

Spring 2018

York IBD Matters

IBD Patient Education Evening & Patient Forum

Our next patient education evening will be on Thursday 19th April at 18.30 and will be held the Friargate Quaker Meeting House in York. We are hoping to be joined by Dr Simon Smale Gastroenterologist at York Hospital who will be talking about Functional Gut disorders and how they overlap with IBD.



The nearest car park to the meeting house is Clifford's Tower. Parking cost is £2.00 after 6pm or free to city of York discount badge holders



PRESCRIPTION CHARGES...

Did you know that England is now the only part of the UK that charges for prescriptions, with charges having been abolished in Wales in 2007, Northern Ireland in 2010 and Scotland in 2011. Controversial from the outset, prescription charges were introduced in 1952, abolished in 1965 and reintroduced in 1968 with a system of exemptions that persists in modified form today. The charge itself has risen every year but one since 1979, increasing from 20p to the current level of £8.60 per item during that time. Around 90% of prescriptions in England are currently dispensed without charge, but most of the remainder are paid for by working-age people with long-term conditions. While certain medical conditions entitle people to a medical exemption certificate and therefore free prescriptions, only a handful of conditions qualify. Aside from the addition of cancer in 2009 the list of exempt

conditions have not changed since 1968, despite the lack of any clear underlying rationale. As a result, most people with a long-term condition who are diagnosed at a young age can expect to pay for their prescription medications throughout their entire working lives. Crohn's Colitis UK have worked as lead organisation for the Prescription Charges Coalition since 2012, they are working to increase the momentum and impact of the campaign. In England, it is acknowledged that the criteria for medical exemption from prescription charges are outdated, illogical and arbitrary. Yet there has been no commitment to addressing this. Crohn's and Colitis UK will continue to campaign for everyone with IBD and other long-term conditions to be exempt from prescription charges wherever they live in the UK – but they need your help to do so.

Please visit:

www.prescriptionchargescoalition.org.uk

Sign the petition and help end prescription charges for people with long term conditions.

Employment Information and Advice

Whether you're looking for a job, have been offered a job, or you already have a job, you might be worried about telling your employer about your Crohn's or Colitis. What should you say? Do you need to tell them anything at all?

...during the recruitment process

You may be concerned that you will be at a disadvantage if you declare your IBD, whether on an application form, CV or at an interview.

The Equality Act 2010 makes it unlawful for employers to ask invasive questions about your health - including previous sickness absence - before making a job offer. This applies to questions on an application form as well as questions asked during an interview. This is to encourage employers to consider whether you can do the job rather than ruling you out early in the process because of your health condition.

...once you've been offered the job

Some job offers may be conditional on a medical examination or on satisfactory completion of a medical questionnaire after the job offer stage. A conditional offer should only be withdrawn on medical grounds at this stage if it can be shown that you would not be able to do the job once reasonable adjustments have been made. If you deliberately withhold information at this stage and it comes out later, you could risk being dismissed.

...in your current job

If your diagnosis comes once you are already working, or if your condition becomes worse,



you may wonder whether to tell your manager about it. There is generally no legal requirement to disclose a medical condition – unless it is required in your own personal contract of employment. While some people with IBD decide that they do not wish to disclose their IBD to their employer, there can be some advantages in sharing information about your condition.

Know your rights

All employees have certain legal rights in the UK, but many people with Crohn's or Colitis are also classed as having a disability under the Equality Act 2010. This means they qualify for extra protection against discrimination as well as the legal right to have support from their employers (known as 'reasonable adjustments') to help them do their job...

What are Reasonable Adjustments?

You can ask your employer for reasonable adjustments when any aspect of your working arrangements, including the building or place of work or your working hours, puts you at a substantial disadvantage compared to a non-disabled person doing your job. If the Equality Act applies to you, these adjustments are not favours but rights. However, there is no exact definition about what is or is such as the cost and difficulty in

making the adjustment and the size of the employer will be taken into account. Generally, an adjustment is likely to be considered reasonable if it is not too expensive considering the resources of the employer and the type of business.

Helpful adjustments that would not generally be too expensive could include:

- allowing time for medical appointments or treatment,
- flexible working arrangements, such as shorter or different hours,
- unlimited toilet breaks,
- moving your work station close to a toilet,
- providing a car parking space close to the entrance into work,
- allocating some of your duties to someone else,
- offering another place of work,
- providing you with relevant training, if some of your duties have been reallocated and you take on new tasks that are more suitable to your needs.

In talking to your employer, it may be useful to have some suggestions ready of changes that would help you. Where adjustments are expensive, such as installing separate toilet facilities, a scheme called "Access to Work" may be able to help (www.gov.uk).

For more information Crohn's colitis have produced very helpful information leaflets for both employers and employees.

Work begins on York's new endoscopy unit

Work has begun at York Hospital on what will be one of the most modern and largest endoscopy units in England. The £10 million project will take around a year to complete and will increase capacity from three treatment rooms to seven, reflecting the growing need for endoscopic investigations nationally. The building has been designed to increase capacity to meet growing demand, improve the efficiency of patient flow and enhance the patient experience. The new unit will deliver improvements to diagnostic and therapeutic endoscopy waiting times and increase the range of procedures offered, meaning fewer patients will have to travel to Leeds or Hull. The current unit provides around 13,000 treatments each year and has out grown its current location within the main hospital. The new unit is being built above the hospital's existing physiotherapy department. It will be connected into the hospital at first floor level.



Patrick Crowley, Chief Executive, said "this is the biggest capital investment for many years and will allow the Trust to provide clinical services to a growing number of patient's needing endoscopy.

This is an exciting development for the Trust and it will transform our service into a centre of excellence for endoscopy, providing enhanced high-quality care to our patients."

Can you help?

IBD BioResource which is being run with the help of National Institute of Health Research (NIHR) is an exciting new study which is hoped will significantly help research into the causes and new treatment options for Crohn's disease and ulcerative colitis. The triggers for IBD are currently unknown, but recent years have seen major advances in understanding the factors and pathways that predispose people to developing IBD. Much of this knowledge has stemmed from new genetic technologies, and the UK the IBD genetics consortium has played a central role in driving forward this research. IBD BioResource aims to help research into the causes of Crohn's and colitis and understand determinants of IBD severity and treatment response. By understanding which genes and environmental factors are involved, and their impact on the immune system, we can investigate

why some people get Crohn's or colitis, why some of the existing treatments work in some patients but not in others, how better treatments might be developed and whether it might be possible to prevent or cure IBD.

Taking part in the study involves one visit that could be arranged to take place while you are already attending the hospital (e.g. for your IBD clinic appointment, infusion appointment etc...). Alternatively, another day or time could be arranged that best suits you. A visit takes between 30-40mins and involves talking about your IBD history, health, lifestyle and then, finally, donating a blood sample. Routine clinic bloods can also be taken at the same time, if required.

If you are interested in helping then please contact the research nurses at York Hospital – Naomi Gott, Holly Alcock or Samantha Roche 01904 721890.





WALK IT 2018

Crohn's Colitis UK need you to help to raise vital funds and awareness in their fight against Crohn's and colitis.

Funds raised through WALK IT events directly enable them to do vital new research, answer more calls from people needing help and provide patient packs to hospitals across the UK. But there is so much more to do!

Come as a team, bring your friends, family and dogs or come alone and meet new people with shared experiences.

These fantastic community days, with walks starting and finishing at the fun-filled event village, have entertainment, food and fun for all ages.

Every 5km and 10km route will take in iconic sights and landmarks, as well as helping you discover secret gems.

When you WALK IT you will be joining thousands of like-minded Crohn's & Colitis UK supporters for a fun day, standing strong against stigma and taking part in their biggest fundraising event ever!

1. Plymouth - Saturday 5 May
2. Bristol - Saturday 12 May
3. Swansea - Saturday 2 June
4. London - Saturday 9 June
5. Manchester - Saturday 16 June
6. Edinburgh - Sunday 24 June
7. Newcastle - Saturday 30 June
8. Birmingham - Saturday 7 July

Register for any of the WALK IT events and CCUK will be there to support you every step of the way. Online registration is quick and easy for individuals or teams. They will even help you set up your JustGiving page; the most popular and successful

Once you have registered, CCUK will be in touch with all you need for the day, including WALK IT t-shirts and our fundraising guide - packed with useful tips to support your amazing efforts for the fight against Inflammatory Bowel Disease.

World IBD Day 2018 – May 19th

World IBD Day is led by patient organisations representing over 50 countries on five continents and is coordinated by EFCCA. Many other IBD organisations and IBD activists and other stakeholders have joined our fight against IBD over the years.

During the global campaign famous landmarks will be lit in purple to raise awareness about the daily challenges of living with IBD. Many countries, cities and people worldwide will join our fight against IBD. Alongside illuminated landmarks patient associations and activists will organise local supporting events aimed at lobbying and providing information about IBD.



Blue badge holders only

95% of people with Crohn's or Colitis feel that these conditions should be covered in the new Blue Badge Scheme

The Government are considering changes to the criteria for getting a Blue Badge in England. This could make it easier for people with non-physical or hidden disabilities such as IBD to get a Blue Badge. When many people think of Blue Badges they often think of people in wheelchairs or with walking sticks. However, 'invisible' disabilities such as IBD have a negative effect on all aspects of body and wellbeing. The fear of having an accident in public can be crippling and incredibly isolating.

CCUK recently asked members to complete a survey telling them what they thought about the Blue Badge system. They had over 4,000 responses. CCUK are now going to ensure that the voices of people with Crohn's and Colitis are heard by the government on this issue.

Therefore, Blue Badges, which allow parking close to shops and facilities, could be a positive step in allowing people with IBD to leave their house feeling confident that they can reach a toilet in time.

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