Summer 2009 | Issue 14

colostomy association

Tidings

Dedicated to Colostomates their Families and their Carers

inside...

Open Door
dedicated to
stoma care
Christine Hyde
RGN/CNS
The Hillingdon
Hospital Middlesex

Aspects of
medical treatment
Pat Black writes
about...**Prolapse**

Health
Support Garments

plus...
- **Readers' stories**
- **Dear Nurse**
- **Your letters**

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SenSura Click and **SenSura** Flex are not available in the Republic of Ireland.

SenSura

Coloplast

welcome to SUMMER

Sue Hatton pictured with Mr Brendon Moran - Colorectal Director, and Consultant Surgeon at the Basingstoke and North Hampshire Foundation Trust.

The Colostomy Association goes to Coloproctology Conference...

The Association attended this year's Coloproctology Conference at Harrogate - in order to raise awareness about the work of the charity to attending colorectal surgeons and stoma care nurses.

A big thank you to Coloplast who sponsored the CA exhibition graphics, furniture and literature and to Dansac who sponsored the accommodation for Sue Hatton and Jane Wood and the prize for the draw, a case of Champagne!

The event was a great success enabling the Association to "reach out" to colorectal surgeons and stoma care nurses from all over the UK and the World!

Prize Draw Winner...
The case of Champagne goes to:-

Ms Elizabeth Paling
Deputy Sister
Nottingham University
Hospital NHS Trust

"Summer afternoon - Summer afternoon...the two most beautiful words in the English language." - Henry James

At present we are lucky enough to have beautiful blue skies and warm summer sunshine, dare I say hot!

It's amazing how quickly the weeks and months go...as soon as one calendar event like the London Marathon or the Boat Race comes round we're on to the next, Ascot, and now Wimbledon!

Here we are again with another packed issue of Tidings! In this summer issue we have a feature on support garments which, I'm sure, will be of interest to you all. Open Door visits the Hillingdon Hospital NHS and interviews Christine Hyde who was just eighteen when she began her career as a student nurse in the 1960's. Christine tells Tidings about her experiences and is passionate about passing on her knowledge to the next generation of stoma care nurses.

Bob Buckley (volunteer) and Ernie Millington talk about exercise and tell their stories, which make fascinating reading. Professor Gordon Williams MS FRCS Medical Director of the Addis Ababa Fistula Hospital gives us an insight into the history and work of the hospital - and appeals for spare stoma care supplies for the hospital. You can also catch up on what's happening on World Ostomy Day, which is coming up fast - 3rd October 2009! Perhaps you are already organising an event. Please write and let us know how it goes!

A big thank you to all of you who sent in donations and feedback in response to the outer wrap on the last issue of Tidings - Fantastic!

I would also like to take this opportunity to mention the £10,000 CA Appeal - perhaps you can think up ways of helping us raise funds for some of the following:-

- Publicity Materials
- Volunteer Support Materials
- Patient Literature
- Professionals Literature
- Computers and software

Please keep your letters and emails coming. They are so important and I can assure you that each and every one is read; we try and respond to all.

Look out for our Freepost envelopes - the Association wants to make it even easier for you to get in touch. So, as a trial, we are randomly inserting 1000 Freepost envelopes into this print run - so pens at the ready if you are lucky enough to receive one! If this trial is successful, Freepost envelopes will be made freely available.

As always I would like to encourage you to get involved with Tidings - YOU make it what it is - YOUR magazine!

Jane

Email:
editor@colostomyassociation.org.uk

Readers' Panel - Any reader who succeeds in having an article, top tip or particular topic featured in Tidings will see this acknowledgement.

Reader PANEL contributor

inside

contents

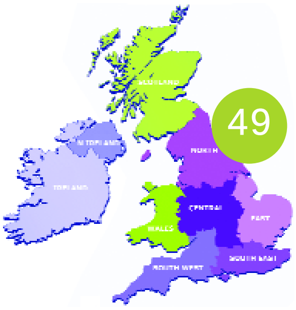
Kind thanks to all who have contributed to this issue of Tidings.

WORLD OSTOMY DAY 3rd October 2009

Tidings is YOUR Magazine...

Editorial Submissions:
We welcome your contributions to Tidings - if you have a story, article or letter that you would like featured in the magazine we would like to hear from YOU!

If you have an idea for an article and would like to discuss this with the Editor or would like help writing your



story please get in touch. Tidings is also interested in commissioning articles please contact the Editor.

We will always do our best to include your contributions in the next issue of Tidings or will hold them back for a future issue. When submitting your information don't forget to supply your name, address, phone number and e-mail address if you have one.

Please include any relevant photos or illustrations as these really help to bring YOUR magazine to life! You can send these as prints or digital images.

Supply of digital images:
When supplying digital images for inclusion in Tidings please try to observe some or all of the following criteria;

- Images should be in RGB mode
- Images should not be less than 2480 pixels x 1772 pixels at 300 pixels per inch (equal to 21cm x 15cm).
- File sizes not less than 10Mbytes uncompressed
- Images compressed in JPEG format.
- For scanned images please set at 300 ppi in RGB mode and scan original @100%.

Feedback... We are always trying to improve your Magazine and welcome your feedback. Enjoy this edition of Tidings we look forward to bringing you the next edition...

colostomy association

About...
the Colostomy Association

The Association represents the interests of colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

The Colostomy Association is a charitable company limited by guarantee
(Registered Charity No: 1113471).

How to get to in touch...

By post:
Colostomy Association
2 London Court,
East Street, Reading RG1 4QL

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Helpline: 0800 328 4257

By E-mail:
cass@colostomyassociation.org.uk

How to become a member of the Colostomy Association...

Simply visit our **website** and **register** at:
www.colostomyassociation.org.uk
or contact
General Enquires:
0118 939 1537 for more information

Tidings Magazine Autumn Edition advert booking space by 28 August copy by 7 September publication October

How to contact the Editor

Write to:
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East Street Reading
Berkshire RG1 4QL

or e-mail:
cass@colostomyassociation.org.uk

or e-mail the editor direct:
editor@colostomyassociation.org.uk

Advertising Enquiries
For advertising enquiries and media pack
Tel: 0118 983 6226

Enthusiasm...dedication and generosity drives the CA forward

Summer at last! - I never thought I would be so pleased to have a huge thunderstorm and my lovely garden (and me) breathe a huge sigh of relief and for me to feel no guilt at being in front of the computer instead of propping up wilting flower beds!

I am mastering the art of finding inexpensive ways of getting around the country. I have been surfing the web for good deals and propelling myself from one end of a terminal to another. The ultimate goal being to raise awareness and support for the work of the charity from those working in stoma care - healthcare professionals and industry - the rewards have been immeasurable!

On my travels I have met so many wonderful people. I have been gratified by the enthusiasm of our new volunteers, impressed by the dedication of colorectal surgeons and stoma care nurses and with the ongoing generosity and good will of the stoma care companies.

Our greatest achievement this year has been to devise and pilot several training programmes. Volunteers - Bob Buckley, Jean Scott (an ex-teacher who has run our Helpline for many years) and Vice-Chairman of Trustees Ernie Hulme must be congratulated for all their hard work and for making each training day a success! We want those of you who are willing to help us, help other colostomates, to get involved. We will be reporting on these programmes fully in the next issue when we have analysed all the feedback! Thank you all for being so positive and for those volunteers that feel you are being underused at this time, please bear with us!

Our thanks go to Coloplast who have offered to support all our training events and have sponsored a recent awareness drive at the Coloproctology Conference in Harrogate. We would also like to thank CliniMed for hosting one of our training pilot days and Dansac for their assistance with a number of promotional projects. I am currently discussing and negotiating funding for research into Rectal Pain and Irrigation, as well as trying to take the Colostomy Association into Southern Ireland.

CA Open Day - The Liberty Stadium, Swansea - 10th September

We are really looking forward to hosting a great Open Day! We want this to be the first of many regional Open Days that the CA take around the country and with the help and support of the stoma care companies we will!

The Swansea Open Day in September will begin at 12:30pm and includes workshops on different stoma care related topics, plus manufacturers displays and a presentation from Lynn's Bowel Campaign finishing around 7:30pm.

Please come and meet all of us, and let us know what we can do to help you!

Sue

Sue Hatton
Executive Trustee
Colostomy Association

Introducing Richard...New General Manager at CA

Richard Bray (far right) pictured with his family

I would like to take this opportunity to introduce myself; I have recently joined the permanent staff of the Colostomy Association as the new General Manager.

I started my working life in the motor racing industry as an engineer, travelling the world and meeting some very interesting people.

In 1974 I joined the Grundon Group of Companies. This was to be the start of a long career in the Waste Industry and remained with Grundons as the Operations' Director for twenty years.

I then moved to Hampshire Waste Services, based near Winchester. Our Company won the largest waste recycling and processing contract ever awarded (processing 1 million tonnes of waste per annum!) in the UK. Following this I spent three years working for a Dutch company based in Basildon, Essex, processing and recycling white and electrical goods.

For the past twelve months I have been working as a Consultant on the processing of waste to produce green energy.

I live in Streatley-on-Thames with my wife Jan. We have two daughters, Charlotte and Georgie and a five-month-old grandson called Alfie.

I was diagnosed with Crohn's disease at the age of 25 and persevered with various drugs and treatments until just after my 35th birthday when I was finally forced to have it all removed. Over the next five years I had about seven operations at the John Radcliffe Hospital near Oxford. My only regret is not having had surgery earlier as it has really improved my quality of life.

I look forward to meeting you all in the near future.

Regards,

Richard Bray
General Manager

Fundraising is an immensely **important source of income** for the **Colostomy Association**...as we rely solely on donations to continue our work of **giving support to colostomates...**

Your FUNDraisers...

Coffee Morning

I held a coffee morning last week and have halved the proceeds – one half to you and the other to Acorns. Please accept our donation £140.00.

Yours faithfully
RG (Mrs)
Birmingham

Notelets - designed!

Bill designed and sold his own notelets featuring his church Sanctuary Flowers on the cover.
Bill Watson sent in a donation of £80.

To the Editor

In 2008, I made a decision to raise funds for the CA. So with the help of my friend Jasmine Glencross, we made jam, pies and crumbles. So please accept my donation of £200. Thanks to all those connected with putting the magazine together - long may it continue.

Yours sincerely
M M
Hull

Thank you for your kind donations

Dear Colostomy Association

At our Annual Christmas Dinner in December 2008, our Mothers' Union raised money through running a raffle and it was decided in the last meeting to donate the proceeds to the 'Colostomy Association'. Therefore please accept our donation of £40.00 towards a very worthy cause.

Yours faithfully
Mrs WVAB
Pencader

A BIG thank you to Oliver Carne and his Cornish garden..

Bank Holiday Monday June 4th was a perfect day in the village of Constantine. Oliver Carne a beloved member of the community opened his six acre garden. The event raised over £2000 for Macmillan Cancer Support, £800 of which Oliver kindly donated to the Colostomy Association. Oliver and Sue Hatton are great friends, and he was delighted to help raise funds and awareness for the CA. Oliver, now 80 has raised thousands of pounds for charities over the years.

Tell us more about your fundraising events...for CA

Lisa Tubbs jumps for CA...

Lisa Tubbs featured in Tidings Autumn Issue 11 - decided to do something out of the ordinary, a tandem skydive! "It was something I would have never contemplated before and the only way to make sure I would go through with it was to do it for charity, I raised over £350 for the CA". It was one of the most amazing experiences of my life and one I can't wait to enjoy again!
Lisa has also become a CA volunteer we will be following up her story in the next issue of Tidings.

£10,000 CA Appeal

Dear Colostomy Association

The committee of MORS (Men of Rose St) met recently to decide on the disbursement of funds to local charities. At the request of Mr Bill Watson we have agreed to support the Colostomy Association Appeal, please accept our donation of £100 for this purpose.

Yours sincerely
Dr. DNS
Reading

Lucky winners 500 Club

Anonymous	£20.35
Anonymous	£40.70
Anonymous	£40.70
Mrs Ball of Southport	£40.70
Mrs Denton of West Bridgford	£20.35
Mrs Hensman of King's Lynn	£81.40
Mr Herpe of Oxted	£81.40
Mr Pratley of Hampton	£203.50
Mrs Vickers of Redcar	£407.00
Mrs Wright of Salisbury	£20.35

There are still a few more place left in the **500 Club** - why not join in you could be on list next time!

Donations - In memory

Diane Sybil Burchett	£210.00

Donations - Legacies

Mrs Brenda Meggison	£1035.40
Ethel Sheppard	£6699.25
Mrs Gerda Czajko	£1000.00

Help us to raise funds for the following:-

- **Publicity Materials**
- **Volunteer Support Materials**
- **Patient and Healthcare Literature**
- **Professionals Literature**
- **Computers and software**

Please mark your donation CA Appeal - thank you

Taking a look at....
World Ostomy Day 2009

WORLD OSTOMY DAY
3rd October 2009

World Ostomy Day 2009 (WOD 2009) will take place on 3rd October 2009.

The theme for **WOD 2009** is **"reaching out"** the idea behind the day is to **raise awareness of the part Ostomates, Ostomy Associations, Support groups and Health professional organisations play in the rehabilitation of Ostomates in the general community.**

Kind thanks go to Peter McQueen for supplying the background information for this article about WOD2009

Peter McQueen
WOD 2009 Co-ordinator
World Ostomy Day

E-mail:
peter_mcqueen@optusnet.com.au

About WOD 2009

Promoting World Ostomy Day is an ideal forum to let the general community know what needs and aspirations Ostomates have.

"Reaching Out" - the theme for WOD 2009 suggests ostomates from all walks of life reach out to help others and in doing so help to educate their local communities to understand the needs and aspirations of ostomates and their families.

What are the aims of World Ostomy Day 2009

The aim of World Ostomy Day is to improve the rehabilitation of ostomates worldwide by bringing to the attention of the general public and the global community:

- **The life situation of ostomates**
- **The contributions of Ostomy Associations and Ostomy Professionals**
- **The value of the multidisciplinary approach in ostomy care - teamwork**

Coloplast will be promoting **World Ostomy Day 2009** by re-introducing the **"Coloplast Merit Award"** - the aim of the award is to encourage the spread of enterprising initiatives of National Ostomy Associations to other member Associations throughout the world.

There will be three regional contests:
- **Europe**
- **The Americas**
- **Asia & South Pacific**

Entries will be accepted from Member Countries of IOA and prizes will be given, there will also be three encouragement awards.

Some of the suggested activities to promote awareness follow:-
- educational programmes, seminars, support meetings and demonstrations/displays,
- electronic information networks,
- newspaper and magazine announcements, advertisements and articles,
- publication of informative handout materials and brochures,
- audio and video announcements and films,
- lobbying activities, official Government proclamations and joint activities with allied agencies and professional health organisations.

As part of WOD 2009 there will also be an **International Photographic Competition** sponsored by **Hollister** called **"The World Ostomy Day Photo Contest".** The theme of this competition is to indicate that having a stoma does not stop ostomates leading a full and active life.

Entries for the competition will be accepted from ostomates or non ostomates but must show ostomates being involved in some activity or other.

Entry forms and criteria including closing dates and where to lodge entries for both competitions are available on the IOA Website: www.ostomyinternational.org

Joint initiative for World Ostomy Day 2009

The CA is working as part of a joint initiative with the other patient organisations IA and UA on a National Awareness Campaign here in the UK. The advert opposite is part of this campaign.

There will also be promotional events taking place during September in shopping malls in - Belfast, Manchester, Glasgow and culminating in Birmingham on Saturday 3rd October.

Pin badges will be available soon.

For further information, please contact the office on:
0118 939 1537

World Ostomy Day
Saturday 3rd October 2009

you can make a difference

World Ostomy Day takes place every three years, this year it is being celebrated on the 3rd October 2009. The worldwide campaign in the lead up to this day is designed to raise awareness by highlighting to the general public and global community the challenges faced by Ostomates, their courage, needs and aspirations. This year's theme is "Reaching Out".

For more information visit: www.ostomyinternational.org/WOD2009.htm

Pin badges are available from the Colostomy Association for a small donation.

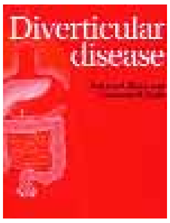
For more details contact: 0118 939 1537

WORLD OSTOMY DAY
3 OCTOBER 2009

colostomy association

dedicated to stoma care Christine Hyde RGN
colorectal nurse specialist
and team player in the hospital and the community

Tidings hit the road again… and what a day it was, blue skies, warm summer sunshine and light traffic on the M4 - incredible! As part of our Open Door series Tidings was invited to meet Christine Hyde RGN and Colorectal Nurse Specialist at The Hillingdon Hospital, Middlesex. Christine has written many articles and also co-authored a book with her friend and colleague Pat Black entitled Diverticular Disease.



Editors Comment

A big thank you to Christine for opening the door to Tidings, for giving up her own time and for sharing her story with us. Watch this space as Christine has agreed to work on more articles with Tidings in the future.

Tidings interviews **Christine Hyde** - an experienced and caring member of the Specialist Nursing Team - Hillingdon Hospital

Arriving at Hillingdon Hospital NHS around mid morning the place was buzzing with activity, just what you would expect from a busy NHS Hospital. The sliding doors of the foyer opened to reveal a frenzy of patients, visitors and staff all walking in different directions. Stepping up to reception Tidings was met by a very friendly hospital volunteer and was booked in as a visitor by an equally friendly and welcoming receptionist. Directed to the seventh floor, Jersey ward - Tidings was taken by a member of staff to the Colorectal and Stoma Specialist Nursing Team offices, was greeted with a warm welcome and a coffee, then it was down to business…

Christine Hyde was just eighteen when she began her career as a student nurse in the 1960's. Once qualified, she worked in the Gastroenterology Department at the Central Middlesex Hospital (headed by Sir Francis Avery Jones – a physician with a special interest in gastroenterology). Stoma care nursing was in its infancy at this time and appliances were few and basic. Skin care and accessory products as we know them today were almost non-existent.

Christine said, "As a young student nurse I was often unsure of how to treat stoma patients and hoped they were discharged quickly."

The issue of stoma care support for ostomates was not really addressed until the late 1950's when it was pioneered by Rupert B. Turnbull, Jr., M.D, a colorectal surgeon at the Cleveland Clinic in the US. He learned that one of his former ileostomy patients, Norma Gill, was assisting stoma patients in her hometown of Akron, Ohio and so he decided to offer her a position as the world's first full-time enterostomal therapist (a nurse who cares for patients with an ostomy) and coined the term "enterostomal therapy." The two established the first enterostomal therapy-training programme, later named the R.B. Turnbull Jr., M.D., School of Enterostomal Therapy Nursing. This development led to a new way forward for the care of patients with a stoma – a programme of helping ostomates adjust to living with their stoma.

1954…Norma Gill enters the Cleveland Clinic Hospital, Ohio severely ill, meets Dr. Rupert Turnbull, Jr., to discuss the possibility of an ileostomy to save her life. After nine weeks and several surgeries, Norma begins a new life. Wanting to give back to society, she contacts several surgeons offering to assist with patient education.

Norma Gill - became the first president of WCET (World Council of Enterostomal Therapists) in 1977

In the UK this new development was reflected by an increasing awareness that patients with a stoma required specialist care whilst in hospital and that on-going support needed to be continued long-after hospital discharge. Christine talked about early stoma care and the work of Sir Francis Avery Jones (see page 12) at the Central Middlesex Hospital and the contribution he made to gastroenterology within the hospital and throughout the UK.

After time spent at the Central Middlesex Hospital and a stint in Neurology and A&E as a Sister, Christine went to work as an Occupational Nurse for Heinz. At this point Christine took a break from nursing to raise her family but found herself drifting back into nursing in 1980, this time working in the private sector at the Chiltern Hospital in Great Missenden. The hospital offered her hours that were compatible with bringing up a young family.

Tidings asked Christine how she got involved with stoma care and she replied with a humorous tone, "One day I was caring for a stoma patient when a very bossy stoma care nurse came and gave me a pasting but

> “when I meet a new patient I tell them that they are mine for life, no patient is ever discharged – we are here for them, they can just pick up the phone, there’s no such thing as a silly question and they can come in if they want to”

About...Sir Francis Avery Jones MD, FRCP; Kt, CBE (1910-1998), Physician and gastroenterologist St Bartholomew’s, Central Middlesex and St Mark’s Hospitals.

Opening a gastrointestinal unit at the Central Middlesex Hospital, Sir Avery-Jones almost singlehandedly built up the first British clinical and research base in that specialty. From Britain and many other countries came hundreds of young doctors, each welcomed by Avery to the unit and his home—and many went on to head new similar units elsewhere. They were taught how to be calm, caring, and competent clinicians, methodical and indefatigable, questioning the new and evaluating the old.

He attended the inauguration of the British Society of Gastroenterology in 1937 and helped start Gut in 1960, becoming its first editor.

He had a special interest in nutrition and recognised early the importance of dietary fibre; his unit at the Central Middlesex Hospital (there is now an Avery Jones Postgraduate Medical Centre and an annual Avery Jones lecture) is now the Department of Gastroenterology and Nutrition.

afterwards realising my potential she took me under her wing and encouraged me to head in the direction of stoma care”.

Christine commented, “The more I learnt the more I wanted to work with stoma patients. They are special patients. Stoma care pulls you in, once you dip your toe in the water you just end up getting in deeper and deeper”. Recognising the need for training Christine asked if she could be sent to do a specialist course at the Royal Marsden Hospital known as a ‘980’ (ENB course 980: Principles of Stoma Care).

After her course Christine started looking around for work within the NHS. At that time there were not many jobs available so she went to work for Salts & Son Ltd as a stoma care company nurse. Christine covered sick leave and holiday relief for most of the London Hospitals, High Wycombe and Banbury. Soon learning that all hospitals were the same, she said laughing, “As a stoma care nurse all you need to know is where the cupboard is - it doesn’t matter where you are!”

Christine explained a little about Salts & Son Ltd - in the early days of ostomy care, Professor Lionel Hardy returned from the US with a rubber bag which was being used ‘over there’. Professor Bryan Brooke from Birmingham General Hospital, full of enthusiasm for the work the Americans were doing with colostomy patients took the bag along to Salts. He asked Salts if they could make a collection of devices similar to those being produced in the US. An approach was made to the American manufacturer led by Ted Salt (father of the current generation) for a supply or licensing arrangement but this proved fruitless. So, Salts did some basic development work and produced a limited range of ‘handmade’ bags. (Salts as a company have a 300 year history, you can read all about it on their website – www.salts.co.uk) Today, Salts continues to develop, manufacture and supply stoma care products. Christine worked for Salts for nine years and went on to become Clinical Manager, looking after nurse sponsorship in the south of Birmingham until she was made redundant in 1998. But for a lady with her experience it wasn’t long before another post came her way and in 1999 she took up her present post at The Hillingdon Hospital, which was one of the sponsored posts, she had previously looked after.

Talking about her work Christine discussed the new guidelines in place for referral of patients with suspected lower G.I cancer and mentioned that all patients should have access to individual support and guidance from members of their specialist colorectal cancer team from the outset of their treatment.

Christine’s department is patient friendly and this is her overview of a patient’s referral journey:-

- Patients are referred by a GP, a practice nurse or via social services within 24hrs to see a consultant within a two-week period.
- Christine attends the patient appointment with the consultant or a senior registrar.
- A history of symptoms is taken.
- Investigations take place within a 2-3 week period.
- The patient is monitored quickly and then once diagnosed they are either referred back to clinic or discharged.
- On being given a diagnosis of colorectal cancer patients must have their operation within 31 days.

Guidelines for urgent referral of patients with suspected cancer of the lower gastrointestinal tract

Lower gastrointestinal cancer affects the lower part of the digestive system. This includes the colon, the rectum and the anus. A patient with symptoms of colorectal or anal cancer should be referred by the GP to a team specialising in lower gastrointestinal cancer. If your symptoms are not clear, and you are not overly anxious, it is reasonable for the GP to treat the symptoms and see if they get better.

Urgent referral

Urgent referral should be made in patients:

- aged 40 years and older, with rectal bleeding with a change in stool frequency or stool consistency that has persisted for 6 weeks or more
- aged 60 years and older, with rectal bleeding persisting for 6 weeks or more without a change in bowel movements and without anal symptoms (anal symptoms include discomfort, itching and lumps as well as pain)
- aged 60 years and older, with a change in bowel movement with looser stools and/or more frequent stools persisting for 6 weeks or more without rectal bleeding
- of any age with a lump in the lower abdomen on the right side
- of any age with a lump in the rectum
- who are men of any age with unexplained anaemia
- who are non-menstruating women with unexplained anaemia.

Risk factors

The GP should follow up patients with a disease called ulcerative colitis or who have had this disease in the past (this disease involves inflammation of the colon and rectum). Patients with this disease have a higher risk of colorectal cancer. The GP should agree a follow-up plan with a specialist and offer it to the patient. The aim of follow-up is to spot cancer early.

There is not enough evidence to suggest that the GP should use family history of colorectal cancer as a factor when making a decision about referral.

Tests

Any patients with unexplained symptoms related to the lower gastrointestinal tract should be offered a digital rectal examination. This is usually carried out by the GP and involves the GP feeling inside the rectum with a finger to check for anything unusual.

A blood test may be carried out by the GP. This will help to identify anaemia which may indicate lower gastrointestinal cancer. The results of this test will also be useful for the specialist if you are being referred.

Apart from an abdominal or digital rectal examination and blood tests, GPs should not carry out any other tests as they may delay referral.

Christine said, “patients who require a stoma - whether temporary or permanent - are counselled before surgery and after surgery. In fact when I meet a new patient I tell them that they are mine for life and no patient is ever discharged – we are here for them, they can just pick up the phone, there’s no such thing as a silly question and they can come in if they want to.”

Christine talks with her patients about their diagnosis for however long it takes and provides reassurance and supportive information showing them examples of appliances and because of her wealth of experience puts patients at their ease reducing their fear of the unknown.

When a patient comes in for their operation Christine greets them and takes them through what will happen, telling them that she will see them after their operation.

Soon after the operation self-care is taught keeping it simple and basic, a transparent one-piece pouch is used. Tidings asked why a transparent one-piece pouch is used and Christine replied “it is easy for the doctors, nurses and patient to see the stoma and prevents the bag being repeatedly removed to check to see if it is working. This has the added benefit of the skin being protected. The nurses on the ward also feel confident with this type of appliance.” Christine felt patients should know that there is no time limit to changing their bag, suggesting it becomes part of their daily routine just like putting on their make-up or shaving.

Talking about going home - Christine’s department provides going home packs containing helpful booklets and advice leaflets. She tells patients that they should always listen to their body, not what their brain tells them. Recovery is not always straightforward and there may be peaks and troughs. It is normal to be tired and exhausted. Eat what you like and give yourself a break as you’ve been through a tough time.

Finally, as the interview was closing Christine added that she would prefer surgeons not to suggest to patients that they can have a reversal as this is not always the case and can give people false hopes. She said, “some patients are happy with their colostomy and don’t want to undergo surgery again,” she felt patients should have their say and be given the choice to say ‘No’ if they wanted to.

Tidings will be back to interview Christine further. As Christine points out herself, “I have over forty years experience that I would like to be able to pass on to the up and coming generation of nurses.” Tidings will certainly help Christine to do just that!

Editors Comment

If you would like to be featured in our Open Door Series please contact us
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

Update on **new stoma care products** and **services**

If you have seen or heard about a product and you are not sure where to find out about it and want to obtain a sample why not email your query to cass@colostomyassociation.org.uk

CliniMed

CliniMed are pleased to announce their new look website.
Visit: www.clinimed.co.uk

OstoMART

OstoMART are pleased to introduce their **NEW Cool Comfort Unisex Light Control Support Garment.** The Cool Comfort is available in three styles (Belt, brief and boxer) and in a choice of Black or white. We believe these are the only garments of their kind to be MRSA Resistant for 50 washes at 40ºC. The fabric is Hydrophilic moving sweat and moisture from the skin making the garments quick dry and breathable. The garments are non-restrictive allowing maximum movement and comfort.

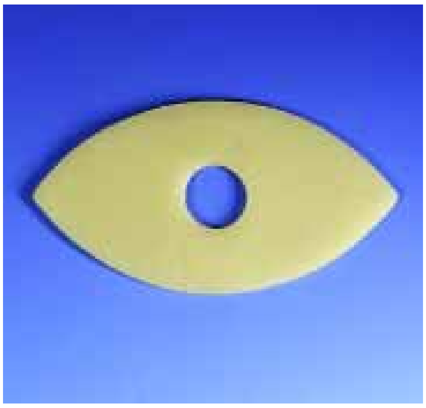
The **Cool Comfort Range** is available in dual sizes of Small/Medium, Large/XLarge and XXLarge/XXXLarge in convenient packs of three. Very competitively priced and represent good value for the NHS.

They are available on prescription from the 1st June either direct from OstoMART or from your usual supplier.

Peak Medical

Peak Medical has launched an addition to the popular Varimate range of products. **Varimate Resist 'eye shaped' Washers** are, as the name suggests, resistant to moisture and the aggressive output from faecal stomas. They are also resistant to the effects of acid urine.

These stretchable, mouldable washers can be stretched to twice their original size and will remain in the desired shape. For partially retracted stomas, the washers can be folded and used as a filler to help prevent unwanted leaks and potential skin breakdown and will remain sticky even when rolled and stretched repeatedly.



The Varimate Resist 'eye shaped' Washers have an 18mm starter hole which can be stretched to 35mm and are available in packs of 10. Varimate Resist 'eye shaped' Washers are available on FP10 prescription.

If you would like to receive a sample, please call the Peak Medical helpline on Freephone 0800 6520424.

Pelican Perform

Pelican Healthcare is pleased to announce the launch of **Pelican Perform**, a Solidifying Agent which is available on prescription now.

Pelican Perform works exceptionally well for anyone with a liquid/high output stoma to increase security, improve filter performance and offers odour reducing properties.

Pelican Perform has been specifically designed to improve confidence and security by minimising the risk of leaks, especially at night.

Only a single sachet is required, and Pelican Perform will not affect the colour of your output or cause any staining.

To request your complimentary sample please see our advert within this Tidings magazine.
Simply e-mail: contactus@pelicanhealthcare.co.uk or alternatively call the Freephone Sample Request Helpline on: 0800 052 7471.

Salts Medilink

Over the years, Salts Medilink has earned a reputation for offering an exceptional level of care, but it's never rested on its laurels. Salts has continued to grow and adapt Medilink in line with customer needs, and now this much-loved service has been given a fresh new image to mirror the ongoing improvements.

Designed to represent "Your Link to Better Care", the new logo uses linking arms to form the "M" in Medilink. Customers will soon start to see this bold and distinctive new logo emblazoned on corporate literature, product literature, advertising and packaging designs.

Customers of Salts Medilink are now entitled to receive 4 bottles of hand sanitiser each year. There is also a team of Community Stoma Care Nurses who cover many areas of England and Wales, offering free advice. **For further details on nurse coverage or any other aspect of the service, please call Freephone 0800 626388.**

Why not write or email the editor about **what stoma care products work for you and why** or comment **about your delivery service...editor@colostomyassociation.org.uk**

What **are** those **sticky labels** for and why are they in **my box of stoma bags - do I need them?**

Well the answer is... although they look like sticky labels they are in fact filter covers

Ostomy bags as we know are there, primarily to collect bodily waste. The waste is usually made up of a mixture of solids, liquid and gas and varies dramatically from one person to the next, and for some from one day to the next. The type of output is dependent on several variables diet, medication, metabolism, and fluid intake.

In addition, the waste that collects in the bag, being the breakdown products of the food we eat, contains chemical bi-products which can generate a lot of odour, which is released into the air inside the bag. These bi-products contain either a lot of sulphur, giving a characteristic bad egg smell, or organic molecules called indoles and skatoles, which result in a cabbage type smell.

Most bags are made from film-like materials specifically designed to keep the smell inside the bag. The problem is that bags have a fixed capacity, and so when, in addition to the solid and liquid waste, the body also produces gas, the capacity of the bag can be overwhelmed. (Our digestive systems work like a fermentation plant and some gas or ‘flatus’ is an inevitable consequence).

Some people produce a lot of gas quite suddenly, while others produce very low levels indeed. Both are perfectly normal.

If a lot of gas is produced rapidly and enters the bag, without any means of escape, the bag will inflate very quickly. It may become very uncomfortable and in some cases could even become detached from the body (the pressure in the bag causing the flange to lift) resulting in leakage and possible spillage. This is called ‘ballooning’.

On the other hand, some people produce very low levels of gas, barely enough to separate the walls of the bag. This combined with the consistency of the waste can result in a different problem - the waste does not enter and fall to the bottom of the bag as it should, instead it masses around the stoma itself. This is called ‘pancaking’. A small amount of gas in the bag can reduce this problem.

Manufacturers have provided filters on both closed and drainable bags to allow a means to vent the gas to the outside of the bag. The challenge to the manufacturer is two fold.

The first being how to remove the odour from the gas stream. This has been achieved by the introduction of a filter into the design of the bag. The filter is made from activated carbon in one form or another, and has usually been treated to make it very effective at removing or reducing smells. Typically the gas will need to flow through the carbon filter to escape. Even a short passage through the filter should be sufficient to take away the odour. The carbon surface is very porous and traps odour in just the same way as a filter would in a ‘cooker hood’ except more efficiently.

The second is more of a technical challenge for manufacturers, and that is how to control the rate of gas flow through the filter. The rate must be slow enough to allow the carbon to do its job of removing odour, but fast enough to deal with potentially high volumes of gas. The flow rate can be controlled by how densely the carbon in the filter is packed, the length of the passage from the inside to the outside of the bag and the size of the inlet and outlet apertures on the filter. Each of these can be accurately defined in design and production.

However the over-riding challenge is that once the filter design is fixed, the flow rate will also be fixed. Manufacturers try to set the flow rate to deal with the ‘average’ flow rate. The problem is that although the flow rate should work well for most people with ‘average’ levels of gas production, there will always be some people who produce high levels of gas, sometimes very quickly and others who produce very little gas at all. A persons’ level of gas production can vary from day to day. In extreme situations ‘ballooning’ or ‘pancaking’ can still result.

Here are some practical solutions that can deal with these problems. For ballooning, wearers of two-piece appliances can discretely partially separate the bag from the flange to reduce pressure. Some one-piece wearers have described ‘puncturing’ the bag slightly to reduce ballooning but this should be done with extreme care, and again discretely.

For ‘pancaking’ there is help at hand as far as controlling the escape of gas from the bag is concerned. Manufacturers normally supply a few sheets of self-adhesive labels (see illustration) usually sufficient for each bag in the box. The backing film will not allow gas through, and so if the label is applied over the exit aperture of the filter, gas can no longer escape. When the level of gas production is very low, the gas can be retained inside the bag with one of the labels in place. As the gas slowly builds up the walls of the bag separate allowing waste to fall to the bottom of the bag, hopefully minimising ‘pancaking’.

Article contributed by
Dr Rory Smith, Director of Research and Development at Welland Medical

Editors Comment

In future issues product focus will be looking in depth at other stoma care products if you have any questions or suggestions on how a product could be improved why not get in touch via e-mail:
editor@colostomy association.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL

GREATCOMEBACKS™

The GREATCOMEBACKS® Programme Announces 2008 National Award Winners

National Awards Recognise Achievements of Linda Lewis-Garwood from Devon

From left to right - Monty Taylor - CA Chairman, Linda Lewis-Garwood and Andrew Thelwell

> Linda Lewis-Garwood, 57 from Devon won the Colostomy Great Comebacks® Award. The awards were announced during a ceremony at One Whitehall Place in London.

These awards are sponsored by ConvaTec, and supported by the Colostomy Association, the IA (Ileostomy Association), UA (Urostomy Association), the Prince's Foundation for Integrated Health and the World Council of Enterostomal Therapists (WCET).

Great Comebacks® is a patient support programme that recognises the inspirational achievements of adults and young people who prevail over debilitating intestinal diseases and ostomy surgery. The Great Comebacks® Awards encourages stoma patients, family members, carers, specialist nurses and friends to nominate an individual who has made a recovery from stoma surgery that enables them to achieve their goals and whose stories can help inspire others and provide information to those faced with life-changing surgery.

Linda Lewis-Garwood, mother and former nurse was diagnosed with colorectal cancer early 2006 and in February underwent stoma surgery as she knew it would significantly alleviate her suffering. ‘I was totally shocked and my confidence plummeted. In June 2006, I also underwent radio and chemotherapy which failed and for me was an absolute nightmare. I was read my last rites twice. I lost five stone in weight but in time regained my strength and appetite. Today I feel comfortable with my health and now am able to do even more than before, including swimming, going to the theatre, travelling and socialising with friends. One day I even hope to complete Route 66 on a Harley Davidson! Whilst I am living life to the full, it is important to recognise that there are others still encountering daily challenges. I am actively involved with local charities and am currently trying set up a support group. “I feel honoured to have won a Great Comebacks® Award and I hope that other stoma patients see what I have achieved and feel inspired to reach their own goals.”

The other 2008 Great Comebacks® regional recipients include:

- **Great Comebacks® 2008 Overall Winner and Young Persons Winner:**
  Jade Whitehouse, 14
  from Birmingham
- **Ileostomy Winner:**
  Krystyna Kraus, 53
  from Selby
- **Urostomy Winner:**
  Ian Bagwell, 61
  from Preston


100% Comfort & Discretion
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Pathways to a colostomy

Enabling Ethiopian women to live independent lives

Professor Gordon Williams
MS FRCS
Medical Director
Addis Ababa Fistula Hospital

Professor Gordon Williams has been a friend of the Addis Ababa Fistula Hospital for more than 20 years assisting with Urological surgery on a voluntary basis sometimes once or twice a year. Professor Williams retired from Hammersmith Hospital in 2007 and went to Ethiopia to take up the post of Dean at a newly formed Medical College but has since become Medical Director at the Addis Ababa Fistula Hospital.

The Addis Ababa Hospital was founded by Catherine Hamlin and her husband in 1974 and has provided free reconstructive surgery to thousands of African women with fistulae caused by difficult births.

Gordon Williams has done, and continues to do, valiant work for this very special hospital. It was he who in 1992 persuaded the BBC that it should make a documentary about the hospital and the work of Reg and Catherine Hamlin who have cared for the young victims of unattended childbirth since their arrival in Ethiopia in 1959.

The history...

Addis Ababa Fistula Hospital

The Doctors Hamlin

In the late 1950s, two young doctors, Reginald and Catherine Hamlin, were dedicated obstetricians living and working in Catherine's native Australia. Early in their careers, the couple practiced gynecology in Sydney, but they were eager to seek out and aid the women who needed them most.

They got their chance in 1959, when they were called upon to come to Ethiopia and set up practice in a hospital in the capital city of Addis Ababa. When they arrived, Reginald and Catherine discovered a very poor country with almost no resources for expectant mothers. The Hamlins planned to open a midwifery school at the Princess Tshai Memorial Hospital and to stay for three years.

Pioneering fistula treatment

On the evening of their arrival, the Hamlins were doing their best to settle into their new home, when a fellow gynecologist came to visit. That doctor described obstetric fistula to the Hamlins, neither of whom had ever seen an obstetric fistula before. "To us they were an academic rarity," Catherine recalls in her book, The Hospital by the River.

Before the Hamlins came to Addis Ababa, there was no treatment available for fistula victims anywhere in the world. Most such injured women – and there were thousands – had suffered in silence for years. Reginald and Catherine quickly began to learn everything they could about obstetric fistula, a condition that had all but disappeared in the United States in 1895, when the first fistula hospital closed its doors in New York. The Hamlins perfected a surgical technique to mend the injuries, while continuing to treat a broad range of obstetric cases. In their first year in Ethiopia, the Hamlins treated 30 fistula patients.

The founding of a hospital

Through first hand experience, the Hamlins quickly became aware of the suffering endured by women with fistulas. Fistula victims are usually shunned so severely due to their odor that even other patients refuse to be near them. Reginald and Catherine knew the fistula women deserved a hospital of their own. The Hamlins worked for more than a decade to establish a fistula hospital, even through a military coup when most foreigners fled Ethiopia. Finally, in 1974, the Hamlins opened the doors of Addis Ababa Fistula Hospital. It remains the only medical centre in the world dedicated exclusively to fistula repair.

"Saint Catherine"

Reginald Hamlin worked diligently at Fistula Hospital until his death in 1993. Catherine Hamlin, now 84 years old, has been nominated for a Nobel Peace Prize, and the list of her humanitarian awards is impressive. She continues to oversee the work of the hospital and can frequently be found in the operating room performing the delicate fistula repair surgery she pioneered more than 40 years ago.

Professor Gordon writes...

Since its opening in 1974, the Addis Ababa Fistula Hospital and its four outreach hospitals across Ethiopia have treated over thirty-five thousand women with a vesico-vaginal or recto-vaginal fistula. 50% of the women treated are teenagers. A fistula is a hole between the bladder and the vagina or the rectum and the vagina or sometimes both. It is invariably due to prolonged obstructed labour when the baby's head gets stuck in the bony pelvis and causes an area of the bladder or rectum to die. When these dead tissues separate, the patient becomes totally incontinent of urine and/or faeces.

50% of the women treated at the hospital are teenagers - patients with a urostomy or colostomy are often unable to return to their village, even though with our four - soon to be five - outreach centres, necessary appliances could be made available.

Prolonged obstructed labour occurs in developed societies in about 5% of women and is easily resolved by Caesarean section. In the rural areas of the developing world such a facility is not available and these young women spend an average of four days in labour and sometimes up to nine days. The majority of births take place in their village where there is no medical supervision.

The holes in the bladder/rectum draining into the vagina are just part of the problems which occur. 15% develop paralysis of their feet due to damage to the nerves in the pelvis and as a result can not carry out the duties of a woman such as fetching water and firewood and working in the fields. In 50% of the cases, the husband divorces them because of the smell from the total incontinence, their other physical disabilities and in many the inability to have further children.

Injuries which occur in Ethiopia are more severe than those which occur in other developing countries due to a combination of early marriage, poor nutrition and almost total absence of health care in rural areas. In patients with a rectal injury, it is not uncommon for a very tight narrowing (a stricture) to occur just above the hole between the rectum and vagina. In those cases, and, where there is a very large rectal defect a colostomy is necessary to allow resolution of infection and relief of the obstruction caused by the stricture. The degree of scarring caused by the injury is sometimes so great that the colostomy has to be permanent.

Patients with a urostomy or colostomy are usually unable to return to their village, even though with our four - soon to be five - outreach centres, necessary appliances could be made available. To deal with this problem and to enable these women to live an independent life, we have built a village just outside Addis Ababa where they are taught a trade - this can be dairy farming (so they can sell the milk or make butter or cheese), cafeteria work (they can learn to cook, wait at table, and prepare meals), in a spice mill (where they can sell ground spices), needlework, tailoring or any aspect of horticulture. They are also taught the skills necessary to be able to buy and sell.

Recently, because of the changes in the way appliances are ordered and provided, we ran out of colostomy appliances, but after an appeal to the members of the Colostomy Association we were very rapidly provided with a temporary solution to our problem and could confidently await our main order from the manufacturers to come through. With changes in health care provision in the UK, I have no doubt that many appliances may be superseded by new devices. We can use anything that you no longer require. We can also arrange to have unwanted appliances to be flown out.

Editors Comment

If you would like to learn more about the **Addis Ababa Hospital** visit: www.hamlinfistulauk.org or wish to help **Professor Gordon Williams MS FRCS** please contact the Colostomy Association and we will put you in touch with him.

e-mail:
cass@colostomy association.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
or telephone head office:
0118 939 1537

Stoma Prolapse

Pat Black M.Sc, RGN, RCNT, FETC, FPA Cert.
Specialist Nursing Team (Colorectal and Stoma Care)
The Hillingdon Hospital NHS Trust Middlesex

A prolapse of the stoma can be very alarming for the patient and can occur without any apparent reason. Prolapse can be seen more frequently in patients who have temporary loop stomas, either colostomy or ileostomy. A stoma prolapse is when the bowel telescopes out of the skin opening making it longer in length.

A prolapse is not an uncommon complication and can be found alone or in association with a parastomal hernia. When a temporary or loop stoma, either colostomy or ileostomy, is not fixed by sutures there is always the risk of either or both of the loops prolapsing.

Often in a loop stoma, the part of the stoma nearest the back passage (distal segment) is most likely to prolapse.

Common reasons are:

- An excessively large opening in the abdominal wall, which may be the result of surgical technique or an oedematous bowel at the time of construction.
- Inadequate fixation of the bowel to the abdominal wall.
- Poorly developed abdominal muscular support (as in infants).
- Increased abdominal pressure from disease, coughing, sneezing and crying (such as in infants).

Conservative Management

It can be a distressing and frightening situation for the patient to experience a stoma prolapse, which may cause them to rush to the Accident and Emergency department. Reassurance that the condition is not serious is needed and information on how the patient may help him or herself is required.

Conservative management is often the way forward for the patient to manage a prolapsed stoma. Often the prolapse can be reduced by the patient lying down on the bed for about 20 minutes to relax the abdominal muscle and reduce the intra abdominal pressure. Gentle pressure applied continuously against the prolapsed distal loop will aid the bowel to return to the intraperitoneal space. If the prolapsed bowel is swollen a cold compress (ice cubes in a plastic bag wrapped in a towel and applied to the stoma) will reduce the swelling.

When a prolapse is managed conservatively the patient will need frequent supervision by the stoma care nurse and the prolapse and appliance regularly evaluated. Help after the prolapse has been reduced can be obtained in the form of a support belt across the stoma and a specialised plastic stoma cap that is held in place by the belt. Many ostomy product manufacturers now make specialist pouches to help in the management of both herniated and prolapsed stomas.

Surgical Intervention

This is only needed if the blood supply to the prolapsed piece of bowel is compromised or if there is a bowel obstruction associated with the prolapse. Surgical correction consists of cutting away the excess bowel and removing it and re-suturing the stoma to the abdominal wall. Alternatively, the stoma may be re-sited and if previously a loop stoma, an end stoma constructed.

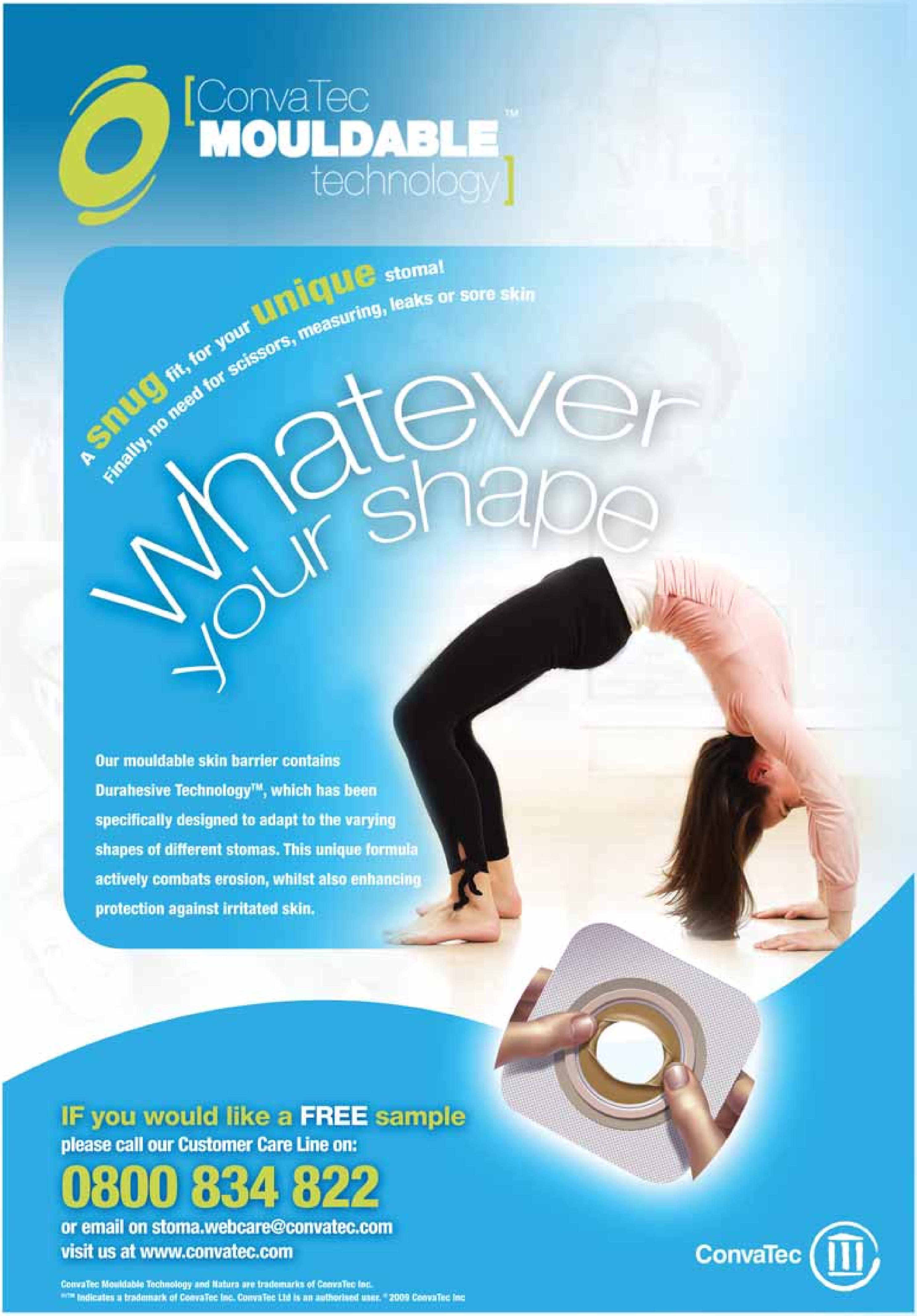
Ongoing care

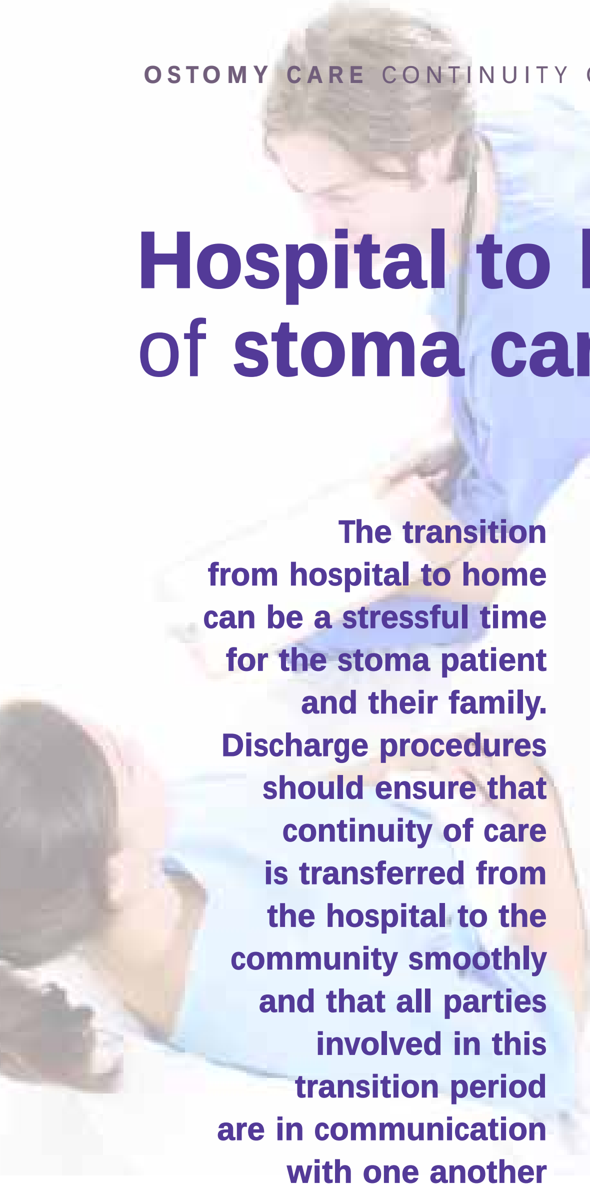
Because the prolapsed stoma will extend into the pouch and will increase in diameter the mucosa (outside) of the stoma may rub and bleed. This may also cause mechanical trauma and interference with the pouch seal. Two-piece appliances should be used cautiously to prevent the prolapsed stoma becoming pinched between the flange and the appliance when securing.

Editors Comment

If you are experiencing any problems with your stoma such as prolapse always consult your stoma care nurse.

If you have had a prolapse and would like to share your experiences please contact Tidings;
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL


Whatever
your shape



Hospital to home continuity of stoma care supplies...

The transition from hospital to home can be a stressful time for the stoma patient and their family. Discharge procedures should ensure that continuity of care is transferred from the hospital to the community smoothly and that all parties involved in this transition period are in communication with one another and the patient.

On discharge from hospital the stoma care nurse should ensure that the following information is given to the patient, family or caregiver:-

- Pass to the patient contact details of the stoma care nurse/s and the hospital stoma care department – in case there is a need to get in touch when at home
- Inform the patient's GP, district nurse and other community services of the return of the patient to the community
- Give the contact details of the district nurse to the patient
- Explain to the patient that they will receive a home visit within a 48hr period to assess how well they are adapting to 'living with their stoma'
- Explain how to correctly store appliances and accessories to the patient and give them a list of equipment they are using - this should include - manufacturer and suppliers details, product order code or number/description of appliance and sizes/number of items in a box or pack
- Explain to the patient how to obtain stoma care supplies once they are home

The last thing any patient should be worrying about when they get home is how to obtain future stoma care supplies and accessories. So, let's take a look at how to obtain your stoma care supplies.

Whilst in hospital your stoma care nurse will have taken good care of you, providing all the necessary items needed after surgery. While your stoma settles down, you will be taught self-care and be advised of potential problems that may occur on your return home and how to cope with them.

Your stoma care nurse will discuss your appliance supplies with you and explain the methods of obtaining your supplies. In the UK people who have a permanent stoma do not have to pay for their prescriptions or stoma equipment, however those with a temporary stoma do have to pay unless they are eligible not to, for example because they are over 60 or on benefits because of low income. If you do have a permanent stoma and are under the age of 60 you should fill in form FP92A to apply for a medical exemption certificate, ticking the section stating you have 'a permanent fistula' which requires an appliance. Most stoma care nurses carry the form which will require your signature and that of your GP or hospital doctor. It is preferable for this to be done in hospital, rather than putting you in a position where you have to visit your GP for verification that your stoma is permanent and complete a form FP92A on your return home. Prior to discharge your stoma care nurse will contact your GP to advise of your ongoing prescription requirement.

When it comes to leaving hospital most nurses will send you home with enough pouches to last a few days and will have informed you how to obtain further supplies. If you are to be discharged over a weekend, it is important you have enough supplies to cover any emergency. (we often drop the first few pouches as we attempt to cope on our own). If you find yourself in difficulty or need further supplies, contact the ward you were discharged from – they should be able to help.

On your return home, you may, as has already been discussed, have had your stoma supplies organised. If not you now have a few choices of how to obtain your stoma supplies. Your GP should have already been informed of your discharge so your prescription will be available – it is always advisable to check if this is the case.

Choices...

- You can either, visit your GP surgery in person to collect your prescription, which you can then take to a dispensing chemist of your choice. Some people like to visit their local pharmacy, where they are well known. (Chemists are working hard to provide facilities so patients can discuss matters in private).

- Or, you can (whilst in hospital or afterwards) opt to have your prescription forwarded to a specialist stoma care supply company, that not only dispenses your prescription, but also makes home deliveries. Many GP's are happy for you to ask a delivery company or chemist to collect the prescription on your behalf.

If you are using a local pharmacy – it's a good idea to check to see if they offer a delivery service, as carrying large boxes of supplies is not always easy, especially if you do not have access to transport. It should be pointed out that Pharmacies do not usually supply complimentary dry wipes or disposal bags, they are also unlikely to offer a free cutting service for your pouches or flanges. Many specialist stoma care supply companies provide these additional services. They will cut your pouch to a template that you or your nurse has provided, thus ensuring a good fit so helping to reduce leakage and subsequently sore skin.

Many ostomists prefer using a specialist stoma care supply home delivery company, finding this to be the easiest and most convenient way of obtaining their supplies. There are several home delivery companies that hold large stocks of every type of pouch and accessory, so enabling quick home delivery once the prescription has been received.

Some delivery companies will send out your requested supplies immediately, some wait until they receive the prescription from your GP. Either way, the stoma care supply company will deliver direct to your door within a day or two. Most companies have a fleet of vans and discreet drivers, some use a courier service.

Both methods of obtaining supplies are equally as good, it is entirely up to you to choose the method which best suits your needs.

If you start to run low on supplies you should re-order, allowing plenty of time for delivery so you do not run out. Over the coming months your stoma care nurse will be monitoring the shape and size of your stoma as it can change as you recover from your operation. It is very important that the pouches continue to fit correctly. Try to assess on a daily basis how many you use so you do not over-order or you may find yourself with pouches and flanges that you can't use. Always check with your stoma care nurse before you change any part of your daily regime.

Changes Coming in 2010 for Ostomists in England and Wales

The NHS has been consulting over the past few years on a better way to supply stoma goods to ostomists. This has recently been finalised and will start to come into effect in 2010. These changes mostly affect the way the supply is administered and in general will not affect you directly.

You will still be able to use a home delivery company or a chemist. You can also expect that all suppliers should continue to give you complimentary disposal bags and dry wipes, and cut your pouches for you if you wish. They should also have qualified staff available to provide advice on caring for your stoma.

One area where there will be less flexibility is that both chemists and delivery companies must have a prescription before they send you your pouches, the only exception is if your GP or stoma care nurse tells them that you have an emergency situation and that the prescription will be sent later. This will mean that you will need to watch your supplies carefully, getting a prescription from your GP in time for it to be posted or to give the delivery company or chemist enough time to request and collect the prescription on your behalf.

There is no change to the supply of goods to ostomists in Scotland.

Ostomy Supplies Home Delivery Companies

For a full list of Home Delivery Companies contact: CA Head Office: Telephone 0118 939 1537 or visit: www.colostomyassociation.org.uk and register then go to Find Information to download our Factsheet - Stoma Product Supplies.

Convatec - Amcare
Freephone: 0800 885 050
Email: amcare.orders@bms.com
Web: www.convatec.co.uk/amcare

Bullen Healthcare
Contact: 0800 269 327
Email: info@bullens.com
Web: www.bullens.com

Charter Healthcare
in Association with Coloplast
Freephone: 0800 132 787
Email: gbccare@charter-healthcare.co.uk
Web: www.charterhealthcare.co.uk

Countrywide Supplies
Freephone: 0800 783 1659
Email:
orders@countrywidesupplies.co.uk
Web: www.countrywidesupplies.co.uk

Fittleworth
Freephone: 0800 378 846
Email: caring@fittleworth.com
www.fittleworth.com

Ostomart Responder
Contact: 0800 220 300
Email: enquiries@ostomart.co.uk
Web: www.ostomart.co.uk

Pelican Healthcare
Contact: 029 2074 7000
Email: contactus@pelicanhealthcare.co.uk
Freephone: 0800 052 7471

Respond Plus Ltd
Sister company to OstoMart -Northern Ireland
Freephone: 0800 028 6848
Email: larne@respondplus.co.uk

Salts Medilink
Freephone: 0800 626 388
Email: web@salts.co.uk
Web:
www.saltsstomacare.co.uk/medilink.aspx

SecuriCare (Medical) Ltd
Freephone: 0800 585 125
Email: info@securicaremedical.co.uk
Web: www.securicaremedical.co.uk

UCI Healthcare
Contact: 0800 731 4376
Email: enquiries@ucihealthcare.co.uk
Web: www.ucihealthcare.co.uk

STOMA CARE SERVICE PROVIDER CELEBRATES SILVER JUBILEE 1984-2009

Fittleworth's celebrate 25 years...

of discreet reliable and convenient home delivery

2009 is the Silver Jubilee of Fittleworth Medical Ltd. Today the service provided by companies like Fittleworth is taken very much for granted. We now expect to be able to place an order for goods, medical or otherwise over the phone or the internet and expect them to be delivered next day. However this has not always been the case.

The early stoma appliances required bespoke fitting and a new category of chemist was created to service this requirement, the Dispensing Appliance Contractor. These DACs as they became known, ensured that belts, seals and rubber pouches fitted and leaks were kept to a minimum.

Fittleworth started in 1984 and from the beginning was an innovator in the home delivery of stoma pouches. The modern pouch was more sophisticated than the earlier incarnations, but the flanges still needed to be cut to fit properly. Rather than leaving this to the customer, many of whom find using small, sharp scissors difficult, Jaqueline and Alan Seymour who founded Fittleworth, decided it would be a valuable and unique service to pre-cut each pouch before delivery. This innovation helped get the company off to a flying start when the doors of the Seymour's garage in the picturesque West Sussex village of Fittleworth opened and the first orders were dispatched in the autumn of 1984.

Alan and Jaqueline had decided from the outset that Fittleworth would be a company that really did put the needs of the customer first. So in addition to being one of the first to cut pouches, they also ensured that deliveries were prompt, discreet and reliable and that they always had a large stock that was supplied without bias to any particular manufacturer. This founding principle remains true 25 years later. By 1994 the company had started to grow significantly and was now based in Ford, West Sussex. Although the company was larger, the small team of staff were still as dedicated and needed to be multi skilled – taking orders, picking, cutting and packing in turn. One unit soon had to be knocked through into next door and then as room became constrained once again the customer service team had to be moved to a small unit by Ford railway station.

The company continued to grow and finally larger premises were found back in Ford. The entire company moved in a single day and still managed to dispatch orders. The industrial estate was part of the old WWII airfield and shortly after moving into the new premises the police suddenly arrived and evacuated everyone because an unexploded bomb had been found during building works!

A number of other dispensing licences were acquired and soon Fittleworth had 5 Care Centres across the country. In 2003 the company merged with Thames Valley Medical gaining several more Care Centres including those in Reading and Glasgow and in the following year began offering continence appliances in addition to the stoma service. This was followed in 2005 when the business of Homecare, a DAC in Keighley, West Yorkshire was combined into the Fittleworth business.

Today Fittleworth is still based in West Sussex with a Care Centre in Ford and 13 other locations from Glasgow to Bournemouth, a national distribution that allows local delivery using company drivers rather than couriers for most customers.

Even though the company is now much larger than when it started in a garage, it still operates on the ethos with which it was founded and prides itself on offering a first class service. A service where deliveries are prompt, discreet and reliable and where customer service always comes first through practical innovations such our samples service, website and the unique World Assist Alliance and Life Assist initiatives – always finding ways to help ostomists live an easier lifestyle.

If you would like to ask one of our nurses for some non urgent medical advice then e-mail us at askanurse@fittleworth.com

fittleworth

To find out more about the Fittleworth delivery service, please contact us on freephone 0800 378 846, email caring@fittleworth.com or visit our website www.fittleworth.com

25 fittleworth
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Celebrating 25 years of delivering an easier lifestyle with

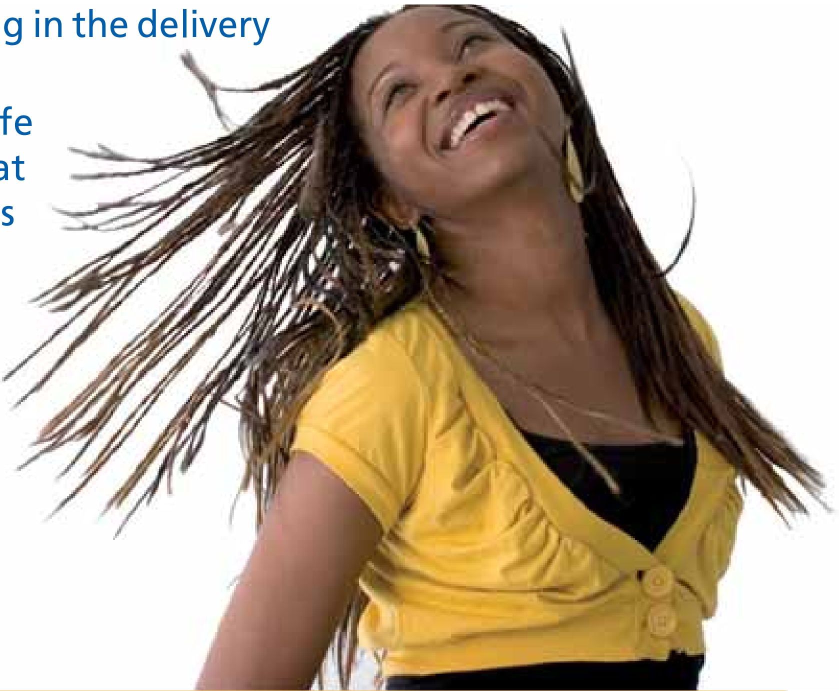
Life Assist

2009 is Fittleworth's 25th year specialising in the delivery of continence and stoma products.

To celebrate we will be launching Life Assist - an opportunity to share all that we have learned over the last 25 years about living an easier lifestyle.

We have produced a Life Assist pack with useful hints and tips on a range of ostomy lifestyle issues.

These are available free to ostomists. To request a copy please fill in the form below and return to us at our freepost address.



Freephone 0800 378 846
www.fittleworth.com

I would like to register for a free Life Assist Pack.

Return to:

Fittleworth
FREEPOST
Hawthorn Road
Littlehampton
West Sussex
BN17 7LT

Name: ____________________
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SJA/0509/1

Department of Health Consultation:

Arrangements under Part IX of the Drug Tariff for the provision of stoma and incontinence appliances and related services to Primary Care.

An overview of the new arrangements under Part IX of the Drug Tariff for the provision of stoma and urology appliances – and related services – in primary care has been published on the Department of Health website at:

http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_097226

Some of the key points are:

- The new arrangements will be implemented from 1 April 2010 subject to amendment Regulations being laid and amendment Directions being made.
- Dispensing Appliance Contractors (DACs) and Pharmacy Contractors (PCs) who dispense prescriptions can choose to offer either Essential Services or Essential plus either both or one of the Advanced Services.
- Essential services that must be provided include a repeat dispensing service, appropriate advice, a home delivery service and a supply of wipes and disposal bags.
- Advanced services include stoma appliance customisation and appliance use reviews (AURs).
- AURs must be conducted by a specialist nurse working on behalf of the DAC or PC or by a pharmacist, either in the home of the user or at the DAC or PC premises, where there must be a specially designated area for confidential consultation. Where possible, these specialists must maintain close contact with the NHS healthcare professional looking after the user.
- The new arrangements have been put in place to ensure that DACs operate within a similar clinical governance framework to PCs and that PCs offer a similar level of service as the DACs.

The Department of Health lists the key aims as:

- Maintain – and where applicable – improve patient care;
- Ensure equitable payment to DACs and PCs for the provision of equivalent services;
- Achieve transparency between what is paid for services and what is reimbursed for items.

- The detail is in the remuneration and reimbursement arrangements that apply to the contractors (DAC and PC).

April 2009

Article reproduced courtesy of

Anne Demick
IA National Secretary

IA The Ileostomy & Internal Pouch Support Group

Support for you and your stoma

Support garments provide ostomates with extra abdominal support and help with the management of hernias. They can prevent the stomal opening from enlarging.

A wide range of garments are available to the ostomate - from gentle support for everyday use to firmer support for work and sporting activities.

For more information about how support garments may be able to help you, always talk to your stoma care nurse who will be able to advise on what is best for you.

After stoma surgery it is important to get back to full health as soon as possible. Recovery from an operation of this nature takes time and is dependant on how physically able you were before your operation and the complexity of the procedure. You will have been advised by your stoma care nurse and consultant to listen to your body and take plenty of rest. It is important that no heavy lifting or straining takes place during this time.

Following your surgery you need to allow your injured muscles to heal. After about 6 - 8 weeks you can start some gentle exercises such as walking and swimming, gradually building up your exercise tolerance. If you wish to try other exercises it is advisable to consult your doctor or stoma care nurse.

Prevention is better than cure!

Ostomates can lower the risk of having a hernia by losing weight if need be and by eating healthily and stopping smoking. Try to avoid putting any strain on your abdominal muscles and support the stoma and wound when coughing or sneezing. To avoid constipation drink plenty of fluids and eat a high fibre diet or take bulking agents.

Mechanical strain like lifting, pushing or pulling heavy objects early on can induce secondary changes in cells that repair muscles and may lead to diminished muscle tone. Always use proper lifting techniques and do not attempt to lift weights that are too heavy or require you to close off your throat in order to tense your abdominal muscles as this can cause pressure and therefore increase the risk of a hernia. Never be afraid to ask for help!

If you regularly engage in hard physical work as part of your job or hobbies (eg carpenter, builder, cleaner, gardener), even if you do not have a hernia or bulge, it could be a sensible idea to wear a support garment or belt during your activities and gentle or intermediate support garments at other times.

How soon you return to work depends on the type of work you do. If it is physically demanding then you may need to wait longer to avoid putting strain on your body. Driving a car puts a strain on your abdominal muscles and your insurance is invalid if you cannot do an emergency stop. It is advised, like other abdominal surgery that you do not drive for at least six weeks, always consult your GP for more information.

You may resume sexual activity as soon as you feel able, remember there are more ways of making love than full intercourse. Cuddles and hugs are probably enough in the beginning. The important thing is not to be afraid of what comes naturally. (The CA has literature on sex after surgery and body image).

After you have recovered from your surgery and resumed your normal activities you may choose to wear light or intermediate support garments all day as a preventive measure and even if you do not have a hernia or bulge it may be sensible to wear a support belt when playing vigorous sports such as golf or tennis.

If you have any reason to believe you may have a hernia, always seek advice from your stoma care nurse.

What is a Hernia?

There are two types of hernia that an ostomate may develop. The first is called a parastomal hernia and the second is an incisional hernia.

Under the skin of the abdomen there is a flat sheet of muscle which holds our intestines in. When a surgeon

Support for you and your stoma

Photos courtesy of **OstoMart**

creates a stoma, a hole is cut in this muscle to bring the end of the large intestine (colon) out to the surface of the abdomen. This therefore makes a weak area around the stoma, which sometimes allows a section of small intestine to be pushed up around the stoma, causing a swelling. Similarly, with an incisional hernia the scar may tear causing the intestine underneath to push through and a hernia may develop here.

A hernia may develop further and enlarge, (it may start at the size of a small tangerine but become as large as a melon) for no apparent reason. The simple action of coughing or sneezing can increase the pressure inside the abdomen causing the muscle to push forward and the skin to bulge around the stoma. To help support the abdominal muscle you can hold your abdomen whilst coughing or sneezing. The skin can stretch around the stoma, causing the stomal opening to enlarge in diameter. This can impact on your appliance, requiring progressively bigger holes to be cut. You may also need to change to a different style that has a larger or more flexible adhesive area, or add tape or a skin friendly accessory to help anchor the edges onto the contours of the bulge. Wearing a support garment can help prevent these changes in size as you change position, especially if you lie down and position the support garment while the hernia is reduced.

What support garments are available?

Fortunately, there are a number of support belts and garments that have been specifically designed to effectively support the hernia as well as reduce "the lump".

These take the form of firm belts or pants offering excellent support in the stoma region yet do not inhibit movement or "roll" upward. They really are effective - and are available for men and women who have either incisional or parastomal hernias as they hold the pouch close to the skin which has the added benefit of helping the flange adhere to the skin properly.

There are so many to choose from, where do you start? The first thing to do is to contact your stoma care nurse, she will have a look at your hernia and be able to advise on the most suitable item for you, one which will offer you the best support. Once decided upon your stoma care nurse will arrange a fitting session where you can try on the support garment and be correctly measured. If you are to have an aperture for your pouch to fit through then it is important to be correctly marked up for the aperture. The National Stoma Advisory Panel has recommended that a maximum of three garments a year should be prescribed and supplied each year. (Wash, wear, spare!!)

Remember if you are likely to be wearing a belt or support garment all day it is important that it fits comfortably and is not so restrictive that it is difficult to get on and off. If it is too restrictive you may find yourself not wanting to wear it thereby defeating the objective – support.

Belts come in differing widths, with or without holes for your pouch, fastened by clips or Velcro®, in sizes small, medium or large and with or without adjustment panels, so it is important to get advice about the many products on offer. The belts and support garments can offer mild or firm support. For heavy work, lifting, gardening etc: you will need a very strong support belt or garment. For everyday wear a lighter support may be appropriate. The garments are worn during the daytime only; you should take them off when having a bath or shower and when going to bed. If you think you need to wear the support garment in bed, then you must discuss this further with your stoma care nurse.

If you have a colostomy you may choose to have a garment with no hole for the stoma pouch as your stoma only works occasionally. If you have two stomas, (usually a colostomy and a urostomy) the garments will need to be tailor made to ensure that both the fit and support is correct. It is so important to discuss your needs with your stoma care nurse; garments need to be made to measure to ensure the holes are in the right place.

One of the "side effects" of wearing a good support garment can be that it sometimes causes "pancaking". This is where the output from your stoma refuses to go into the pouch, because it is restricted by the tight garment. So the faeces gather around the top of the pouch, sometimes forcing the pouch off the skin. This is an unwelcome side effect of wearing a firm support garment but it can be resolved by using a gel or a little oil inside the pouch, so enabling your output to slide into the pouch more easily. Most manufacturers of pouches produce gels, so discuss it with their helpline (or your stoma care nurse) when you next place an order for pouches. However, with the firm support of the belt the problem of "leakage" can be eliminated by the belt keeping the adhesive section of the pouch firmly pressed against the body.

Fortunately, there are many companies who design and make ranges of effective support garments especially for those who wear a pouch. Support garments, are for both men and women. The garments are made of specialist comfort friendly fabrics and are available in various designs. Some come with a hidden inner pocket that will hold and support the pouch and stop the pouch dropping below the leg line thus giving extra support and confidence. Ladies can choose from luxury satin to pure cotton to supple microfibre. There are also high-legged briefs, thongs and French knickers – all have support systems to hold the pouch in place.

Men have the choice of Y-front briefs or boxer shorts also with an inner pocket. Higher waistline underwear for extra comfort is also available with special inner pouch pockets that keep the bag away from the skin and under control. The trunks have extended button fly for easier access.

These support garments really can give a boost to all ostomates who worry about their femininity or masculinity. The underwear garments offer comfort, freedom of movement and assured confidence which in turn enhances "body image". They can give an added sense of security and extra confidence when out walking or socialising.

There are many ostomates who do not need any support garments and are happy to wear something from the high street, designed to give only light control. We have Trinny and Susannah to thank for that! But if you do need the hidden pouch support and a hole cut in the garment to allow your pouch through, then a custom made garment may be the solution.

A good way of learning about support garments and accessories is to attend manufacturers open days. It is a great way to see these items for yourself. You can then discuss different options with your stoma care nurse before making that all important decision to go ahead and order a belt or support garment. On page 53, Notebook - you will find a selection of open days alternatively why not visit - www.colostomyassociation.org.uk to find an open day in your area.

Helpful Advice

Always consult your stoma care nurse before using a support garment in any of the following situations:

- if you wish to wear the garment whilst sleeping.
- if you use a convex appliance.
- if you are in discomfort or pain.
- if a drain is situated in the area which will be compressed.

Also consult your stoma care nurse if whilst using your garment:

- your bowel function changes.
- if you have gained weight and the garment feels small.

Editors Comment

We anticipate a lot of feedback from this article, so don't be shy! Let us know about your experiences, recommendations or horror stories

e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

Support garment suppliers:

Bullen Healthcare
Contact: 0800 269327
Email: info@bullens.com
Web: www.bullens.com

CUI Wear
Contact: 0800 2792050
Email: info@cuiwear.com
Web: www.cuiwear.com

Corsinel by Coloplast
Contact: 0800 220622
Web: www.coloplast.co.uk

Moorland Surgical Supplies
Contact: 0161 320 9400

Ostomart
Contact: 0800 220300
Email:
enquiries@ostomart.co.uk
Web: www.ostomart.co.uk

Sash
Contact: 0800 3893111
Email:
info@sashstomabelts.com
Web:
www.sashstomabelts.com

Salts Healthcare
Contact: 0800 626388
Email: web@salts.co.uk
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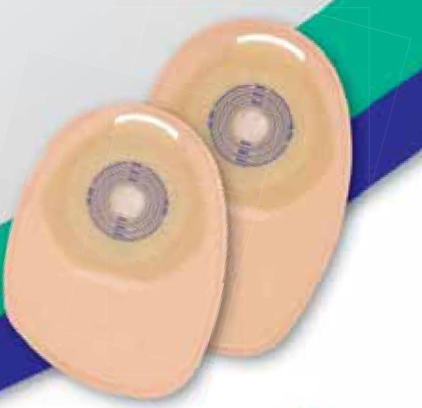

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Can I Swim - Snorkel or Dive?

The answer is “Yes – you certainly can.”

Swimming as we all know is an excellent form of exercise. As soon as you are healed and fully recovered, swimming can be of real benefit to the ostomate. The water gives support and gently soothes the body leaving you feeling refreshed and invigorated. So why not give it a go!

Choosing swimwear...
there are one or two things to remember about design which may help! Patterned fabrics hide secrets that plain ones expose. A good swimsuit lining or double layered fabric will support your abdomen and help to hide the pouch. If you are worried about your pouch becoming detached whilst swimming buy a specially made swimsuit or pair of shorts with a special security pouch included. Board shorts are also a popular choice for men who may opt to also wear biking shorts underneath for extra security.

You could try wearing a smaller stoma bag under your swimming costume or trunks as these can be more discreet. Filters on your appliance can work poorly or not at all once they’re wet or damp. Some ostomates tape the flange edges, some don’t. If you have a filter on your appliance this should be taped so water doesn’t damage the filter. If you’ve changed your flange before swimming it’s a good idea to wait an hour before going swimming to make sure it has adhered properly.

Your stoma care nurse will be able to advise on the many different varieties of appliances available. If you are worried about damaging your stoma whilst swimming, although this is unlikely to happen, you could try wearing a stoma shield.

Remember that the great majority of ‘normal’ people have lumps, bumps and imperfections on their bodies - very few of us are model - perfect in the first place - and nobody is going to be staring at you.

(NB: It is recommended to avoid swimming in artificial pools, spas and the sea for at least six to eight weeks or until your wounds are completely healed because of possible infection.)

Swimwear Specialist Suppliers:

Bybonnesen.com
Frederiksberg Alle 92, 6.tv.
DK-1820 Frederiksberg C
Email: info@bybonnesen.com
Web: www.bybonnesen.com

Comfizz
Ladies and Gents swimwear
designed by an ostomate.
Contact: 0113 289 6876
Web: www.comfizz.com

Cui Wear
Call for full colour brochure.
Contact: 0800 2792050
Web: www.cuiwear.com

Ostomart
Ladies and Gents swimwear.
You can order by phone or on line.
Contact: 0800 220300
Web: www.ostomart.co.uk

Vanilla Blush
Contact: 0141 556 1035
Web: www.vblush.com

White Rose Collection Ltd
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‘Just Men' catalogues available.
Contact: 01202 854 634

Web: www.whiterosecollection.com
Woman Zone
Contact: 01925 768992
Web: www.woman-zone.co.uk

Readers’ Experience: I am so looking forward to the Summer Holidays, when I shall be spending 10 weeks in Brittany, just 20 mins from my favourite beach. When the weather is kind, I like to spend a couple of hours or so on the beach in the morning, reading, wandering and swimming, before most people arrive. Failing that, I go for a quick dip late afternoon, as the French are all leaving to go home for supper. I wear a 2-piece Tankini Swimsuit (I’m on my 3rd. from White Rose) and a tiny waterproof Braun Mini-Pouch, I take a towel (to sit on in the car, when I’m wet) and a skirt (to slip on for the journey) and never have to change on the beach. If I do have to change, it’s easy enough in a 2-piece, under a towel! I can’t wait – why don’t you try the sea this year? Judith (aged 66)

Kind thanks go to the Swimwear companies for their contributions to this article.

Reader
PANEL
contributor

Talking about Exercise...

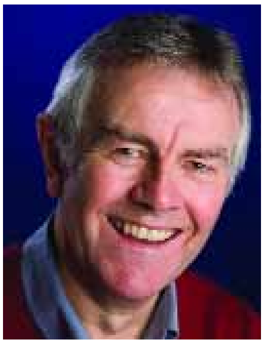
Thousands of colostomates enjoy a huge range of activities such as sailing, cycling and swimming as well as more down to earth pursuits like gardening and rambling. Bob Buckley (CA volunteer) tells his story extolling the benefits of exercise before and after surgery, whilst fellow ostomate, Ernie Millington tells us how he enjoyed exercise before he had his stoma and explains his remarkable journey back to health.

The benefits of exercise after surgery and beyond...

A few days after surgery exercise can be resumed. Light aerobic activity such as walking stimulates the return of bowel function and will get you back on the road to recovery, helping you regain the muscle tone lost whilst in hospital. Exercise also increases blood flow and thus aids healing, likewise deep breathing exercises. Always remember to keep hydrated - drink plenty of fluids.

Make exercise fun, find something that you enjoy.

Always check with your doctor or stoma care nurse before taking up any form of exercise.



Mark Twain once said "I am pushing sixty. That is enough exercise for me."

I have to say I don't agree with the great author - I have always been keen on exercise, e.g. running, going to the gym, even football, until I broke my patella in my forties! I have always believed in *sit mens sana in corpore sano* (a healthy mind in a healthy body). I was always good at cross country running at school; however like most young men other pursuits took over!

However, in line with the boom in jogging, I picked up the running bug again in my 30's and joined Durham Harriers, taking part in nine great north runs (best time of 1 hour 23 mins). Into my late 50's I was still competing and very fit when to my huge surprise and chagrin I was diagnosed with bowel cancer and received the double whammy of being told I would need a permanent colostomy. I kept up my fitness regime right up to my operation; in fact I went for a five mile run the day before my surgery. I think my exercises helped in three ways;

- I firmly believe the fitter you are the better you recover from surgery
- Exercise helped keep me positive, all those endorphins released and
- The exercise helped me sleep at a very worrying time.

So off I went for the dreaded appointment still convinced I was going to recover in world record time, boy was I in for a shock. The operation went well and the good news was my cancer was diagnosed as Dukes A, which apparently is the lowest grade you can get, phew!! All down hill from there, my bowel went into sleep mode so they had to feed me intravenously, my stitches burst open so I needed another bout of surgery and to cap it all I contracted an infection. At this stage Mrs B was very worried and stressed and it's worth mentioning that it is often much worse for our loved ones. After about three weeks I was discharged weighing about 2 stone less than my fighting weight, which is only 11 stone to start with. I felt very weak and was certainly in the most vulnerable position of my life. Nevertheless I have always been very positive so I decided to plan how I could get back to fitness.

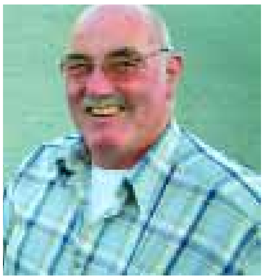
To start with I listened to all the medical advice, e.g. don't strain or lift anything too heavy because of the danger of herniation. After a couple of days I decided to start walking, bearing in mind pre-op I had no problem running 10 miles or more. However to start with I just walked around the corner and back. This felt enough and to anyone recovering from surgery I would always say, don't overdo it, listen to your body. I continued to build up my distance over a few weeks until I could walk about 8 miles at a good pace.

At this stage I restarted my running regime, easy at first, gradually building up. I also went back to the gym to do some light weights for my upper body and some abdominal exercises. Previously, my stoma nurse Sue had given me a booklet which showed some gentle abdominal exercises so I built on those. If you want to do abdominal exercises take advice because most people do them incorrectly with the danger of injuring their back.

I am now 62 and still exercise as much as possible. However, I do get more tired than I did in my 40's. Nothing to do with having a stoma, just Father Time creeping up on me. So I listen to my body and take the required rest days.

I never intended to let my stoma get in the way of what I want to do with my life and it's fair to say it hasn't. In fact I hardly ever discuss it. To sum up I would say whatever your sport there are some basic principles involved following surgery;

- Listen to the medical people, e.g. SCN, doctors, consultants when you are discharged from hospital.
- Discuss your fitness plan with your SCN and/or doctor before you begin, especially if you have to take any special precautions, e.g. for a heart condition
- Take your time. Getting fit and well should be treated as a marathon not a sprint
- Listen to your body and rest if you feel tired
- Seek advice in terms of the type of exercise you can and can't do. The suppliers of stoma care product have some great exercise booklets, ask the Colostomy Association for details.



"How so much good came from having my stoma"

I had been fit and athletic for most of my life. I had served in the British Army (para regiment) in my youth and always enjoyed keeping fit. I played squash, did weight training and some running before chronic ulcerative colitis affected my health eventually forcing an Ileostomy on me in 2004. I felt like I'd become an invalid, no longer 'normal' and I became depressed. I was told there was a possibility of reversal and so clung on to this hope, which didn't help me accept my stoma at all.

I became self conscious of my stoma, aware of it filling and felt sure that everyone around me must be too. I developed a habit of holding my bag as I walked about, feeling like it needed supporting as it filled and started dragging.

Before my stoma I used to sleep without PJs but now felt my bag needed holding in place during the night and so resorted to underwear. However the position of my stoma meant that I couldn't find comfortable underwear to fit properly. Swimming was too embarrassing to even consider at that stage and so life had become quite limited. All the time though I still believed I could have a reversal and go back to 'normal' and couldn't wait for that day to come. That day never arrived because the surgeons were unable to reconnect the remaining bowel. It had 'rotted' away and so I had to accept that I was lucky to be alive and come to terms with my stoma.

It's funny though how unexpectedly things can turn around! I got talking about my stoma to my daughter and son-in-law who ran a small business designing and producing high performance sports wear (Comfizz), I suggested we work together on a new range of stoma support garments. Initially this was just for my own benefit but I was so delighted with the results that I showed them to my stoma nurse at St James Hospital in Leeds. She was so impressed that she asked us to attend a local open day, which was to become the first of many.
You could say I was the perfect candidate to test out our new products. I soon found the garments supported my bag and almost forgot at times that I even had a stoma. The design of the garment sitting comfortably over my stoma, and the gentle pressure and support seemed to help expel gas and prevent the bag from bloating. The waistband was great for night time, holding the bag in place without the need to wear underwear. I also tested them out under my swimwear when I on holiday!

By now I was feeling much better and so positive about having helped create something that could benefit others like myself with a stoma. I wondered whether I ever would have achieved anything like this had I not suffered a stoma? As the saying goes "Every cloud has a silver lining!"
If anyone is reading this has a new stoma or is about to have one, please believe there is always light at the end of the tunnel and I'm sure many great things lie ahead for you too.

I'm now over 70 years old and feel as if I have a new life. I walk my dog several miles every day, something I couldn't do when I was suffering with colitis. Although I'm not up to playing squash or running these days I am an active member of my local bowling club, playing in a league competing every week. I have four wonderful grandchildren, one is into motorsport, two are national divers (Olympic hopefuls!) and the fourth is too young to be into sports yet, plenty of reasons for me to feel inspired and to continue to live a full and active life. They all call my stoma "Grandad's hot water bottle" and it doesn't seem to bother them at all. They're just glad to have me around to taxi them to training, school or college and to cheer them on in competitions etc!

Editors Comment

If you have a similar story to tell or would like to reply to either Bob or Ernie please contact the Colostomy Association

e-mail:
editor@colostomy association.org.uk
or write to:
Colostomy Association
2 London Court East Street
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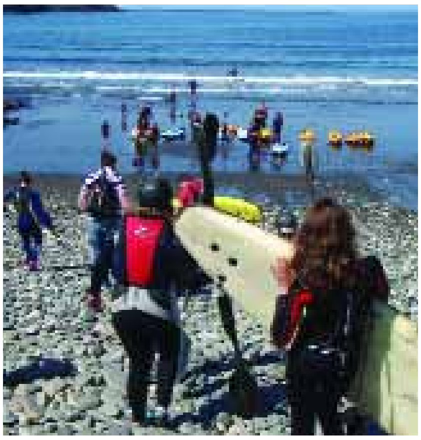
BreakAway

Rachel Clarkson BreakAway Co-Founder and Trustee talks about BreakAway receiving Charitable status (Registered charity number 1129759) and the success of this years event at Broadhaven. Ailsa and her Mum tell us about their experiences and Hannah writes a special report!

Having been back from Broadhaven for several weeks now, I am still overwhelmed by the huge success BreakAway has become. The third BreakAway weekend attracted 61 guests, double the number of people we had back in 2007 at our first weekend. There were many new families who travelled from all over England and Wales to join us.

The event kicked off with us proudly announcing that BreakAway Visits is now a registered charity in England and Wales. Then it was on to traditional team games and challenges, splitting up guests into small groups to get them talking and working together. The first night is crucial for BreakAway. Both old and new families can relax and get to know each other, without the added pressure of talking about the problems they face - having a child with a bowel and/or bladder diversion or dysfunction.

At any BreakAway event we never force anyone to talk unless they want to but the relaxed atmosphere and the underlying knowledge that everyone is going through similar issues, helps families feel able to discuss their stories or share tips with people who completely understand.



The weekend activities aim to build confidence - we look for things that will push the children that little bit further without being too daunting. This year all the activities were based around the beach. We offered coasteering, surfing, sea kayaking and raft building. The idea behind our events are encouragement and personal skill building - just because you have a stoma it shouldn't stop you doing anything – even getting wet!

Stoma nurses are on hand at all our weekends to help out with any advice if its needed and we have a mini exhibition on the last day where stoma care companies and patient associations come along and offer their support and show their products. This is really helpful as families don't often realise what products are available and that there is support out there for them.

The last night is party night, my emotions usually get the better of me but I am so passionate about this charity. This year we had an Hawaiian themed disco and everybody entered into the party spirit with their fancy dress. It has become something of a BreakAway tradition to have a last song where all of us join hands and dance in a big circle. Just when we thought we had finished for the night Julie and I were asked to stand in the centre of the circle and the last song from our first weekend was played. Julie and I brought all the children into the centre with us and then the tears flowed.

It's difficult to explain, but when I see all those people, some of whom I have never met, come together in one room and act like one big family, I realise the difference BreakAway makes.

As an adult with Crohn's Disease and a colostomy I can empathise with the issues young people face on

▶

a daily basis - BreakAway ensures that none of these young people or their families ever have to feel like they are on their own. Plans are now afoot for the 2009 Christmas party and two BreakAway weekend events in 2010. We will also be updating our website and message board very soon.

Julie and I want to make sure we reach as many families as we can. Our focus is spreading the word about BreakAway - getting funding and sponsorship (so that no family is excluded due to limited finances) and building upon the success we have had so far.

Ailsa (aged 10)...

When I found out that we were going to the BreakAway Weekend and that I would meet other children who had the same kind of thing as me I was SO EXCITED! I could not stop talking about it for days to my friends – I think I drove them mad. I was just so looking forward to all the activities, meeting new people who would hopefully become my new friends.

So what was it like? The activities were BRILLIANT – I especially liked the coasteering. I was the first one in the FREEZING COLD water and I didn't mind it at all. The rock climbing bit was hard but falling back into the water again was fine. Raft building was really fun and everyone was just laughing all the time. My mum was hopeless at it.

I think I can make friends quite easily. By the end of the evening on day one I had met a family who had a girl my age. We did fun games together and this helped us to get to know everyone.

I have to say it was a bit strange meeting others like me. I am so used to being the only one (I have a stoma that I call Plum – 'Plum on my tum'). It made me realise I wasn't alone. Each child had a 'something' but no-one was moaning about it – we just get on with life. There were some children there with an ACE which I had never seen before. I know that in the future I could have one but for now, I am happy with Plum. I have had her most of the time since I was four. She is a part of me now and I kind of missed her when I didn't have her.

So do I want to go back to BreakAway again? DEFINITELY! I had such a good time and I know my mum liked it cos she spent for ages chatting and stuff to other mums. She said it was a good experience for her too.

Ailsa's Mum
(of indeterminate age)...

The brilliant stoma nurse at Bristol Children's Hospital Claire Bohr, told me about BreakAway and I was lucky enough to get a place on their summer weekend. When I told my daughter she was beside herself with excitement. We live in Cornwall and she had never met anyone her own age with a similar condition.

The weekend was everything I hoped it would be. I knew there would be families who already knew one another from previous BreakAway events, but there were also those who, like me, were new to the group and this included a family with a girl the same age as Ailsa. I really valued the opportunity to talk to others away from the intensity of a medical environment.

The organisers and parents were welcoming and open about their experiences – from the humorous to the harrowing. It was good to share both. I found the weekend really good fun and it was clear that a lot of thought and care had gone into the planning of the event. It caters for parent/carers and for children of all ages. As Ailsa has made clear we WILL be going again.

Special report...
My special friends
by Hannah Adams age 8
(Julie Bastin's daughter)

I love going to BreakAway!
At BreakAway I have made lots of new friends who all have problems like me. Before my Mummy started BreakAway I thought that I was the only one that had problems with my bowel and my bladder. It is nice to have lots of friends who are just like me!

My friends at school, when I first got Mr Pluggy (my stoma) thought that it was an electricity plug stuck into my tummy!! But how were they to know, I tell all my friends at school and they think its fab! I like BreakAway because I do not have to explain anything to anyone as we are all just the same?

Sometimes people come to BreakAway who have not had their operation yet, and do not know what it is like. If they want to know, I will tell them. I used to be scared of stuff like that, but now I am not scared at all. I used to have a colostomy and now I have an ACE (Mr Pluggy!)

At this year's BreakAway we did sea kayaking, coasteering, raft building, and surfing. It was so much fun. On the last night we had an Hawaiian fancy dress party. Everyone joined in, it was great. On the Sunday afternoon, it was really hot so we all went to play on the beach. My Daddy soaked all the kids by chucking buckets of water over their heads!
I am so excited about the Christmas party weekend. I know what the surprises are but I can't tell you what they are!

BreakAway

Christmas Party 27th & 28th November 2009

For more details and booking forms or to enquire about our funding applications please call Julie 07939 690311 or Rachel 07751560013 or alternatively why not visit the BreakAway website:
www.breakaway-visit.co.uk
and hit the contact us button!

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Readers' writes

Why not write or email the Editor of Tidings with your thoughts, experiences or hints and tips...

Dear Editor 'Tidings' helps people find and share information!

I would like to say thank you to the contributor to "Readers Writes" Mrs J.R. from Tyne and Wear for her letter in the spring edition. Back in the summer 2008 edition you printed my letter regarding rectal pain as the result of an abdominoperineal resection.

In my original letter I pointed out that I was able to conclusively verify most side effects of various pain-killing drugs, and arrived at a position of taking the medication and still having pain. I made the decision to stop taking the lot, however being constantly worn down by the now identifiably different types of pain, I was soon back at the pain management clinic.

Pain blocking injections that had been mentioned on previous visits to the clinic had frankly scared me, however they now took on a more appealing character. Knowing that at best the chances of the injections working in my case was twenty five percent I still thought anything was better than the current state of play. The explanation of these injections can be very off putting, but in reality I was pleasantly surprised and felt nothing. Sadly that is what the injection did!

Next up hypnotherapy. After three sessions I concluded that yes I did need to relax more but I could not convince myself I did not have a pain you know where.
Back at the pain clinic one last possible injection was on offer, but to reach the nerves needles would need to be bent to go around things!

Luckily at this point I read in Tidings about Lidocaine patches, and subsequent discussions with my G.P. lead to me trying them out, and at this moment things are looking very promising, not totally the answer, but a good general improvement, visible to and commented on by my friends.

Once more a big thank you to Mrs J.R. of Tyne and Wear and of course Tidings, illustrating how important it is to share what we experience and try to help each other by it. I have nothing but praise for all the people that have helped me throughout my problems, but I do wonder if we would have come across Lidocaine on our own, or how long it would have taken.

Thanks again for a great association.
Yours sincerely.

D.S
Bedworth, Warwickshire

From Ed: D.S is the lucky winner of the star letter and will receive a £20.00 gift card from M&S

Dear Tidings A rather nasty surprise...

I had a rather nasty surprise recently, and I wondered how many others have been affected. I have had a colostomy since October 2007 as a result of a perforated bowel, from a diverticulitis abscess. Having decided in 2008 not to have a reversal I have got on with my life, managing quite well.

However, about two months ago I had been having some discomfort in my rectum so went to my GP. I was amazed to hear, after internal examination, that I had faeces in the rectum. (17 months after my operation). And it was hard, about the size of a golf ball. It took weeks of administering, firstly enemas and then suppositories and enema combined to shift it. All in all, not a very pleasant experience. I feel that this should have been cleared while I was in hospital for three weeks, so I mentioned this to my GP. However, she says this happens to many people, so don't complain. I still think this is negligence, but I didn't write to the hospital.

It seems to me that a lot of people could be saved a lot of later trouble if an examination was done before discharge from hospital. Thoughts on this from other colostomates would be welcomed.

Sincerely,

E.S
Nuneaton
Warwickshire

If you want to be involved in the next issue of Tidings magazine **- simply drop us a line** via email:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court,
East Street,
Reading RG1 4QL

Look out for our Reader Button (opposite) to see where readers have contributed to Tidings.

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Readers' writes

Dear Editor
Light at the end of the tunnel

I had an AP resection with a permanent colostomy at the end of January 2009. I was given a 'Tidings' magazine to read which I found most helpful, and knowing there is light at the end of the tunnel having read other peoples letters - thank you.
Yours sincerely,

P.M.
Cleethorpes
North East Lincs

Dear Tidings
Request for feature on mucus and prolapsed rectum

Could you do another feature about mucus and prolapsed rectum. I am 80 years and coping OK with colostomy which I had in 1985. Despite two operations 8 years ago for prolapsed rectum I am still uncomfortable walking some days.
I saw a surgeon privately at Bristol but he says there is too much scar tissue to attempt any more surgery.
Looking forward to the next Tidings.

Yours faithfully,
M.L (Mrs)

Dear Editor
Sangenic Hygiene Plus Nappy Disposal Unit again!

For the first time since my colostomy in 2004 I picked up my telephone and called your helpline. I was thinking about a holiday in Cornwall and was worried about 'where to put my bags'. Would there be a Wheelie bin on site, should I notify the owners that I had a colostomy, I was really worried about it all.

The lady who answered the helpline was Iris. I talked to her and explained my worries and she was so encouraging. She told me about the Tommee Tippee Nappy wrapper. At first I laughed because I could not visualise it. I decided to go to my local Mothercare the next day it was on offer at £9.99 instead of the usual retail price of £19.99. I couldn't wait to try it! Well, I got up in the morning full of doubts that the nappy wrapper was as good as everyone said it was. I WAS WRONG.

The nappy wrapper is a brilliant invention and absolutely no odour at all remains in the bathroom, once the bag has fallen to the bottom of the unit. It has changed my life.

I can travel anywhere in the U.K. now with it in my car, it is compact and light and solves my problem, when travelling, of 'where to put my bags'.

I would like to say a big thank you to Iris for telling me about this unit and then later when my Winter Tidings Magazine arrived, there was an article about it in there.

I would recommend all Colostomates, to hotfoot it down to their local Mothercare to buy one. At the moment the special offer of £9.99 is still ongoing. No More constant trips to the wheelie bin. Hooray !

I just wanted to share this with all your readers as constant trips to the wheelie bin was really getting me down and now I can empty my nappy wrapper unit at my convenience.

With best wishes to all and thanks for a brilliant magazine.
Yours most sincerely,

C.M.
Aspley Guise,
Bedfordshire

Toilets who needs them...

we do - more and better quality but tailored to the needs of the user...

There are an increasing number of specialist user groups, such as ostomates, whose lives are affected by the state of Britain's public toilets.

Tidings is shocked to hear increasing stories and comments from ostomates about the state and quality of many of our public toilets.

We would like to hear your stories, and feedback - whether it is positive or negative. We want to know your experiences!

We will then use this information as basis for a future article. Please contact the editor details are on Page 5.

You might also be interested to know that the British Toilet Association would also be interested to hear you points of view.

How to contact:
British Toilet Association, PO Box 847, Horsham, West Sussex, UK RH12 5AL
Phone: 01403 258779 E-mail: enquiries@britloos.co.uk
Web: www.britloos.co.uk

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How to obtain a key to gain access to toilets for the disabled

Colostomates are entitled to a key which will open 7,000 locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

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Keys can also be purchased for £3.50 from RADAR:
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www radar-shop.org.uk

RADAR also publish a guide which lists all the NKS toilets throughout the UK (cost £10.25).

Dear Nurse

Julie Rust RGN. Dip, N. MSc.
Clinical Nurse Specialist
Stoma Care
University Hospital
of North Staffordshire

Q: *I had my colostomy in March of 2008. I do not mind the colostomy but what does concern me a little is that I have seepage or mucus all day long. When I had my colostomy I was told that I would only have discharge once a month. Boy! were they wrong! I don't know how to handle this. I for one don't like the odour that it causes. Nothing that I do eliminates the smell. I am embarrassed to go out or even be around people for the fear that they too can smell it. Do I need a rectum removal to correct this problem? Any advice that you can give me would be greatly appreciated. Please let me know if there is anyone out there with the same experience as me. It would be nice to know that I am not the only one.*

A: Discharge from the rectum following this type of operation is not unusual but it is impossible to say how frequently this discharge will occur. Some people get it daily whilst others only have a problem every few weeks or months. If you are finding there is an unpleasant smell with the discharge it may be worth having a medical review with either your GP or Consultant to see if there is an infection there and whether a course of Antibiotics would help. Removal of the rectum would also be a solution but you would need to discuss the problems and benefits of this course of action with your surgeon. Another alternative would be to have a Glycerine Suppository inserted into the rectum to help to remove any buildup of mucous you have there, this may need to be done on a regular basis and medical review prior to this would be needed.

Q: *Can you help me? My Dad has had a colostomy for a number of years. He suffers from terrible diarrhoea and can go to the toilet 5 or 6 times a day. He can't go back to hospital for a operation because they found a problem with his heart. He is 85 years old. What I need to know is whether there is something wrong with his diet and if so are there any tablets or medicine that might help him? He also lives on his own. He can't leave his home because he's got leg ulcers. Can you please advise me?*

A: It sounds like your Dad needs a medical review to see if he can get any help with what seems to be a group of problems. The output from the stoma may be a simple thing to sort with a change of diet or some medication such as Fybogel, taken twice daily dissolved in a glass of water, to help to regulate the output. However it may be useful to get a full review from the GP who can then assess your Dad and refer him for social services support or District Nurse support for the other problems. I hope this helps.

Q: *My husband had surgery in January for colorectal cancer and because he was vehement about not having a permanent colostomy he opted for surgery followed by chemo and radiation. He began the chemo two weeks ago and aside from some of the expected effects he has been fine.*

However, yesterday, when we were scheduled for the disconnect from the portable chemo bottle he became aware that nothing was passing through the stoma into the bag, but rather was going through his rectum. It was not that he had the urge to go, it was just passing through.

I contacted the chemo centre who suggested that he might be constipated and recommended taking laxatives for 48 hours. He tried that but is still having the same problem. Now we are concerned that there is some kind of blockage by the stoma. I guess I just want to know and so I can calm my fears that more surgery might be needed. My husband is opposing that. Any response from you will be appreciated.

A: This is a difficult question to answer as I do not have access to your medical records. I would think the best option is to have a review by your surgeon, this can be arranged through the chemotherapy unit. The surgeon would be able to investigate why this problem is occurring and could then discuss the treatment options with you. I cannot guarantee that this would not involve further surgery but you need to see the surgeon to discuss this further.

Q: *I have a relative who has had a colostomy for just over two years and is still overweight. She wants to lose weight and exercise but wants to contact you to find out what abdominal exercises can be done without risking herniation. She is very busy and will probably not make time to contact you so I wanted to find out for her. Are there any prohibited exercises? Also, can irrigation be taught even though she is still suffering from diarrhoea? She says it is problematic, but can it still be taught? Thank you for your help in advance.*

A: Your relative should be alright doing any sort of exercise as long as it is performed correctly. It may be worth her joining a gym or sports centre where she can discuss her surgical history with a personal trainer who can then suggest an exercise programme to suit her. Alternatively general exercise such as walking or swimming may help. Obviously a suitable diet would also be necessary for any weight loss and she should undertake this correctly so that she looses weight slowly. With regard to irrigation she would need to see her stoma care nurse to discuss her suitability for this and also for training if she feels she wishes to try it.

Q: *I had an operation for Crohn's disease and ended up with an ileostomy, which I have managed for nineteen years, now into my twentieth with the bag. I am suffering from very red and sore skin around the stoma, I try to watch what I eat and find my diet is very limited, my stoma care nurse hasn't been very helpful, however, it is a struggle trying to cope. I would appreciate any help you could give me, I am now into my seventy eighth year. Thank you*

A: Obviously it is difficult to say why you are having this problem without more information. The soreness could be due to several things including a change in size of the stoma, a change in your weight or even an allergy to the adhesive on the pouch. If the skin is very red and wet it may be useful to try a powder such as Orahesive by Convatec and an adhesive ring such as those made by Salts (Cohesive Seal). This would help with the adherence of the pouch and would help to improve the condition of the skin. It may be worth you revisiting your stoma care nurse for a further assessment regarding the product you are currently using to see if there is an alternative for you to try. With regard to your diet you can get more information from the Ileostomy Association website on www.iasupport.org or telephone 0800 0184724. Certainly some patients find they need to alter their diet slightly but it sounds like you have really had to restrict your diet. Certain foods may cause a looser motion such as citrus fruits, green vegetables, salad, prunes, fruit juices whilst other foods can help to thicken the output such as pasta, rice, potatoes, jelly sweets and cubes of jelly. If necessary you can also use medication such as immodium or codeine to thicken the stool but you would need to see your GP for this.

Q: *I hope you can advise. My daughter had a colostomy 5 months ago and she is having problems with wind which is causing the bag to blow up like a balloon. She is becoming very distressed as she feels uncomfortable and embarrassed that the bag is very noticeable. There are air holes in the bag but this is not helping. She is also having problems getting underwear as the top of the bag is above the waistline.*
Hope you can help.

A: The excess wind that your daughter reports is possibly due to her diet. She needs to eat regularly, avoid too much fizzy liquid and try to chew her food well and eat without talking. Also it may be helpful to keep a dietary diary so that she can see if there are certain foods which cause an increase in the wind, certain foods in some people can increase the amount of wind they produce and once she is aware of what foods effect her then she can either avoid them or at least eat them in smaller quantities or at a time that will cause less problem. Some people report a reduction in the amount of wind they produce if they use probiotic yoghurts or drinks such as Actimel or Danone, whilst others have found peppermint, fennel or charcoal useful, but again this is a personal approach and does not work for everyone.

Editors Comment

If you have a medical question or a query about stoma care management

Why not write to us at:-

Colostomy Association
2 London Court
East Street
Reading
RG1 4QL

or e-mail
cass@colostomyassociation.org.uk

We will forward them to Julie Rust and publish her answers in the next issue of Tidings.

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Accessories or Necessities...

L to R: Lesley Law, Heather Dennis and Caroline Rudoni

Clinical Nurse Specialists (CNS) Lesley Law, Heather Dennis and Caroline Rudoni in Stoma Care at St George's Healthcare NHS Trust, London, are currently undertaking a research study on the use of accessory products in stoma care, with the aim of identifying whether there is any consensus of opinion regarding their use.

Their interest in the use of accessory products follows a service evaluation undertaken in 2008 on the use of silicone-based adhesive remover.

Caroline takes up the story - "as a department our usage of silicone-based adhesive remover, at that time, was intermittent, and the use was based on each CNS's own opinion of how much discomfort they felt the patient appeared to experience when removing a stoma pouch". An evaluation was completed to identify whether the patients themselves found it beneficial to use a silicone-based adhesive remover when removing their stoma pouch. The results of the study overwhelmingly suggested that patients do experience great benefit from the use of a silicone-based adhesive remover, with 91% of patients confirming this, and 93% of patients stating that they felt it should be offered to all stoma patients.

Following presentation and publication of these results, many stoma nurses have informed us that they have altered their own practice based on evidence from this study, and now also offer silicone-based adhesive remover to their patients.

However, surprisingly a few stoma nurses have mentioned that whilst they agree with the results of the evaluation and identify the value to patients of using a silicone-based adhesive remover, they would still not offer it to their patients unless they were in considerable pain when removing their pouch.

As a department we were concerned to hear comments like this, particularly as – like many stoma nurses – we strive to provide the best service we possibly can for our patients.

While there are Best Practice Guidelines published for many practical aspects of stoma care (CREST, 2006), there is still a lack of evidence available upon which we can base our clinical decisions regarding more subjective issues, like the use of some accessory products such as silicone-based adhesive remover.

This is what prompted our decision to choose the use of accessory products in stoma care for our study.

Questionnaires have been distributed to 420 Stoma Nurses and 150 patients within the UK. The patient group consists of 50 patients with a Colostomy, 50 with an Ileostomy and 50 with a Urostomy.

The study will hopefully highlight the following:-

- What products do Stoma Nurses consider to be accessories? And is this view shared by patients?

- When is an accessory product considered to be a necessity for the patient?

- Is the use of an accessory product based on physical, psychological or financial assessment?

- Should patients obtain the advice of their stoma nurse prior to obtaining these products?

We expect that the results of the study will provide some insight into the current use of accessory products and how well the decision to use them or not is based on clinical appropriateness, cost effectiveness and positive outcome for the patient.

The results will help to provide evidence upon which best practice can be based.

The results will be presented at the WCET UK conference, 30 September to 2 October 2009. Publication of the results will follow in the nursing press in October 2009 and also the patient association magazines.

We would like to thank the patient associations, CA, IA and UA, for their help and support in distributing questionnaires to patients for this study, and to all patients and nurses who took the time to complete and return the questionnaires to us.

This study has been funded by the annual Opus Healthcare Bursary research grant, which was awarded to the Stoma Care Department at St George's Healthcare NHS Trust in October 2008.

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- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
- The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch

Ref. no. SR103

Sash Medical Limited
"Woodhouse", Woodside Road, Hockley, Essex, SS5 4RU.

Stoma Support and Hernia Belt

- The Stoma Support and Hernia Belt is made of a 50mm (2") non elasticized webbing attached to a restraining flange that fits between the bag and the adhesive section of the pouch.
- The SASH Stoma Support and Hernia belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.
- Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region while wearing the belt.
- Used by ostomists with a pasastomal hernia (a bulging around the stoma) the belt will also help prevent muscle damage and enlargement of the hernia.
- Ideal for work, sports, gardening, housework, DIY or at any time stomach muscles require a firm support.
- With support from the Sash belt and periodic consultations with a consultant some Ostomists are delaying, maybe permanently, the need for hernia surgery.

Ref. no. S1

Freephone 0800 389 3111
Website:- www.sashstomabelts.com

SASH stoma support and parastomal hernia belts are suitable for Colostomy, Ileostomy, Urostomy, Umbilical and waistline Incisional hernias. The SASH stoma hernia belt has been designed and developed by an ostomist to give support to a hernia that surrounds the stoma without restricting normal body movement or limiting muscle use.

For more information:
SASH Woodhouse Woodside Road Hockley Essex, SS5 4RU England
Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111
E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com

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Pouch Size (please tick one): ☐ Maxi ☐ Standard ☐ Mini

Pouch Type (please tick one): ☐ Closed ☐ Drainable

Stoma Cap (please tick one): ☐ Minuet 10-40mm ☐ Minuet Plus 10-55mm

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"Members discuss their stoma care problems with others who empathise and offer practical advice and verbal support"...

Maria Culleton SCN talks about her view of support groups and introduces a new support group for South East Kent

In conversation with Tidings...

Maria Culleton tells us about her involvement with stoma care and gives her view on why support groups are so valuable.

I have been a stoma care nurse since 1998 working within my local Trust hospitals.

I left last year due to family illness to enable me to spend more time with my husband and two young children. I have been very lucky to secure a job which enables me to work from home as a stoma care nurse. This also allows me to be much more flexible in my approach to work as I am available to patients most of the time to deal with urgent queries or emergencies.

I am passionate about stoma care and have two family members with stomas. I became interested in stoma care whilst working as a surgical sister dealing with patients undergoing procedures such as colonoscopies and chemotherapy.

I think from a nursing point of view, support groups are not only very supportive to patients, but can also be rewarding and informative. Most nurses do not have stomas and though we may empathise it is not the same as having to deal with a stoma on a daily basis. I feel that getting people together with similar experiences is so important and can really aid the healing process. Just being part of a group is so useful. Members can offer solutions and advice. It really helps to combat some patients feelings of isolation and helps them back into society gently which they may have found daunting at first.

Maria talks about the new support group for South East Kent

We have recently started a support group for Ostomates in South East Kent covering Canterbury, Faversham, Whitstable, Herne Bay and the surrounding areas but as yet we are undecided on a name! There are no restrictions on who can attend and from how far they'd like to come!

The group is open to all ages and both sexes; we have patients with each type of stoma, from all walks of life, with a wealth of experiences and from different professions.

We are still very much in our infancy and have only held a few meetings but each have been well attended and enjoyed by all. The focus of the group is on support and having a fun time and many partners attend as well.

The initial idea was a long term dream of Roz Charter who lives locally in Canterbury. She has wanted to bring stoma patients together for many years not only to offer support and friendship, but also to arrange an active and fun social calendar. We hope this will include trips to events and shows as well as visits to places of interest.

We still have to decide on some ground rules. A committee needs to be put in place to help with fundraising. We hope to do this by a minimal charge for teas and coffees with a raffle being held at each meeting.

We have found that the majority of patients who attend like to use the group as a way of meeting likeminded people. Members discuss their stoma care problems with others who empathise and offer practical advice and verbal support. Support groups are invaluable and prevent people feeling alone and isolated.

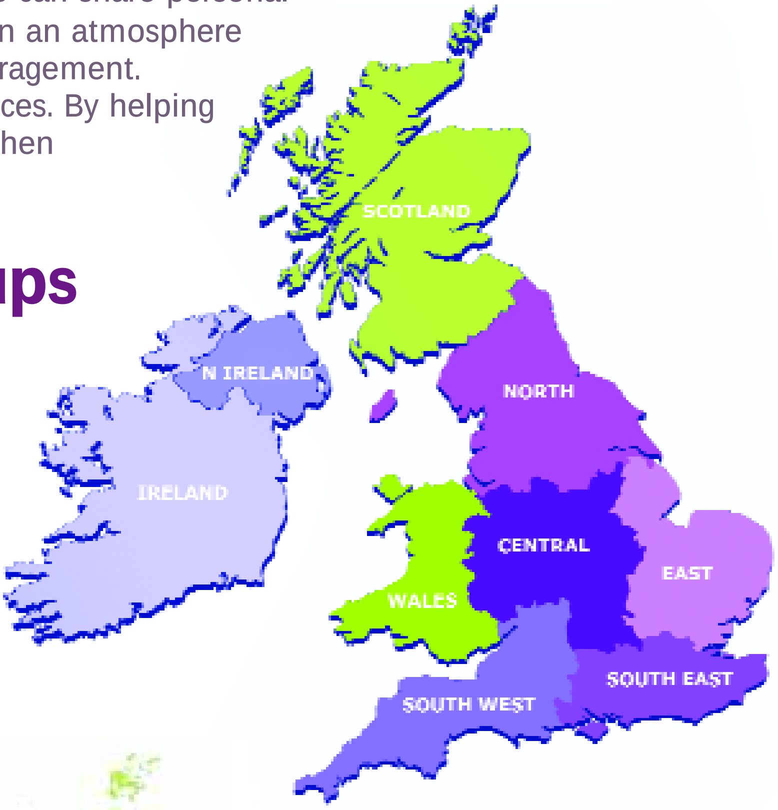
We have met at several different locations so far but are in the process of deciding whether or not to use the same venue each month. It has been suggested that we rotate meetings to make it easier for members to attend.

We would also like to invite guest speakers and have topical discussions either stoma related or on more general subjects.

We also hold a monthly meeting in the physiotherapy department at Buckland Hospital in Dover. It is a small but very friendly group. We meet for support and friendship and anyone in the local area is welcome to attend.

For further details of meeting dates, times and venues please contact Maria Culleton on: 01227 769679

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.



Stoma support groups in your region...

The following support groups have been revised thanks to your responses from the spring edition of Tidings.

No support group in your area? If there is no support group available in your area - why not set up your own group...

Weigh up the pros and cons and, if you decide to go ahead, find a small group of people to start the group with you, rather than going it alone.

Helpful advice...

- Contact the CA Head Office and they will put you in touch with a volunteer who can help.

- Healthcare professionals may also be able to give some advice.

- Your local library may suggest books for you to read.

- Your local council or voluntary services should also be able to provide help.

- Search the Internet for help and advice.

Scotland

Midlothian:
GOSH
Contact: Alex Topping 01501 772154
Maggie's Edinburgh Timetable
Contact: 0131 5373131

Glasgow:
Fittleworth Support Group
Contact: Maureen (SCN) 0800 7837148

Ayrshire:
North Ayrshire Stoma Support
Contact: Jim 01292 220945
(S.C.A.R)
Contact: Maggie 0781 7736147 or John 01290 550551

Fife:
Fife Ostomy Support Group
Contact: Ishbel Barr 01592 772200

England

Cheshire:
Hand in Hand
Contact: Julie Davis Secretary
Cestrian Support Group
Contact: David Burgham 01244 310461
Warrington Ostomy Support Group
Contact: Jane Shaw 01925 662103
Countess of Chester Hospital
Contact: Julie Clements 01244 365490
Drop in Clinic
Contact: Angela Perks/Deborah Singleton 01625 661598

Cleveland
Oops Group
Contact: Julie Morrisroe SCN 01287284113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Pouch cutting service
Prescription collection service

County Durham:
South West Durham Ostomy Group
Contact: Betty 01388-814535 Brian 01388 763684

Derbyshire:
Stoma Support Group
Contact: Anne Wilcox
01283 214389

Lancashire:
Trafford Bowel Care
Contact: Jackie Carey Secretary 0161 7489659 Doreen 0161 9627818 John 0161 7484655
Oldham Stoma Support
Contact: June Wilde 0161 6787086
Salvation Army - Sr Georges
Contact: Stella Prince
01204 413718

Leicestershire:
Moving on (Leicester Royal Infirmary Colorectal Support group)
Contact: Wilf Patterson (secretary)
01455 220344

Merseyside:
Olivia Thomas Suite University Hospital
Contact: (Evening) Barbara Percy 0151 5292842
I.C.U.P.S
Contact: Carol Anderson 0151 3277589
Liverpool Support Group
Contact: Barbara Percy 0151 5292842 (Afternoon)

Northumberland:
Northumberland Cancer Support
Contact: Pat Fogg 0191 4102679

Teeside:
Bowel Cancer support (Semi Colon)
Contact: Mr G Dickson 01642 563747

Tyneside:
Gateshead Health NHS trust
(Stoma drop in clinic)
Contact: 0191 4878989 ext 2221
Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn 0191 2341109
NHS Molineaux Centre
Contact: Lesley Brown 0191 2195656

Yorkshire:
Airedale Stoma Support
Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Scarborough Stoma Support Group
Contact: Sister Jean Campbell 01723 342388

Rotherham Ostomates Caring Support
Contact: Karen Kilford 078880 575758
CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503

Isle of Man:
Stoma Support Group
Contact: Carole 01624 650212
Optimistics
Contact: Stoma Nurse Lynne Webb SCN 01983 534009

Nottinghamshire:
Nottingham Colostomy, Ileostomy & Urostomy support group
Contact: Rosemary Brierley 0115 9826691
Mansfield Stoma
Contact: Gerry Marshall 07794 159267

Staffordshire:
Outlook
Contact: Ernie Hulme 01782 324441 Joan 01782 710828

West Midlands:
Colostomy Group
Contact: Pat Keane 0121 4242730

Lincolnshire:
Friends Support Group
Contact: Betty 01205 724120/Sheila 01205 364493 Bobbie/Amanda 01476 464822

Norfolk:
Stars
Contact: Anne Brown 01603 661751

Suffolk:
James Pagett Ostomy Support Group
Contact: Sandra Hutchings 01502 585955
East Suffolk Ostomy Group
Contact: Marion Fisher 01473 311204
West Suffolk Support group
Contact: CA for details

Bedfordhire:
Saturday Social Club
Contact: CA for details

Berkshire:
West Berkshire Ostomy Club (WBOC) (Reading)
Contact: Jackie Dudley 01344 426652
Monday Pop In Group (Bracknell)
Contact: Jackie Dudley 01344 426652

Buckinghamshire
Milton Keynes Stoma Association
Contact: Bruce Pollard 01908 582563

Essex:
M.E.S.S (Mid Essex Stoma Support)
Contact: Clive Blanchard 01245 468750 Jeanette Johnson 01376 511862
North Essex Stoma Support
Contact: Mr W Hatch 01255 503688 Brian Waller Secretary 01206 540449
Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa 0208 9708321
South Essex Young Ostomy Group
Contact: Paul Gray 01708 501268
Optimistic Ostomates
Contact: Janet 01702 385510 Angela 01702 385509
STEPS
Contact: TBA

Hampshire:
Southampton Support Group
Contact: Carol Summer 02380 446779

Hertfordshire:
Colonise
Contact: CA for details
Stoma Fellowship
Contact: Karen/Mandy 01438 781133

Kent:
Dover & District Stoma Support
Contact: Marie Culleton SCN 01233 616646
Ashford Stoma Support
Contact: Chairwoman - Ursula Naish 01233 640863

London:
Whipps Cross University Hospital
Contact: Christina 0208 5395522
Ealing Ostomy Support Group
Contact: CA for details
South Woodford Ostomy Support Group
Contact: CA for details

Middlesex:
Inside Out
Contact: Bob (chairman) 0208 4284242 Sarah Varma 020 82354110
Semi-Colon Club
Contact: 01895 179391

Oxfordshire:
Oxfordshire Ostomy Fellowship
Ernest Draper 01865 391257

Surrey:
Epsom and District Stoma Support
Contact: Jan/Sheena 01372 735232

Sussex:
Brighton & District Stoma care support (SAS)
Contact: Sylvia Bottomley 01273 554407
West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441881 ext 8313
The Ostomy Friends Group
Contact: Jane Quigley 01323 417400 Ext 4552

Avon:
Bristol Ostomy Self Support (BOSS)
Contact: Christina 0117 9558236 Joyce 0117 9075326 Rob 0117 9668021

Cornwall:
Optimists
Contact: Sue Hatton 01326 340058

Devon:
Devon IA
Contact: Margaret Bond 01392 447374

Dorset:
Cupid (Colostomy Urostomy pouch Ileostomy of Dorset)
Contact: CA for details

Wiltshire:
Wessex Stoma Support Group
Contact: Michael Slater 01722 741233
Swindon IA
www.swindon-ia.org.uk

Wales

Blaenau Gwent Self Help
Contact: Marina Heal 01495 310686 (after 6pm)
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245
Wrexham Ostomy Friendship Group
Contact: CA for details

Northern Ireland

Daisy Hill Hospital Belfast
Contact: Bernie Trainor
028 3883500 Ext 2222
Mater Hospital Belfast
Contact: Karen Boyd
028 90741211 Ext 2329
Causeway Patient Support Group
Contact: Mary Kane 028 70346264
Southern Trust
Contact: May Jo/Bernie 028 38612721

Eire

Bowel Cancer Support Group (Irish Cancer Society)
Contact: Olwyn Ryan
+353 12310500
Mayo Stoma Support (Castle Bar Hospital)
Contact: Marion Martyn
094 902 1733

Editors Comment

Support groups are very often invaluable to those who are 'Living with a Colostomy'. We support existing groups and help new support groups set up. If you know of a support group not mentioned in our listings please let us know.

Here's how you can get in touch via e-mail:
editor@colostomy association.org.uk

or write to:
Colostomy Association 2 London Court East Street Reading RG1 4QL
or e-mail:
cass@colostomy association.org.uk

Stoma Care Nursing Professionals and the Colostomy Association

Whether you are a stoma care nursing professional working with a new patient about to have a colostomy or you are working in a follow up clinic with patients who have had a colostomy - the Colostomy Association is here to help...

The following is a list of services we provide:-

- A 24/7 - Helpline 0800 328 4257 - calls are taken by fully trained experienced colostomates.

- Advisory literature - written by colostomates and health care professionals.

- A quarterly 56 page glossy magazine called ‘Tidings’ - featuring real life stories, the latest reviews on new stoma care products and much more.

- Seventy plus contact volunteers (who are colostomates) - happy to talk about their experiences and/or share them with stoma care students and nurse groups.

- Volunteer attendance at ‘Open Days’ – volunteers will attend with literature and chat about ‘everyday living with a colostomy’.

- Volunteers available for patient visits please request further information from the Colostomy Association.

- Nurse/Hospital ‘Open Day’ invitation handling - The Association will send out invitations to ‘Open Days’ on behalf of stoma care nurses, free of charge. Please supply invites and stamped envelopes and we will post out to those registered with us in your area.

About Stoma Care Open Days...

Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family and it can be a very sociable event.

Open Days are organised by stoma care nurses working within the NHS, stoma care manufacturers and/or suppliers. These events offer you the opportunity to chat to stoma care nurses about any problems you may be having, speak to company representatives who may order free samples for you, or meet up with CA volunteers who have everyday experience of living with a stoma. The IA or UA may also be represented.

As an added bonus you may receive free entry into a museum or garden, depending on where the open day is being held.

List of forthcoming Open Days:

Venue: Keepmoat Stadium, Doncaster
Date: 29/07/09
Time: 11am - 2pm
Salts Healthcare open day

Venue: Taunton RFC, Hyde Park, Taunton
Date: 4/09/09
Time: 11am - 3pm
Musgrove Park Hospital Stoma Care Dept open day

Venue: Twycross Zoo (The Napier Centre), Burton Road, Atherstone
Date: 28/07/09
Time: 10.30 -12noon or 2pm - 3.30pm
CliniMed open day

Venue: St. Wulstan’s Community Hall, Church Lane, Wolstanton, Staffs, ST5 0EF
Date: 19/09/09
Time: 1pm - 3.30pm
Outlook (North Staffs Ostomy Support Group) Annual patient day and exhibition.

Venue: Skelmersdale Cricket Club, Firshwood Park, Lathom
Date: 11/09/09
Time: 11am - 3pm
Bullen Healthcare open day

Venue: National Glass Centre, Sunderland
Date: 15/09/09
Time: 10am - 3pm
Sunderland Royal Hospital Stoma Care Dept open day

How to contact the Colostomy Association

By Post: 2 London Court
East Street Reading
Berkshire RG1 4QL

By Telephone:
General Enquiries: 0118 939 1537
Helpline: 0800 328 4257

By E-mail:
cass@colostomyassociation.org.uk

Helpful Groups & Organisations

Other Ostomy Support Associations...

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org

- UA Urostomy Association
  Tel: 01889 563191
  www.urostomyassociation.org.uk

- IOA International Ostomy Association
  www.ostomyinternational.org

- Gay Ostomates
  Tel: 0845 6436858.
  e-mail info@gayostomates.org
  www.gayostomates.org

Support organisations for medical conditions...

- Macmillan Cancer Support
  Freephone:
  CancerLine: 0808 808 2020
  YouthLine: 0808 808 0800
  www.macmillan.org.uk

- Cancerbackup
  Freephone: 0808 800 1234
  www.cancerbackup.org.uk

Macmillan Cancer Support and Cancerbackup have merged all telephone numbers and websites remain the same at the present time.

- National Association for Colitis and Crohn’s disease
  Tel: 0845 130 2233
  www.nacc.org.uk

- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org

- Bladder and Bowel Foundation (B&BF)
  Formerly Incontact and Continence Foundation
  General enquiries: 01536 533255
  Web: www.bladderandbowelfoundation.org

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Freephone: 0800 132787

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Thank you for your support

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Please use this form to make either a **Single donation** or a **Regular donation** by **Banker's Standing Order.** Simply **complete this form** and return by **post** to the **Colostomy Association 2 London Court, East Street, Reading, Berks RG1 4QL.** Telephone: **0118 939 1537** if you have any queries.

Note:
Please ensure that we have your full name, address and postal code thank you

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1 Single donation: (a donation of £12 or more covers production of four issues of Tidings per year)

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☐ Please tick here if you require a receipt acknowledging your kind donation

2 Regular donation: I would like to make a **regular contribution** to the **Colostomy Association** in support of the charity and I have completed the **Banker's Standing Order form below.**

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Date of first payment: and thereafter on the same day every month/quarter/year)*

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Signature: **Date:** / / 20

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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 28p.** For example, a donation of **£15 becomes £19.23 with gift aid,** at no extra cost to you.

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DONATIONS HELP US MAKE A DIFFERENCE

The **Colostomy Association** is an independent charity financed solely by donations. Your **help and support** is **now more important** than ever in this changing world...

Our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - we need to be here for them!

The Association continues, with **your help,** to **give support** and **reassurance** to both experienced colostomates and those who are new to 'living with a colostomy'.

Here's how your donation helps us make a **difference...** to **fellow colostomates**

The Association provides:

- advisory literature, written by colostomates and health care professionals.
- a quarterly magazine 'Tidings' especially written for colostomates, their families and their carers.
- a telephone helpline 0800 328 4257 manned 24 hours a day every day.
- over seventy contact volunteers covering the UK, fully trained and experienced, (who are themselves ostomates) these dedicated individuals bring a human touch.
- a volunteer at the request of a stoma care nurse can visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- attendance at organised stoma care nurses 'open days', that you can visit and where you can learn more about your stoma, in a friendly atmosphere and discuss any problems.
- attendance at manufacturers' and suppliers', 'open days' and exhibitions. This allows us to update you on stoma care products, accessories and services via 'Tidings'.
- a voice for your opinions at on going consultations with the National Health Service and keeps you informed of issues that may affect you.

Here's how **YOU** can continue to support us... simply by making a donation you will ensure our survival

- **Single Donation**
  Single donation from individuals and fundraising events are always welcome and greatly appreciated. So please keep them coming, no matter how small. Just £12.00 (or more) ensures we are able to continue to produce four issues of Tidings per year.
- **Regular Donation**
  Regular donations can be made via standing order (see Donation Form) Regular donations help us to plan ahead and like all donations are vital to our survival.
- **Donate via Payroll Giving**
  Enables you to give direct to us straight from your gross salary (before tax is deducted), and to receive immediate tax relief of up to £4 for every £10 donated.
- **Legacies - A gift in your will**
  If you are about to make a will, or are considering making a change to your current will, please consider leaving a legacy to the Colostomy Association to help us to continue to offer support to all those with a colostomy.

Together we can make **a difference** to the everyday lives of **fellow colostomates...**
by giving today you ensure the Colostomy Association will be here **tomorrow!**

Your donation to the **Colostomy Association today...**will mean we can **reach out** to other **colostomates** their **families** and their **carers** with **support, reassurance and encouragement.** With your **help** we really **can** and **do make a difference - thank you**

colostomy association

Office Address: 2 London Court, East Street, Reading RG1 4QL Tel: 0118 939 1537 Helpline: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk
Registered Office: 2 London Court, East Street, Reading RG1 4QL
Registered Charity No: 1113471