

Winter 2017

York IBD Matters

Welcome to the first 'York IBD Matters' Newsletter.

Our aim of this newsletter is to keep you up to date with what is happening regards Crohn's Disease and Ulcerative Colitis (IBD) and the service we provide for you.

We aim to publish this newsletter on a regular basis and our hope is that you will be able to access it via our Facebook page, our webpage or when you come for your outpatient appointment.

However, if you would like to receive all of the newsletters then please provide us with your email address. Saving money by not printing and posting!

If you would like any particular topics covering, then please let us know – We hope you enjoy. Maxine, Lisa and Michelle and the rest of the IBD Team



IBD Patient Education Evenings & Patient Forum

After feeling unwell for quite a while, most people's reaction to a diagnosis of Inflammatory Bowel Disease (IBD) is a mixture of shock, anxiety, uncertainty and sometimes relief. Shock because you have been told that you have an ongoing disease, something that you're stuck with – and anxiety at the thought of taking daily medication for a long time, perhaps indefinitely.

You may also feel uncertain and unsure of what to expect. After all, you may not have heard of IBD, Ulcerative Colitis or Crohn's Disease before. So, it's natural to feel concerned and confused, particularly when doctors don't know yet the actual cause of the illness.

But you may also be relieved to find that your symptoms have an identifiable name, and that your illness can usually be controlled with medication.

Twice a year we hold patient education evenings which are also combined with the Patient forum (Patient panel) so that you can network with other patients who can offer advice and support and also learn more about the disease and management in a relaxed and friendly environment.

All meetings are held at the Friargate Quaker Meeting House in York. Our next meeting will be posted on our Facebook page, posters in hospital outpatients and on our webpage.

CROHN'S & COLITIS AWARENESS WEEK

CROHN'S AND COLITIS AWARENESS WEEK 1-7 DEC

crohnsandcolitis.org.uk

Purple Friday (1st December) will see the nation Going Purple for Crohn's Colitis UK. They are asking you to wear purple as part of Crohn's Colitis Awareness Week to help make Crohn's and Colitis Visible. Life changing and becoming more common IBD can have a devastating effect on people's education, work, social and family life. Public awareness and understanding of these chronic conditions is just not high enough-but with your help Crohn's Colitis UK can pull these "invisible" illnesses out of the shadows.

For more information visit: -

<https://www.crohnsandcolitis.org.uk/get-involved/crohns-and-colitis-awareness-week/go-purple>

Every **30 minutes** someone in the UK is diagnosed with Crohn's Disease or Ulcerative Colitis – the two main forms of **Inflammatory Bowel Disease**



At least **300,000** people in the UK have been diagnosed

These **chronic** conditions are **becoming more common**, especially among **young people**



The **impact** of these conditions on **education, work, social and family life** can be **devastating**

There is **no known cure**

Inflammatory Bowel Disease can cause **ulceration** and **inflammation** in the colon (Ulcerative Colitis) or any part of the digestive system (Crohn's)

They are unpredictable, lifelong and potentially life-threatening

Symptoms can include:



- diarrhoea (often with blood)
- severe pain
- extreme fatigue
- dramatic weight loss
- swollen joints
- mouth ulcers
- eye, skin & liver problems

IBD Standards



The IBD Standards were originally published in 2009 and were intended to inform Hospital Trusts and Commissioners of the 6 essential components of a quality IBD Service. Since the standards were produced there have been marked improvements in the delivery of IBD services, as shown by the findings of the UK wide IBD Audit.

The first national audit of IBD services and care which took place in 2006, found substantial local variation in the provision, organisation and clinical quality and significant aspects of care that did not meet existing clinical guidelines. As a result, organisations representing patients and professionals collaborated to define for the first time what was required in terms of staffing, support services, organisation, patient education and audit to provide integrated, safe effective, patient-centred, high quality IBD services. The third round of the IBD Audit directly monitored IBD services against the Standards.

The value of the IBD Standards and the IBD Audit has been demonstrated by significant improvements in IBD services over the years. They continue to provide a benchmark for healthcare services. They have recently been used to inform the development of new NICE quality Standards for Inflammatory Bowel Disease.

For a copy of the IBD Standards go to:-
www.bsg.org.uk/clinical/general/ibd-standards

Standard A – High Quality Clinical Care

High quality, safe and integrated clinical care for IBD patients based on multidisciplinary team working and effective collaboration across NHS organisational structures and boundaries.

Standard B – Local Delivery of Care

Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.

Standard C – Maintaining a Patient Centred Service

Patient-centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate.

Standard D – Patient Education and Support

IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their Inflammatory Bowel Disease.

Standard E – Data, Information Technology and Audit

An IBD service that uses data, IT and audit to support patient care effectively and to optimise clinical management.

Standard F – Evidence-Based Practice and Research

A service that is knowledge-based and actively supports service improvement and clinical research.

Accessible Toilets



Crohn's Colitis UK are campaigning to change accessible toilet across the UK to help raise awareness that not every disability is visible and to improve the quality of life for those with Crohn's and Colitis.

Far too many people with hidden disabilities feel stigmatised or are directly challenged when using accessible toilets, with 49% in a recent study by CCUK saying that they received negative comments from a stranger, just for using the facilities they need.

For the first part of their campaign CCUK targeted the largest supermarkets with 100% success rate.

8th August 2016-Asda rolls out new accessible toilet sign in 421 stores.

1st December 2016-Morrisons adopts new accessible toilet signs in 492 stores.

18th January 2017-Tesco rolls out accessible toilet signs in over 700 stores.

23rd June 2017-Waitrose installs new accessible toilet signage in 149 stores.

7th November 2017-Sainsbury's installs new accessible toilet signs in 603 stores.

For the next part of the campaign, the charity is calling for additional signs to be placed on publicly-available accessible toilets within high footfall public areas such as travel hubs and retail areas to raise awareness that Crohn's and Colitis are largely hidden or invisible conditions and that not every disability is visible. It is part of their overall strategic objective to reduce discrimination and raise awareness so that everyone understands Crohn's and Colitis.

See how you can get involved at: - www.crohnsandcolitis.org.uk

Medication-Generic and brand names

Every drug has an approved generic or medical name, decided on by an expert committee. Many drugs are also known by a brand or trade name chosen by the pharmaceutical company making and selling that drug as a medicine. So, for example, the drug Mesalazine (generic name) is also known as Salofalk, Asacol, or Pentasa (brand name). Some drugs are sold in a generic form as well as in a branded form. If several companies market a drug, it will have several different brand names.

Does it matter which I have?



Medicines usually contain inactive ingredients as well as the main active ingredient, the generic drug. These help to formulate the medicine, that is, to make it into its tablet, cream or liquid form. They can also be used to give tablets a particular colour or affect how

long the tablets take to dissolve in the gut.

Usually, for most prescription medicines, such small differences are unlikely to create any problems. Whether you are prescribed the branded medicine or a generic version of a drug, provided your dose contains the same amount of active ingredient your medicine should have the same therapeutic effect.

However, for a very small number of drugs, the differences in formulation may be more significant. For example, some of the different brands of Mesalazine work in a slightly different way. For this reason, we may decide to prescribe a particular brand rather than the generic version.

If you're taking an immunosuppressant, Azathioprine, Mercaptopurine or Methotrexate; a biological drug such as Infliximab, Adalimumab, Golimumab, Vedolizumab or even Ustikinumab then it is important that you have an annual flu vaccination as you're at a greater risk than the general population from the flu.

The flu vaccination works by making you feel slightly ill with the flu virus, allowing your immune system to build a defence against the virus and therefore destroying it on subsequent (real life) exposure. Make sure that you have yours.



Visit our website: - www.yorkhospitals.nhs.uk/our-services/a-z-of-services/inflammatory-bowel-disease/

Find us on Facebook: - York IBD Services

Email us: - yorkibdurses@york.nhs.uk