



WE'VE GOT THIS

This booklet has been produced by MSD and is intended for patients aged 12-17 years who have been prescribed Remicade® (infliximab) to treat Crohn's disease or ulcerative colitis.

YOU'VE GOT IBD.

HOW DOES THAT MAKE YOU FEEL?

WORRIED? ANGRY? CONFUSED?

HOW ABOUT IN CONTROL?

BECAUSE NOW, YOU'RE JUST

STARTING TO GET IT. THE MORE

YOU KNOW, THE EASIER IT GETS.

YOU'VE GOT THIS.

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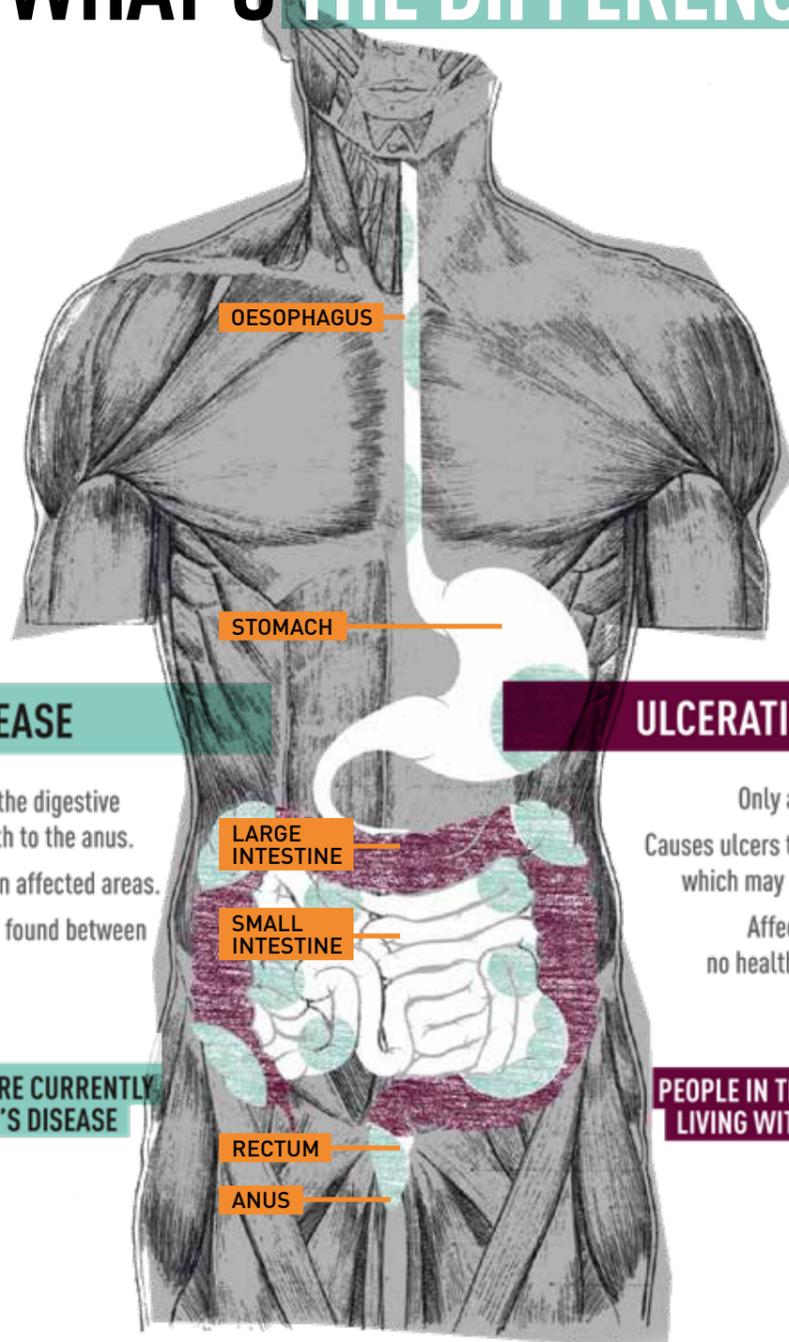
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IBD: THE FACTS

Inflammatory bowel disease (IBD) is a general term that's used to describe two conditions: Crohn's disease and ulcerative colitis.

Both cause inflammation of the digestive system. They can sometimes look similar, but they're actually separate conditions.

SO WHAT'S THE DIFFERENCE?



CROHN'S DISEASE

Can affect any part of the digestive system, from the mouth to the anus.
Causes inflammation in affected areas.
Healthy sections often found between the inflamed patches.

115 000
PEOPLE IN THE UK ARE CURRENTLY LIVING WITH CROHN'S DISEASE

ULCERATIVE COLITIS

Only affects the large intestine.
Causes ulcers to develop in the intestine, which may bleed and produce mucus.
Affected areas are continuous; no healthy sections between them.

146 000
PEOPLE IN THE UK ARE CURRENTLY LIVING WITH ULCERATIVE COLITIS

WHAT ARE THE SYMPTOMS?

DIFFERENT PEOPLE ARE AFFECTED BY IBD IN DIFFERENT WAYS, BUT THE MOST COMMON SYMPTOMS ARE:

- DIARRHOEA
- ABDOMINAL PAIN
- TIREDNESS
- GENERALLY FEELING UNWELL
- LOSS OF APPETITE
- WEIGHT LOSS
- ANAEMIA

Symptoms can change over time. There may be times when you have very few symptoms (a period of 'remission') and other times when they are more severe (a 'relapse' or 'flare-up').

IS THERE A CURE ?

Right now, there's no cure for IBD. But advances in treatment mean many people with IBD are able to control their symptoms and minimise the impact on their everyday life.



Sources

Crohn's and Colitis UK. Crohn's Disease. 2013.
Available from: <https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease/crohn-s-disease> [Accessed November 2018].
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Available from: <https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease/ulcerative-colitis> [Accessed November 2018].
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Available from: <https://www.nhs.uk/conditions/inflammatory-bowel-disease> [Accessed November 2018].

YOUR GUIDE TO REMICADE® (infliximab)

WHAT IS REMICADE®?

Remicade® (also known as 'infliximab') is a medicine that's been used to treat Crohn's disease and ulcerative colitis for more than 18 years.

Remicade® is what's known as a 'biological treatment'. It acts on a specific part of your immune system, helping to reduce the inflammation in your digestive system. It can't be given as tablets because it would get broken down in your stomach – instead, it's given in hospital as an intravenous (IV) infusion (through a drip into a vein in your arm).

HOW OFTEN DO I NEED TO HAVE TREATMENT?

The first three treatments are fairly close together. After the first one, you have another one two weeks later, and one more four weeks later. This is called the 'induction phase'. From then on, you have treatments every 6-8 weeks, depending on your disease.

Because of the way Remicade® is given, you may have to have time off school or college every so often for your appointments.



**LIFE WITH IBD
ISN'T ALWAYS EASY.
BUT TOGETHER...**



WHAT WILL HAPPEN WHEN I GO FOR MY TREATMENT?



While you're in hospital, you'll be looked after by your nurse. You can ask them any questions and talk about anything that's worrying you.



You'll be treated as a day patient – so you won't need to get into bed or stay overnight. You'll have the infusion sitting down in a chair.



The first few infusions will probably take about two hours. You may not have to stay still or even remain in the chair – you can spend the time how you like. It's an ideal time to catch up on your favourite TV series or message your friends.



After the infusion, you'll have to stay in the hospital for an hour or so, to make sure you feel OK. But after that, you're free to go home and get on with your day.

WILL I HAVE OTHER TREATMENTS ALONGSIDE REMICADE®?

The treatment you have will depend on you and your condition. If your doctor thinks you would benefit from an additional treatment they'll discuss it with you first.

Common treatments you might have are:

STERIODS

Most people with IBD will be treated with a course of medicines called steroids. They are man-made hormones which act on your immune system to reduce inflammation. While steroids are very good at treating the symptoms of a flare-up, they aren't suitable in the long term. Speak to your IBD team if you have questions about steroids.

IMMUNOSUPPRESSANTS

Sometimes you may receive Remicade® in combination with an immunosuppressant drug, like azathioprine or methotrexate. But this isn't always the case. Your IBD team will discuss the options with you to decide what's right for you.

Sources

Crohn's and Colitis UK. Infliximab. 2018. Available from: <http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/Infliximab.pdf> [Accessed November 2018].

Crohn's and Colitis UK. Steroids (corticosteroids). 2016. Available from: <http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/Steroids.pdf> [Accessed November 2018].

Remicade® (infliximab) Summary of Product Characteristics.

BE READY FOR ANYTHING



Life with IBD is no walk in the park. Some days, it can feel like an uphill battle. You have to deal with so much more than most people just to get through the day – but you're not about to let it bring you down.

AT SCHOOL OR COLLEGE

Let's be real: school isn't anybody's favourite place. But it can be an even bigger challenge when you have IBD. Between having to ask permission to use the toilet, worrying about what others might think and catching up with missed lessons, it can feel like a daily struggle.



1

Tell your head of year or form tutor about your IBD. They'll be able to make arrangements that will make your life easier, such as:

- Letting you sit near the door and go to the toilet without asking for permission
- Letting you eat when you need to
- Giving you extra time to complete schoolwork and excusing you from PE when you're not feeling well.



2

Keep an emergency kit in your locker, containing a change of clothes, wipes and a plastic bag, so it's always there when you need it.



3

Even if you don't want to tell anyone about your IBD, it's a good idea to **confide in one close friend** so they know what you're going through and can support you.



OUT AND ABOUT

You know the drill: your friends are heading into town at the weekend to grab some lunch and go to the cinema. All they're thinking about is how good that new film's supposed to be, but you're worrying about needing to dash to the toilet.

WHAT CAN YOU DO?



1

Whenever you go anywhere new, **make a mental note of where the toilets are**. That way, you'll be able to get to them as quickly as possible if you need to.



2

Look into getting a **Radar key** from www.disabilityrightsuk.org and/or a **'Can't Wait' card** from www.crohnsandcolitis.org.uk, which will let you have urgent access to public toilets.



3

If you're eating out, **avoid foods that can make your symptoms worse**. Also, instead of having one big meal, try to stick to smaller portions and eat more often.



DEALING WITH IBD AT SCHOOL CAN BE TOUGH. BUT TELLING SOMEONE MAKES EVERYTHING SO MUCH EASIER.



WITH AN IBD EMERGENCY KIT, YOU'RE PREPARED AND IN CONTROL.

IBD CAN TRY TO BRING YOU DOWN. BUT YOU'RE ALWAYS ONE STEP AHEAD.

OLIVIA'S* PROM NIGHT



“My friends and I were so excited for prom. Everyone at school had been talking about it for months, and I’d bought the most beautiful dress that I couldn’t wait to wear. It was going to be such an amazing send-off before we all went to college... but then, with just two weeks to go, my Crohn’s disease started flaring up again.

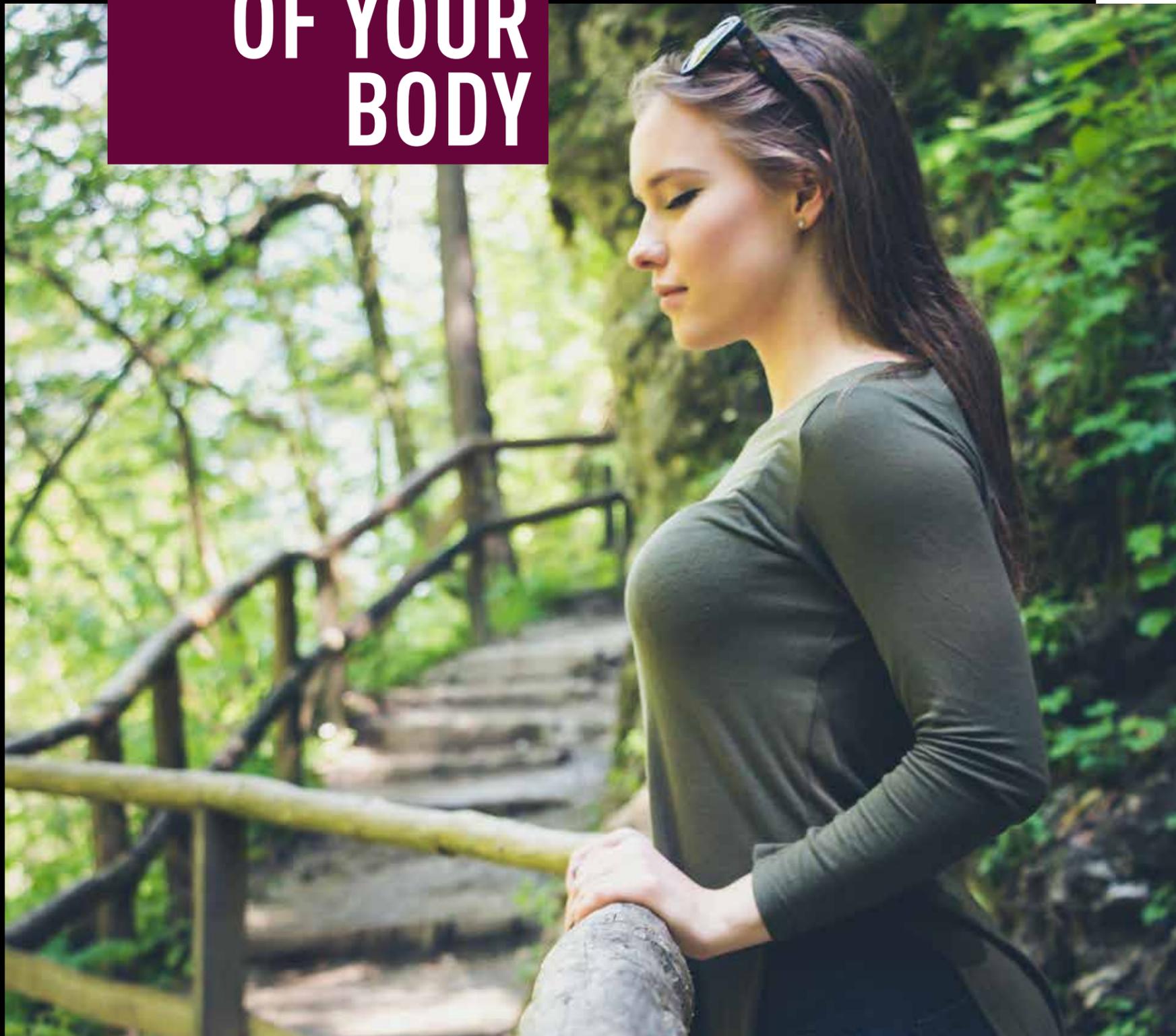
I was so scared it would ruin the night. I didn’t want to be running to the toilet all the time – especially as nobody knew about my condition. The closer it came, the more worried I got, and my friends started wondering why I was so quiet. I realised I couldn’t keep it from them forever, so I came clean.

I thought they’d be grossed out, but they were so understanding and supportive – I wasn’t sure why I’d been worried in the first place! When prom finally arrived, I was determined not to let my Crohn’s stop me from having an amazing night. And it didn’t – I wore my beautiful dress, danced the night away with my friends and laughed harder than ever. Turns out, it didn’t matter if I had to dash to the loos a few times. We were all having way too much fun to notice.”

*Olivia is not a real patient and this account is fictional.

LIFE WITH IBD IS NO WALK IN THE PARK. YOU'VE GOTTA KNOW WHERE YOU'RE AT AND WHAT YOUR NEXT MOVE IS. IBD CAN TRY TO BRING YOU DOWN, BUT THERE'S NO WAY YOU'RE GOING TO LET IT. **YOU'RE ALWAYS ONE STEP AHEAD.** YOUR FRIENDS DON'T KNOW WHAT THEY'D DO WITHOUT YOU. SO NEXT TIME THEY NOTICE THAT YOU'RE A LITTLE QUIET AND ASK "EVERYTHING OK?", **DON'T SHRINK AWAY FROM THE TRUTH.** REMEMBER THE COURAGE AND DETERMINATION THAT GOT YOU WHERE YOU ARE TODAY. **TAKE A DEEP BREATH AND SAY, "IT'S SIMPLE, I GOT IBD, IT'S NOT ALWAYS EASY AND IT CAN GET ME DOWN. BUT IT'S OK, I GOT YOU GUYS, AND TOGETHER, WE'VE GOT THIS."**

TAKE CARE OF YOUR BODY



LIVING WITH IBD CAN BE TOUGH.

Tough on you, and tough on your body. You can do most things, but only when you look after yourself. Listen to your body and know when to take the pressure off.

You don't have to be unstoppable – you just have to know it's OK to slow down.

EATING WELL

It's no surprise that diet and IBD are closely linked. Certain foods (especially fatty or spicy ones) can trigger symptoms, but it varies massively – what one person eats every day might have another running for the bathroom. The important thing is to find out what works for you.

Keeping a food diary can help you track what you eat and the symptoms you get. That way, you can see any patterns and steer clear of food that makes your IBD worse.

It's still important to eat a healthy, balanced diet so your body gets all the right nutrients. If you're having trouble eating a range of foods from different food groups, speak to your IBD team for advice.



STAYING ACTIVE

Does IBD mean you can't exercise? Far from it. You can run, play sport, go to the gym, take up yoga, or do anything else you set your mind to.

You'll probably feel better for it too: exercise can give you more energy and reduce stress.

However, when you have IBD, you may not always feel well enough to do anything too active. And that's OK – the best thing you can do is listen to your body. Time for rest and recuperation is just as important, and will help you get back to feeling your best.



TALKING IT OUT



Your friends have got your back. Together, you've been through it all: braces, break-ups and some seriously bad haircuts. You know you can count on them. So when it comes to your IBD, why keep quiet? A problem shared is a problem halved. With your friends by your side, you can do anything.

YOU'VE GOT THIS.

You're ready. You've been thinking about it for a while, but the time's finally come. Dealing with IBD *would* be easier if your friends understood. So you're going to tell them at last. A deep breath, a moment to prepare... and then you realise you have no idea how to go about this.

DON'T WORRY.

THE STEP-BY-STEP GUIDE TO HAVING *THAT* CONVERSATION

- 1 Choose the right person.**
You don't have to stand on the street with a megaphone and announce to the world that you've got IBD (unless that's your style). For most people, a one-on-one chat with a trusted friend is far less intimidating.
- 2 Pick the right time and place.**
Make sure you've got plenty of time to talk, somewhere you won't be interrupted. You don't want to be halfway through explaining when your mum starts calling you for dinner.
- 3 It doesn't have to be face to face.**
If it feels too daunting, ditch the in-person conversation and do it via text. Just make sure you don't accidentally message the group chat.
- 4 Explain simply that you have IBD, and what it means for you.**
You don't have to have an encyclopaedic knowledge – your personal experience is much more valuable. And don't feel like you have to be super serious. If you can laugh about it, you'll probably find the whole thing a lot less awkward.
- 5 They'll probably have questions.**
That's a good thing, because it means they want to understand what you're going through as best they can. You're the best person to answer them – but remember you don't have to talk about anything you're not comfortable with.

WE'VE
GOT
THIS

A young man and woman are laughing and pointing upwards at a fair. The background is filled with warm, glowing string lights. The woman is on the left, wearing a dark patterned cardigan over a white lace top. The man is on the right, wearing a light purple button-down shirt and suspenders. The overall mood is joyful and nostalgic.

LEWIS* AND SARA'S FIRST DATE

"OK, if I'm being honest... I've liked Sara since year 7. I wanted to talk to her for ages, but was never quite brave enough. So I couldn't believe my luck when we got paired up for a geography project and I could properly get to know her. We clicked straight away – I was trying to psych myself up to ask her on a date when she took me by surprise and did it herself.

She asked me to a concert that Friday, but it couldn't have been worse timing – that was the day I had to go to hospital for my Remicade treatment. No one else knew about my ulcerative colitis, and the last thing I wanted was to have to tell Sara. I thought it'd put her right off me. So I made some pathetic excuse, and spent the rest of the day kicking myself for turning her down.

In the end, I changed my mind. I think I realised it was an opportunity I couldn't waste, so I told Sara the truth. I fully expected her to go off me... but she didn't make it into a big deal at all. We went out the following Friday instead and had a great time. It wasn't awkward at all, and I was so much more relaxed because I didn't have to worry about telling her about my UC. And I must've done something right, because four months later, we're still together."

IBD: THE ULTIMATE MYTH-BUSTER

So now you're getting to grips with IBD. You're starting to figure out where you're at and what works for you. The more you know, the easier it gets. Every day is a new challenge conquered. And at some point, once you've hit your stride and are dealing with what life throws at you without batting an eyelid, you'll realise how far you've come.

Like always, you've got this.

Am I contagious?

IBD isn't contagious. We don't know exactly what the causes are, but you can be sure you haven't caught IBD from anyone else, nor can they catch it from you.

Does having IBD mean I'll have to have surgery?

Not necessarily. For some people with IBD, surgery is the best option to help with their symptoms, but some do just as well on other treatments. It's all about finding what's best for you.

Does having IBD get me out of doing GCSEs or A-levels?

Unfortunately not! You should still try to keep up with your schoolwork – but it's a good idea to let your school know about your IBD. They can make arrangements that'll make your life easier, like giving you more time to complete work or letting you sit exams in a private room near the toilet.

Can following a special diet cure IBD?

Although there are a lot of diets out there claiming to be able to 'cure' IBD, most of them don't have any evidence to back them up. Instead, you should try to follow a healthy, balanced diet and avoid any foods that make your symptoms worse.

Can I use contraception while on Remicade®?

Yes – if you're sexually active, it's recommended that you use contraception while you're being treated with Remicade® and for at least six months after the last dose. If you have questions about suitable methods of contraception, speak to your GP or IBD team for advice.

How long will I be on Remicade®?

It all depends on your condition. Your IBD team will assess you at least every 12 months to decide whether you need to continue treatment. But don't worry – if your treatment is stopped and you have a flare-up, you should be able to start it again.

Does having IBD mean I'll be ill for the rest of my life?

IBD is a lifelong condition, but this doesn't mean you'll always have symptoms. There are lots of treatment options available that can help control your disease.

BUSTED

YOU'RE NOT ALONE

When you live with IBD, you live with a lot. Some days it can feel like a rollercoaster. Not knowing whether you're up or down. But you don't have to face anything alone. Asking for help isn't weakness – it's a sign of your courage. And with the right support, you'll always be on the way up.

YOUR FAMILY AND FRIENDS

Whatever's going on in your life, you'll probably find it helps to take a breather and talk it through with a friend or family member. Not only will it be a relief to get it out in the open, it'll help them support you too.

TALKING THERAPY

If you find it difficult to talk to people you know, or you'd like to speak to a professional, you may find talking therapies helpful. Ask your GP about being referred – you'll be able to get confidential support online, on the phone or in person.

SUPPORT GROUPS

Whatever you're going through, chances are you're not the only one. Thousands of young people in the UK are living with IBD, and sometimes the best person to speak to is the one who knows exactly what you're experiencing. Search online or ask your IBD team for information on support groups for young people with IBD.

USEFUL WEBSITES

My Remicade®

My Remicade® provides further information about treatment for people who have been prescribed Remicade®.

www.myremicade.co.uk

Crohn's and Colitis UK

Crohn's and Colitis UK is a charity that provides information and support for people living with IBD.

www.crohnsandcolitis.org.uk

Guts UK

Guts UK is a charity that funds research into digestive disorders and provides support for people living with these conditions.

<https://gutscharity.org.uk>

NHS

The NHS website provides useful information about IBD.

www.nhs.uk/conditions/inflammatory-bowel-disease/

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Merck Sharp & Dohme Limited (tel: 01992 467272).



By scanning this QR code, you will be taken to the MSD myremicade patient website.

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