and Michelle Boucher presented a remarkable case study, charting the recovery of a lady who was mis-diagnosed as having dementia, a recovery brought about by the simple remedy of regular Vitamin B12 injections. Their study was published in the British Journal of Nursing in 2015: “Deficiency or dementia? Exploring B12 deficiency after urostomy”,

Summary of 'Deficiency or dementia'

The case study described how a urostomy patient, who was well known to the stoma care department, developed a vitamin B12 deficiency that was misdiagnosed as dementia. The patient was a lady who had a urostomy formed due to bladder cancer some years previously, and had been seen regularly in our follow up clinics. She was admitted to the hospital for routine surgery to repair a parastomal hernia, but when we visited her in the days following her operation it was clear that she was not her usual self. She was unable to walk without help, and was a little “muddled” and emotional. The hospital doctors were unable to find anything specifically wrong with her and she was discharged in the hope that she would improve when she was back in her own home surroundings.

A few days later she was readmitted to the medical unit with what was thought to be a urinary tract infection (UTI). Her husband informed us of her admission and told us that she was quite confused. On visiting and assisting her with her stoma care we noted she was not the lady we knew, despite the successful treatment of her UTI. We spoke to the medical staff about this and a multitude of tests and interventions were performed to identify the cause. It was very distressing to our team who knew her well to witness her decline physically and mentally over the next few weeks, and her family were obviously also distressed. She was no longer able to get out of bed alone, eat or drink independently, or communicate easily. Eventually vascular dementia was diagnosed, and because of the downturn in her health, her family were given the terrible prognosis that she had only weeks to live.
After this news had been given, it was eventually identified that she had a low level of vitamin B12, and so she was prescribed B12 injections. This was thought to be an incidental finding and not related to the “dementia,” but in fact once treatment had been established she went on to make a remarkable recovery. In time she went on, from being unable to care for herself or to walk or move unaided, to become fully independent, and she was eventually discharged to continue lifelong supplementary B12 therapy. This experience highlighted to the stoma care team that vitamin B12 deficiency can cause significant morbidity in patients who have had a portion of their small bowel (ileum) resected for creation of an ileal conduit/urostomy, and that symptoms of the deficiency can be misdiagnosed or not looked for in the first instance. This led us to find out more about vitamin B12 deficiency in order to increase our own knowledge, and also to help raise the awareness of other healthcare professionals and patients about this. We found that the risk of developing B12 deficiency increases with time following formation of a urinary stoma, becoming a more significant risk after five years. As stoma care Clinical Nurse Specialists, we are now more proactive in asking GPs to investigate this as a possible cause if we see patients displaying dementia symptoms in our follow up clinics, either in the hospital or GP surgeries. Symptoms can include pins and needles in hands, legs and feet; balance problems and difficulty walking; anaemia; sore tongue; jaundice; difficulties with memory and understanding; paranoia and hallucinations; and weakness and fatigue. Of course these symptoms can also be present for other reasons, which demonstrates the importance of asking your GP for a blood test to check your level of B12 if you are worried about symptoms you may be having. Treatment is inexpensive and simple consisting of regular B12 injections. Our patient’s experience was very distressing to see, both for her and her family, and for us too, but there have been positive outcomes in terms of what we have learned from the situation, and the way in which we are now able to raise awareness of B12 deficiency as a late onset complication of urostomy formation.

Sandra Bryan, Suzie Dukes, Michelle Boucher

Ruby’s Recipes

Roosa-Manna

Ingredients
300ml redcurrant juice
150g sugar
75g semolina
Redcurrants for garnish

Method
Pour juice into a saucepan and add 300ml water & the sugar. Bring the liquid to the boil. Sprinkle in semolina while stirring continuously. Cook for a couple of minutes. Cool the mixture for 5-10 mins by placing pan into sink filled with cold water. Whip with a hand whisk until light & fluffy and pour into dessert bowls of glasses. Serve with cold milk poured over top & garnish with redcurrants.

Recipe submitted by Jean Slater
Who are we?

Healthwatch Wiltshire is an independent organisation which has an important role in assessing the quality of local health and social care services today and influencing the design of services for tomorrow. We want to make sure that the people who use these services have a say in how they are shaped and that their overall views and experiences are heard and taken seriously.

What do we do?

- Listen to your opinions and experiences of health and social care services
- Feedback your views to the people who make the decisions
- Provide effective signposting and information
- Independent from the NHS, Local Authority and other health and social care services so people can talk freely about whatever they like

We want to hear from you....

Healthwatch Wiltshire is out there talking and listening to people of all ages, working towards changing Wiltshire services for the better.

To have your say, volunteer or for more information please contact us:

Healthwatch Wiltshire
Unit 5 Hampton Park West
Melksham SN12 6LH
01225 434218
info@healthwatchwiltshire.co.uk
www.healthwatchwiltshire.co.uk

We want to know what you think about:

- Hospitals
- Doctor’s Surgeries
- Care Homes
- Dentists
- Home Care Services
- Mental Health Services
- Opticians
- Pharmacies

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Kenneth Antony Edwards. Born in Salisbury brought up educated in Salisbury. Attended St Edmunds Church as a choir boy, bell ringer, and server. Took a liking to the stage at an early age appearing in pantomimes for various groups and singing around the town to various groups and talent shows. Wanted to be a pop singer and in his teens joined a local group, performing throughout the South. Also travelling to London for Stage and TV grooming.

Married his wife Pam in 1964 while working for Moss Bros. They moved to Kingston upon Thames in 1967 with Moss Bros Ken was responsible for the windows in Covent Garden store and other stores in the London area. In 1971 they moved back to Salisbury, and Ken took to look after stores in the South of England.

Following their return from Kingston, Ken got involved in politics and served on the District and County Council, serving as Chairman on many committees. 1979/80 he was Mayor of Salisbury and for his Mayor’s Appeal raised over £20,000 for an ambulance/bus for the local Multiple Sclerosis branch which he had been in for a number of years. Ken regularly drove the bus picking up members for social events and taking them on holidays. He is a vice president of the branch. In 1994/95, he was Chairman of the District Council, Ken served for some 25 years on the Council, during which he was also a full time national political agent running by-elections and dealing with the press and television nationally.

Ken also continued his involvement with the clothing trade starting with Chas H Baker in 1984 and joined the management team, working nationally with the Independent Schoolwear Association and Strictly Formal, the National Association for formal hirewear, as well as modelling at a number of fashion shows locally and regionally.

In 2007, he was diagnosed with bowel cancer which had spread to the prostrate. Following chemo and radio therapy, he had surgery in 2008. Having a Colostomy and Mitrofanoff, not knowing anyone else with a Mitrofanoff and finding Kyla Rogers another Mitrofanoff patient, he helped her set up Mitrofanoff Support, becoming National Chairman in 2013, travelling the country to create awareness. He stepped down in 2015 after building a strong board to run the group though is still involved in the background. He joined the Wessex Stoma Support Group in late 2008, becoming Chairman in 2010. He is also Chairman of the Three Swans Surgery Patient Participation Group and continues his civic involvement as Chairman of the St Edmunds Community Group.

Remember...This is YOUR Newsletter

Would you like your profile in your Newsletter? Would you like to share your stories with our readers? Just send your ideas to the Editor at wessex.stoma@yahoo.co.uk or post them to:

The Editor, 55 Wishford Road, Wilton, Salisbury, Wiltshire, SP2 0JG.

For more information about anything you have read in this Newsletter please call 01722 741233.

You can write anything to us and we may publish it. Hints, tips, stories, jokes, recipes, interesting observations. Anything at all.
Poetry Corner
Poem by Kathleen Allen

Bouquet of Friendship

Accept this basket filled with flowers
Picked especially for you.
From my colourful springtime garden
In the early morning dew.

The message, a simple thank you
On you I can depend,
To share my many problems with
You’re a jewel, and a friend.

You bubble forth with kindness
Lend a sympathetic ear,
With countless issues of your own
So we often share a tear.

But laugh a lot we also do
Whenever we have a chance
A true and lasting friendship
My life you do enhance.

Contact
For further information about getting involved with
the running of the Group – or anything featured in
your newsletter, please contact the Secretary,
Michael Slater, on the details below.

Secretary – Michael Slater
Phone: 01722 741233
Address: 55, Wishford Rd., Wilton, Salisbury,
Wiltshire, SP2 0JG
Email: wessex.stoma@yahoo.co.uk

Remember, you can also ‘Like’ us on Facebook and
keep up with everything that is going on!

Kid’s Wit

TEACHER: Donald, what is the chemical formula for water?
DONALD: H I J K L M N O.
TEACHER: What are you talking about?
DONALD: Yesterday you said it’s H to O.

TEACHER: Maria, go to the map and find North America.
MARIA: Here it is.
TEACHER: Correct. Now, Class, who discovered America?
CLASS: Maria.

By Arthur
On 9 January 2016, I had the pleasure of attending the support group meeting to talk about the services that Irwin Mitchell offer.

Irwin Mitchell is over 100 years old and is one of the largest law firms in the UK. There are offices in Birmingham, Bristol, Leeds, Middlesbrough (consulting office), London, Manchester, Newcastle, Sheffield and new offices in Southampton and Cambridge which opened in 2014.

The firm is consistently involved in many of the most important personal legal services cases on behalf of its clients and the independent Legal 500 2013 UK report ranks Irwin Mitchell as number one for Clinical Negligence, Personal Injury, Travel, Product Liability, Family, Court of Protection and the Public Law team’s education expertise.

I gave a presentation about the services that are offered in our Southampton office, which include Serious Injury, Medical Negligence, Armed Forces, Asbestos Related Disease, Court of Protection and Family. This also included some case studies, (which I hope everyone found interesting!) and some information about our Client Liaison Manager Services, which is there to help and support our injured clients and help them gain access to the services they need.

Everyone at the meeting was very friendly and welcoming and I had a very enjoyable afternoon. Thank you for having me.

Rebecca Brown  
Solicitor  
Irwin Mitchell  

Email: Rebecca.Brown@Irwinmitchell.com  
Phone: 02380 930708

Our next meeting is: 4th June 2pm – 4pm at the Bob Blandford Memorial Hall, Wilton
10th Anniversary Celebration

On 23rd April, we will be celebrating our 10th Anniversary with a very special Patient Day at Wilton Community Centre from 10am – 4pm. Anyone who has a stoma, is having stoma surgery, or knows someone with a stoma, is very welcome to attend on the day.

The day will include chances to look at the products of various suppliers and chat with their reps, speakers on various phases of stoma surgery and care, talks from stoma nurses, and all with a chance for questions and answers after each session.

If you would like any further information, please call 01722 741233 or email wessex.stoma@yahoo.co.uk

Agenda for the Day

10.00 am   Registration - visit Exhibitors
10.30 am   Welcome and introduction by Chairman
10.45 am   Talk by Consultant Urology/Colon
11.15 am   Coffee Break
11.30 am   Talk by Stoma Nurses
12.00 noon Question and Answer session with Consultant/Nurse
12.30 pm   Lunch – visit Exhibitors
2.00 pm    Talk by Consultant Urology/Colon
2.30 pm    Talk by Stoma Nurse – Prescriptions
2.45 pm    Question and Answer session with Nurse
3.00 pm    Tea Break – visit Exhibitors
3.15 pm    Cutting of Birthday Cake, Raffle
3.34 pm    Chairman’s Thanks
4.00 pm    End
Introducing...

Platinum Convex experience freedom in your second skin

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- Soft and breathable fabric
- Advanced waterproof filter system
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For complimentary samples call us now on 0800 318 282
All convex pouches should only be used after consulting your stoma care nurse.

pelicanhealthcare.co.uk