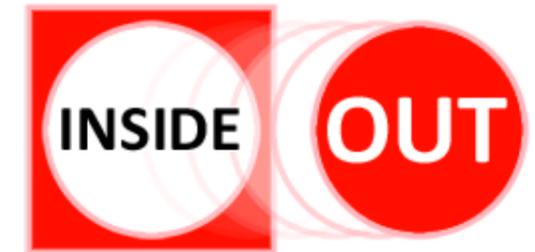


Coffee Mornings 2013

Thursday 2nd May	Marlen	Post Grad Room Level 5
Friday 17th May	Hollister	Seminar Room 1 Level 6
Tuesday 28th May	ConVatec	IFU Room Level 9
Tuesday 11th June	CliniMed	Seminar Room 2 Level 6
Wednesday 26th June	Oakmed	Seminar Room 4 Level 6
Thursday 11th July	Suportx	Post Grad Room Level 5
Friday 26th July	Fittleworth	Post Grad Room Level 5
Monday 9th September	Coloplast	Post Grad Room Level 5
Tuesday 24th September	ConVatec	Seminar Room 1 Level 6
Wednesday 9th October	Pelican	Out Patients Level 3
Thursday 24th October	Dansac	IFU Room Level 9
Friday 1st November	Hollister	Seminar Room 1 Level 6
Monday 11th November	CliniMed	Post Grad Room Level 5
Tuesday 26th November	OstoMart/Salts	Post Grad Room Level 5
Wednesday 11th December	Xmas Party	Post Grad Room Level 5

Volume 9
Spring 2013
Issue 1



STOMA SUPPORT GROUP WORKING WITH ST. MARK'S AND NORTHWICK PARK HOSPITAL
Incorporated with St. Mark's Hospital Foundation Charity Registration No. 1140930

Wow! Fantastic! It's Here Our New Look Website

What's in this Issue?

Wow! It's Here
New Look Website

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A story of
Crohn's Disease and
an Ileostomy

By
Gary Noble

*

Turning intestinal
failure into success

By
Dr Simon Gabe

*

2013
Coffee Mornings

Yes, I know, we have talked about it and talked about it, and it has taken some time to get it here, but we had to get it right before letting you all know that the new website is here.

I hope that you all approve of the new features; search engine, Twitter, Facebook, our forum, where you (by using a password) can talk with confidence.

We will be continuing to update through RSS feeds from other sites, plus by adding our input by updating information from other sources. We would love to receive your feedback, positive or negative, after all we can only continue to improve the site by receiving your comments. Whilst we are talking website, I thought I would let you know how successful our site has been.

We received a request from Pakistan asking if we could help an Ostomist! With the help of Hollister's representative Kevin, we were able to advise, respond and resolve their issue immediately. We have also received a recommendation from a Saudi Arabian Ostomist, that a contact of theirs get in touch with us as we could help and advise them.

These are just a couple things that have come about since we have put our website online five years ago.

Kind Regards
Bob Azevedo-Gilbert
Editor

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Macmillan Cancer Support

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National Association

Crohn's & Colitis

Tel: 01727 830 038

Ostomy Lifestyle Helpline

Tel: 0800 731 4264

Urostomy Association

Tel: 0845 241 2159

Want to join the Support Group?

If you have a Colostomy, Ileostomy or a Urostomy and you would like more information, please complete the section below and send it to: Sarah Varma c/o Stoma Care Department, St.Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex, HA1 3UJ

Name _____

Address _____

Postcode _____

Telephone _____

Annual membership subscription £5.00

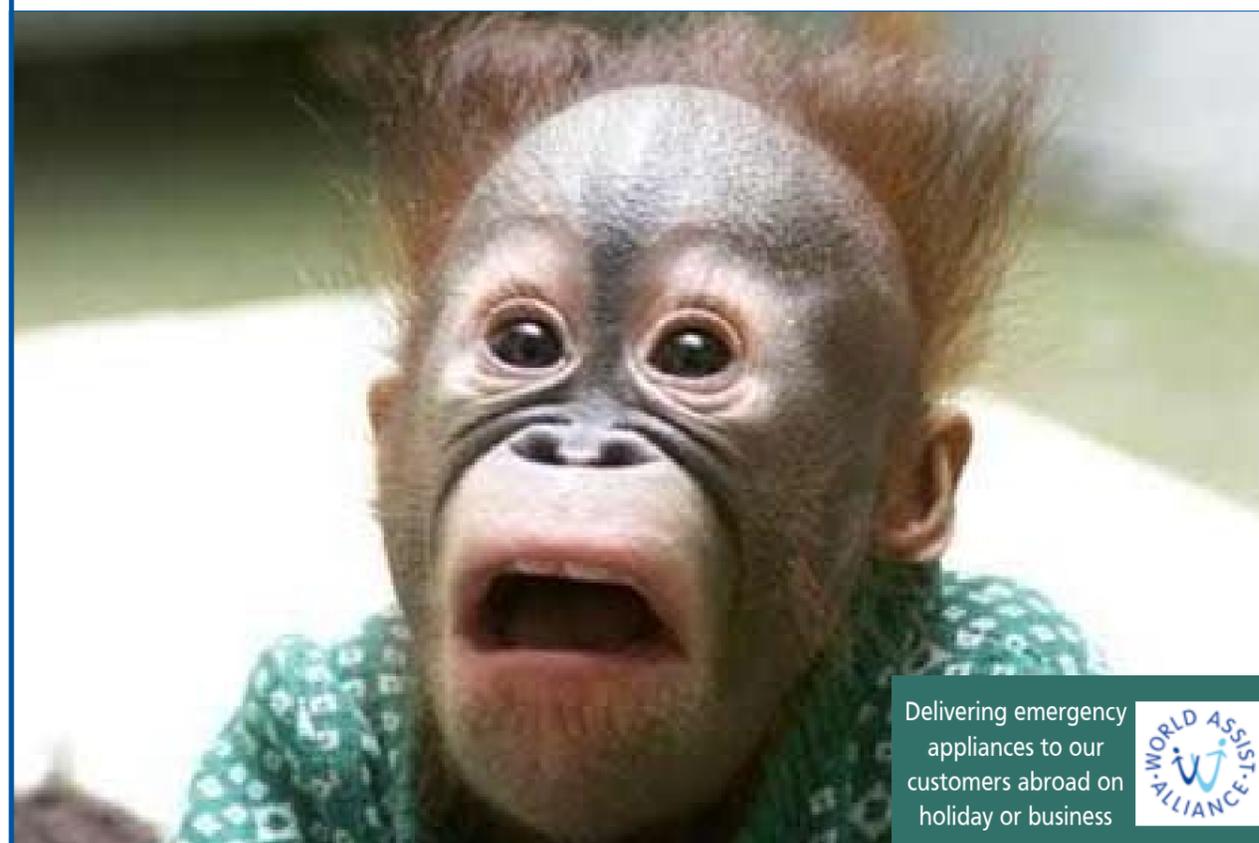
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Membership Renewal 2013

Dear Member,

You will have noticed from the "Useful Contacts" section in the Winter 2012 Newsletter that I have succeeded Diane as Treasurer which means that I have the pleasure of inviting you to renew your subscription for 2013.

It still remains at £5 which I consider, from my comparatively brief period as a member, to be of tremendous value.

I have learned so much at Coffee Mornings about Stomas and how to cope with them, and I am grateful for the advice I have received not only from professionals, but from fellow members who have been willing to share their experience as Ostomists, a word I had never heard of three years ago.

Would you please send your cheque, for £5, made payable to "St Marks Hospital Foundation", to me at:

6 Treve Avenue
Harrow
HA1 4AJ

If you have any questions with regard to membership, please feel free to contact me on [020 8422 1497](tel:02084221497) or you can contact me via email: gordondrewe@aol.com

Best wishes

Gordon

Attention! Important! Please Read:

Whilst every care has been taken to ensure that the information in this publication is accurate and complete, the contents of this newsletter are provided for general information only and should not be relied upon for any specific purpose.

Inside Out Stoma Group accepts no responsibility for the accuracy or statements made. Anyone acting upon them does so at their own risk.

We recommend that you consult your stoma nurse or doctor before changing your procedures.

Crohn's Disease A story of Crohn's Disease and an Ileostomy By Gary Noble



Hello

I'm Gary Noble and I was diagnosed with Crohn's disease when I was 15. I had been suffering with diarrhoea, abdominal pain, bleeding and weight loss for the year prior to my diagnosis, I did not know what Crohn's was and had not heard of it. After a series of tests, a colonoscopy and my diagnosis I was put on lots of medication and steroids which initially helped with getting the Crohn's under control and this helped me continue on with my education and start my working career.

In my early 20's I was put on Azathioprine as I started developing multiple Peri-anal fistulas and had a few small bowel obstructions, these are very painful and as time went on I was finding my medication was not helping, so I had quite a few operations on my rectum to help with the fistulas but none of them worked so the only way for me to deal with these fistulas was to have a temporary Ileostomy to give my bowel a complete rest and let the peri-anal disease try and heal.

After my Stoma surgery things started to look positive, it did take me a while to adjust to life with the stoma. I returned to work, I could eat more food & my rectum was beginning to heal and above all I had no pain, total relief and knew I had made the right decision....I had my life back! Over the next two years my rectum had healed and during that time I had received cycles of Infliximab & Adalimumab which did help and I made the decision to have my stoma reversed, I did have mixed feelings before my surgery as I was off steroids and felt so much better but worried about the pain and fistulas returning.

After a few months things seemed to settle but I had to readjust my eating and restart a lot of medication that stopped when I had my stoma formed. A year down the line I was beginning to get lots of problems again I had immense pain in my rectum, the fistulas didn't return but the small bowel obstructions were becoming more frequent, it was getting me down.

In 2010 I was in a lot of pain, things got bad and I had another Stoma formed & also a multiple Strictureplasty, this got me back on track but recently in 2012 I had another stricture, I had the stricture resected and I am pain free again and back on Adalimumab. Having my stoma back has helped me live my life and I feel confident. I have the right stoma appliances and great support from family and friends, enjoy my career, travel the world, am back to keeping fit and tackle so much more.

I will keep my Ileostomy for the rest of my life.

Keep Positive & Never Give Up!

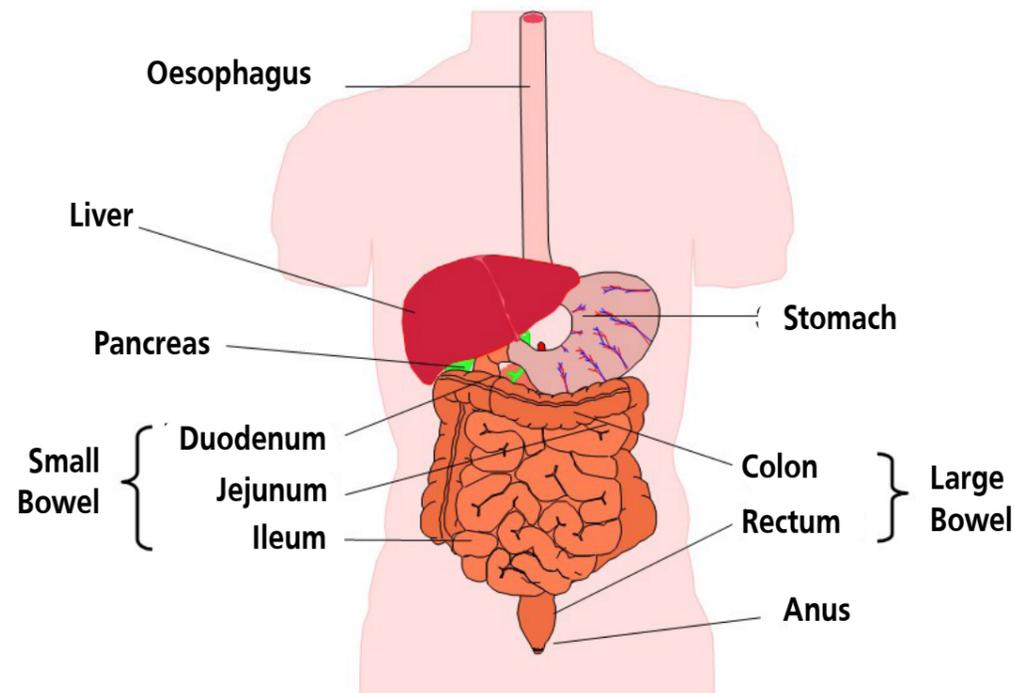
Turning intestinal failure into success

By Dr Simon Gabe



People often refer to their abdomen as their stomach. Unfortunately this is not correct but this only really matters if you have a problem and need to know where the problem is. The intestines are made up of the oesophagus (gullet), stomach, small bowel (duodenum, jejunum and ileum) and the large bowel (colon and rectum) (Figure 1).

Figure 1: the layout of the intestines



DIGESTIVE SYSTEM

All of you reading this will have a stoma which means that your bowel has been brought up to the abdominal wall. There are different types of stoma: jejunostomy, ileostomy or colostomy depending on the position of the stoma along the intestinal tract.

The "IF" Team

Here is the core intestinal failure team at St Mark's. Hopefully you won't need us but if you do... we will be there.



From left to right:

Mia Small (Nurse Consultant), Dr Alison Culkin (Senior & Research Dietitian), Natalie Welsh (Clinical Nurse Specialist in Nutrition), Dr Jeremy Nightingale (Consultant Gastroenterologist), Ummi Hicks (Matron), Dr Simon Gabe (Consultant Gastroenterologist), Sally Crowther (Clinical Nurse Specialist in Nutrition), Joy Odita (Ward Manager), Rasha Salama (Specialist Pharmacist), Jackie Eastwood (Pharmacy Manager), Seema Patel (Intestinal Failure Coordinator)

New Developments on the Horizon

Bowel Lengthening Surgery

Surgical lengthening of the small bowel has been performed for some time in children. It is now being considered in adults and is aimed at people who are on intravenous nutrition because their bowel is too short to absorb their nutrition. The aim of the operation is to lengthen the small bowel to help the body digest food better, thereby reducing the need for intravenous nutrition.

The operation that is usually performed is called serial transverse enteroplasty procedure (STEP) and results in a zigzag appearance to the bowel, making it longer than it was before the operation.

Salford Royal hospital (the other large intestinal failure unit in England) has permission to do this operation in adults and have just done this successfully on their first patient. Together with them we are going to be involved in identifying and assessing patients for this procedure.

If you want to know more about this then contact the intestinal failure team.

Intestinal Transplantation

Over the past 5 years the intestinal transplant service in the UK has really developed. The success and survival rates are similar to the largest centres in America performing intestinal transplants on both children and adults. In adults the transplants are performed at Addenbrooke's hospital, Cambridge and the Churchill hospital in Oxford.

To date the patients that have been considered for an intestinal transplant are patients that have developed serious complications on their intravenous nutrition. However, there are some patients who want to have a transplant for quality of life reasons. This is a difficult decision.

The concept of intestinal transplantation may be attractive for some, as patients generally no longer need intravenous nutrition. However, patients have a new set of issues or problems after a transplant and the balance of risk to benefit is not at all easy.

New Medicines on the Horizon

There is a new medication that may appear on the market over the next year or two called teduglutide (Revistive). This is a new type of drug that is a "growth hormone" for the bowel. It does not make the bowel grow longer, but increases its surface area.

This will allow the small bowel to absorb both fluid and food better, meaning that the need for intravenous nutrition is reduced. Unfortunately this will be a very expensive and will therefore take time to become available more routinely in clinical practice.

Most of you will have had surgery to remove some of your bowel as well as form the stoma. Generally this is not a problem as the remaining bowel is able to absorb the nutrition and the fluids that you require every day. However, for some people the remaining bowel is not long enough or efficient enough to be able to absorb the fluid or nutrition. When that occurs we call that intestinal failure. You will have heard of kidney failure and heart failure, well this is the same sort of thing but affecting the bowels.

Actually intestinal failure is very common. It will occur after any operation on the intestines and even when you are ill with a severe gastroenteritis. However, these problems generally only occur for a day or two and we have enough reserve in our bodies to be able to manage without our bowels working for a number of days or even weeks. When this problem is more prolonged (over 4 weeks or even indefinite) then that is what we mean by intestinal failure. We even call it severe intestinal failure, or Type 3 intestinal failure.

Table 1: types of intestinal failure

Type of intestinal failure	Description
Type 1	This is short-lived. It most commonly occurs after abdominal surgery for a few days. If it lasts a bit longer then often this is referred to as an ileus
Type 2	This occurs after abdominal surgery and when there has been a complication such as a leak from the bowel or an infection in the abdomen. Usually this can be treated but patients may need intravenous nutrition support. This type of intestinal failure lasts up to one month
Type 3	This is long term intestinal failure and can be from continuing problems in the abdomen lasting longer than a month, or if patients have had so much bowel removed that they will need intravenous nutrition for months or even indefinitely

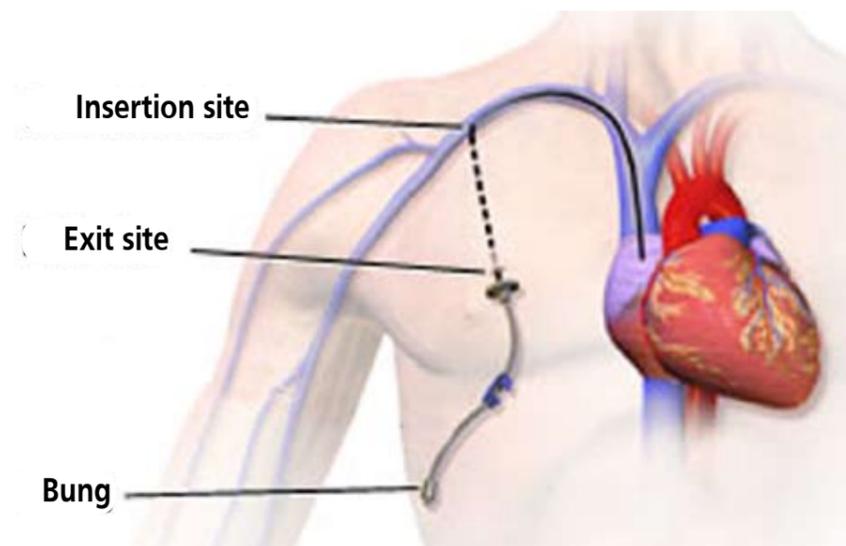
When the intestines fail there are not many options. The small intestine is responsible for absorption of nutrients and when the underlying problem is irreversible, patients have to go on long term intravenous nutrition. Long term intravenous nutrition carries significant risks of infection, central venous thrombosis and liver failure and therefore has to be managed in a specialist centre. In addition, the quality of life is impaired for patients with long term intestinal failure as they have many extra problems to have to deal with.

Intravenous Nutrition

Intravenous nutrition is a sterile liquid feed that goes directly into a vein. It is also called parenteral nutrition, TPN (total parenteral nutrition) and HPN (home parenteral nutrition). Typically it contains amino acids (the building blocks of protein), glucose (the best form of energy for our body to use), lipid (fats), electrolytes (such as sodium, potassium, calcium and magnesium), trace elements (these are elements that we need but in very small amounts such as manganese, selenium, zinc) and vitamins. It can be made up with any combination of these elements according to a patient's requirements.

Intravenous nutrition has to be sterile as if any bacteria are present then they would go directly into the bloodstream, causing septicaemia – a life threatening condition. In addition, intravenous nutrition is concentrated and needs to be given into a large vein with a good blood flow. We use “a central line” to give medications and nutrition into large veins. In hospital patients have temporary central lines, which last a week or two before having to be removed. There are longer term lines that are made of a different material (silicon) and are tunneled under the skin (Figure 2). People often refer to these as Hickman lines, although that is a trade name and most hospitals will use a similar type of line.

Figure 2: *Tunnelled central venous catheter*



Enteral Nutrition

Enteral nutrition is an artificial liquid nutrition. Most of you will be aware of this in the form of supplement drinks. Although these don't taste brilliant, the supplements have been designed to have a reasonable taste. However, when the same sort of liquid is given via a tube directly into the intestines then they don't have to be made to taste good. The commonest way of receiving enteral nutrition is by nasogastric (NG) feeding, when a tube is placed via the nose into the stomach. This is a short term way of having enteral nutrition.

Longer term tubes can be placed and these are usually called PEG tubes. This stands for Percutaneous Endoscopic Gastrostomy tubes, which just means that the tube has been placed using an endoscope and goes from the abdominal wall directly into the stomach. There are other types of gastrostomy tubes that can be placed but they all do the same thing in the end, allowing tube feeding directly into the stomach.

Sometimes the stomach doesn't work properly for some patients or people have had their stomach removed and in that situation a jejunal feeding tube can be placed, this is a feeding tube that is passed directly into the small bowel.

One other new way of feeding the bowel is called enteroclysis or fistuloclysis. This is when the end of the small bowel is supplied with a tube feed, either via a mucous fistula or via an enterocutaneous fistula. This is uncommon and can be complicated and generally only suggested by specialist teams.

The Intestinal Failure Unit at St Mark's

St Mark's was one of the first hospitals to manage patients with long term intestinal failure in the country. This was in the 1980's under the direction of Professor John Lennard-Jones (JLJ as he was known). He helped patients to be able to get home on intravenous nutrition, when this was simply not considered before. Then it pushed the boundaries of the technology available for intravenous catheters, pump development, understanding the amount of all the different nutrients required, making the intravenous nutrition and getting it to a patients home. However, JLJ and the nutrition nurse Suzanne Wood managed to overcome these boundaries and gradually St Mark's got a name for itself.

We have continued over the years to develop our expertise in this area and the number of patients that we care for on home parenteral nutrition has continued to expand (Figure 3).

In 2006, we managed to create the Lennard-Jones Intestinal Fail Unit which was a 12 bedded unit in the Lister block in Northwick Park Hospital. In 2009, we expanded the unit further and went into a 20 bedded ward within the main building in Northwick Park.

We have a large multi-disciplinary team helping to care for our patients and the level of expertise within the team is second to none.

Figure 3: *Numbers of patients cared for at St Mark's on home parenteral nutrition*

