

Autumn 2018

York IBD Matters

IBD Patient Education Evening & Patient Forum

Our next patient education evening will be in October and will be held the Friargate Quaker Meeting House in York. Check our Facebook page for more information nearer the time.

Carmen Nusco, dietitian is attending to talk about diet and nutrition in IBD and answer any questions you may have.



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

It's that time of year again



The treatment of IBD has been revolutionised over the past decade by the increasing use of immunomodulators and biological (immunosuppressant) medications to reduce the symptoms.

Influenza is characterised by the sudden onset of constitutional and respiratory symptoms (myalgia, headache, malaise, cough, sore throat and rhinitis), typically with fever. In most cases, the diagnosis is based upon symptoms and knowledge

of the local active prevalence of influenza infection.

The influenza vaccination works by making the patient slightly ill with the influenza virus, allowing their immune system to build a defence against the virus and therefore destroy it on subsequent (real life) exposure.

While taking immunosuppressants, a patient's immune system capabilities are diminished, which increases their chance of infection.

Therefore, immunization could cause concern for those who have compromised immune systems, fearing that they might be unable to fight off the initial exposure to the vaccine.

However, researchers have found that persons with IBD who

Are undergoing immunosuppressive therapies are not at risk from the influenza vaccine.

Study's further showed that these individuals are at a greater risk than the general population of conducting the virus itself.

This means that it is highly recommended that all IBD patients be vaccinated. The influenza vaccination works by making the patient slightly ill with the influenza virus, allowing their immune system to build a defence against the virus and therefore destroy it on subsequent (real life) exposure.

I'm a smoker – what does this mean for my IBD?

The relationship between smoking and IBD is complex. Many studies have shown that people who smoke are more likely to develop Crohn's Disease, and research suggests that smoking increases the severity of the disease. In contrast, smoking appears to decrease the severity of Ulcerative Colitis, although it still carries many other health risks.

How does smoking affect Crohn's?

People with Crohn's who smoke may find that they:

- have more severe symptoms and complications such as strictures, or narrowings in the bowel that can cause dangerous blockages
- are more likely to develop fistulas, abnormal passageways in the body that often require surgery
- have more flare-ups
- require more immunosuppressant drugs, such as steroids, and biologic drugs – and sometimes these drugs are not as effective in people who smoke
- are more likely to need surgery and to have to return for further surgery
- are more likely to develop extraintestinal manifestations – additional complications in other parts of the body – such as osteoporosis (weak bones), arthritis, skin disorders and eye disorders

How does smoking make you susceptible to Crohn's?

We do not know, although there are lots of theories. Tobacco smoke contains more than 1,000 chemicals including nicotine, carbon monoxide and free radicals. There are a number of ways in which these chemicals may affect the gut. Smoking can change the bacteria that live in the gut, influence how a person's genes function and cause changes to the immune system – all of which may make a person more likely to develop Crohn's. Considering all available evidence, it is widely advised that people with Crohn's disease stop smoking.

How does smoking affect Ulcerative Colitis?

Research shows that UC is less common in smokers than non-smokers. Some people have developed UC once they have given up smoking.

While most studies show that smoking may delay or prevent a person from developing UC, it is still unclear whether smoking affects the progression or course the disease takes. Some studies show that smokers with UC suffer a milder form of the condition. Flare-ups, hospitalisation rates, the need for oral steroids or

immunosuppressants, and colectomy rates have all been reported to be lower in people with UC who smoke. However, not all studies agree with this. One study found that people with UC who smoked had an increased risk of developing joint and skin problems. A study that analysed data from 16 previous studies found no difference in risk of colectomy, flare-ups or pouchitis in those with UC who smoked, compared to those who didn't.

It is important to consider the harmful effects of smoking. Smoking is a known cause of at least 13 types of cancer, including bowel, lung, stomach and ovarian. Smoking is also a known cause of cardiovascular disease – with smokers almost twice as likely to have a heart attack compared to those who have never smoked. In general, health professionals consider that the risks of smoking greatly outweigh any benefits seen in UC, and strongly discourage smoking in everyone, whether or not they have IBD.

Why may smoking have a protective effect against Ulcerative Colitis? We don't really understand why smoking has a protective effect against UC. There are many chemicals in cigarettes that could be contributing to this effect. Nicotine is the most widely studied and is likely to be having an impact. People with UC may have a thinner mucus layer in the colon and rectum when compared to healthy people. Nicotine may increase the

production of this mucus. Nicotine may also suppress the immune system and prevent inflammation in the colon. Another theory is that nitric oxide, released by nicotine, may reduce muscle activity in the colon and so reduce the need to go the toilet urgently. We know that the genes a person has inherited can contribute to developing UC.

Smoking can change how a person's genes are expressed – providing another potential mechanism for how smoking may influence the development of IBD.

Can I get help to give up smoking?

The NHS has a programme to help people stop smoking. For more information see www.smokefree.nhs.uk. Your doctor or any other healthcare professional should also be able to help you. Some pharmacists, private health insurers, employers and local governments offer programmes to help you stop smoking. If you have UC and are interested in giving up smoking, you are advised to discuss this with your IBD care team. Some people with UC may find that their symptoms worsen when they stop smoking, so it could be helpful to have a plan in place in case this happens. The NHS can help with nicotine replacement therapy (NRT), which includes patches, gum, lozenges and inhalers. NRT gets nicotine into the bloodstream without smoking and its harmful side effects. Medicines such as bupropion or varenicline can be used to manage withdrawal symptoms. You may like to consider including counselling as part of your programme to stop smoking. Research has found that a combination of medication and counselling can be more effective than a single approach



Did you know

That you can support and donate to Crohn's Colitis UK through on line shopping or just browsing the web!



AmazonSmile is a simple and automatic way for you to support CCUK every time you shop, at no cost to you. When you shop at smile.amazon.co.uk, you'll find the exact same low prices, vast selection and convenient shopping experience as amazon.co.uk, with the added bonus that Amazon will donate a portion of the purchase price to CCUK.

Millions of products on AmazonSmile are eligible for donations to charities by Amazon. You will see eligible products marked "Eligible for smile.amazon.co.uk" on their product detail pages.

On your first visit to AmazonSmile you need to select CCUK just by entering it into the charity search box for them to receive donations from eligible purchases before you begin shopping. Amazon will remember your selection, and then every eligible purchase you make at AmazonSmile will result in a donation.



Simply use Savoo Search as your default search engine (the same way as you would your current search engine) and Savoo will donate 1p for every search. If you're looking to do some online shopping and want to get a great deal, Savoo has thousands of voucher codes and deals that will help you save money & they will donate to Crohn's and Colitis UK at the same time.



That you can donate to CCUK by simply taking your medication as prescribed each day? Sounds too good to be true, doesn't it? But, this is exactly what the DrugStars app allows you to do.

DrugStars is a patient adherence app that rewards patients for taking their medications. It was developed in Denmark by a professor called Claus Moldrup. The aim of the app is to try and reduce the negative outcomes that occur when people do not take their medicine as prescribed by their doctor. Patient adherence is a massive problem and it is estimated that 125,000 preventable deaths will occur in 2018. That is a frightening figure. DrugStars is hoping to reduce this number by increasing patient adherence through its app.

Each day, the DrugStars app reminds you to take your medicine and rewards you with one star for each dose. One star is the equivalent of 1p. Once you have collected 50 stars, you can donate them to charity.

Donating to charity automatically enters you into a monthly raffle to be in with a chance of winning a gift voucher.

You can gain additional stars by inviting your friends to join the app and by answering surveys. The data gathered from these surveys is then passed onto educational institutes in an effort to improve healthcare.

DrugStars pride themselves on being patient focused. They are not run by big pharma companies and the structure of their organisation ensures that they are not influenced by drug companies either.

The app is currently available to download for free on android and iOS in the UK, US, Denmark, Sweden and Norway.

That Crohn's and Colitis UK believes that no Inflammatory Bowel Disease related initiative, development or service will be as good as it could be without the input of people affected by these conditions at each stage in the cycle of planning and development, implementation and delivery, monitoring and review. Those living with IBD have a personal experience and understanding of the impact this has on their and their families' lives and through receiving health and other public services, they can become 'Experts by Experience'. This wealth of experience plays a vital role in informing and

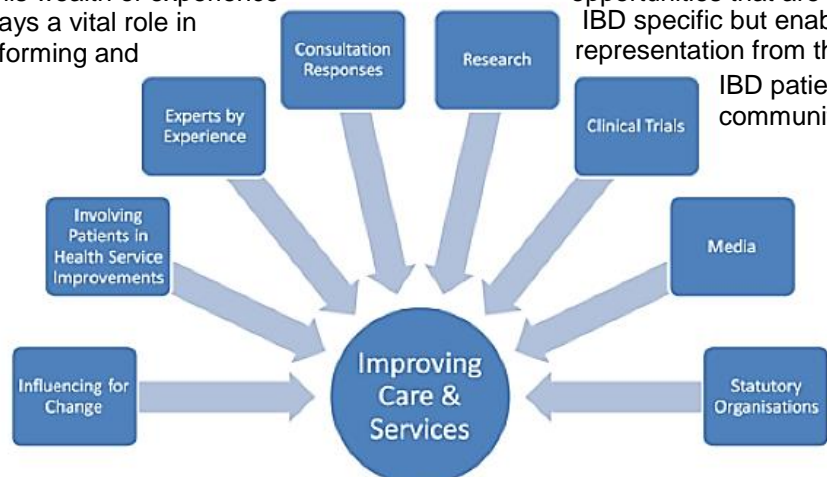
shaping the work of the Charity and improving the way services are delivered for others.

Crohn's and Colitis UK work to ensure that the voice of those living with IBD is valued and heard. They support individuals to become involved with the Charity and with initiatives that can make a real difference to the lives of others with IBD.

In addition to this, they support and encourage individuals to get involved in service improvement more broadly by participating in

opportunities that are not IBD specific but enable representation from the

IBD patient community

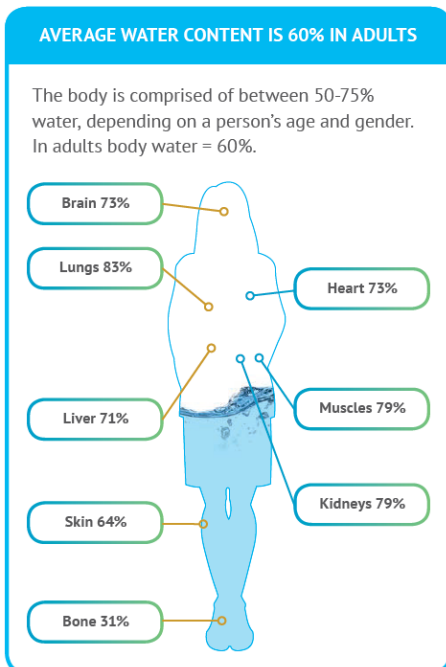


The Essential Guide to Hydration

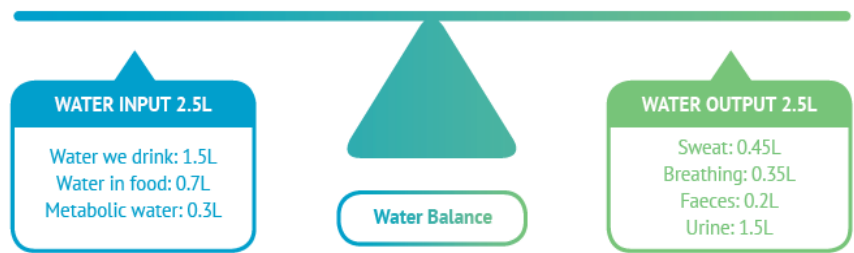
Water is essential for life. It accounts for about 60% of our body weight and performs crucial roles such as carrying nutrients and waste products between our major organs, helping to regulate body temperature, lubricating our joints and acting as a shock absorber. Body water is found both inside cells, and is called, intracellular water.

Intracellular water contains dissolved solutes (electrolytes) which are Essential to maintaining healthy body functions. Water found outside cells is called extracellular water. Blood contains extracellular water which is transported around our body. Water moves easily between cells to wherever it is needed.

The human body works to maintain optimal hydration by using hormones to control how much we urinate and giving our brains signals to tell us that we are thirsty. As our brains are 73% water, insufficient hydration can have an adverse effect on how our brains function. On average, we take in and excrete around two and a half litres of water a day, although this varies from person to person.



Hydration status may fluctuate throughout the day, however, our body will regulate itself over a 24-hour period. Optimal hydration is when our water intake matches requirements. However, when water intake is less than our bodies' requirements, we start to become 'hypo-hydrated' and this can lead to insufficient hydration, or



The Water Balance

'dehydration'.

We are at the greatest risk of dehydration when we are too hot or too dry, have limited access to water or lose more water than usual. Warm or dry environments, such as centrally-heated homes tend to increase our need for fluid. We can lose more fluid through sweating (due to exercise or hot climates), or by suffering vomiting and diarrhoea.

Consequences of Dehydration

Mild dehydration may occur when we lose about 1 per cent of our body weight due to water restriction. Some common symptoms of mild to moderate dehydration are given below:

- **Constipation**
 - **Dark yellow or brown urine**
 - **Dry, sticky mouth**
 - **Few or no tears when crying**
 - **Headache**
 - **Increased thirst**
 - **Muscle tiredness**
 - **Sleepiness or tiredness**
- children may be less active than usual.

Research shows that losses of 2% or more can reduce cognitive (mental) performance.

Inadequate water intake can also contribute to chronic kidney disease.

Elderly people in particular are at

increased risk of dehydration, due to a number of factors. The thirst sensation lessens with age, while using multiple drugs and medicines can also affect water balance which means they might become dehydrated more easily or without realising.

How much water do we need?

Like vitamins and minerals, our fluid requirements are individual and depend on factors such as body weight and size, age and gender, levels of physical activity and the temperature of our environment. European guidelines, however, provide a useful insight into how much water our bodies need each day.

The European Food Safety Authority (EFSA) states that water contributes to the maintenance of normal physical and cognitive functions and normal thermoregulation. Based on the EFSA's scientific opinion on adequate water intake, women should aim for total water intakes of 2 litres per day and men 2.5 litres per day. The same guidelines also apply to older individuals.

| Gender | Age Group | Amount of fluid from drinks and food (litres/day) | Amount of fluid from drinks only (litres/day) |
|----------------|---------------|---------------------------------------------------|-----------------------------------------------|
| Boys and Girls | 4 – 8 years | 1.6 | 1.1 – 1.3 |
| Girls | 9 to 13 years | 1.9 | 1.3 – 1.5 |
| Boys | 9 to 13 years | 2.1 | 1.5 – 1.7 |
| Women | 14 years + | 2.0 | 1.4 – 1.6 |
| Men | 14 years + | 2.5 | 1.75 – 2.0 |

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