

**CROHN'S &  
COLITIS UK**



Rosie



Charlie



Aleesha

# THE UNSTOPPABLES

OUR STORIES OF LIVING  
WITH CROHN'S AND COLITIS



Mason



Evie



Aidan

# EVIE'S COURAGE

Hi, I'm Evie. I'm 13 and I was diagnosed with Crohn's Disease five years ago. I wanted to share my story with you about how I felt then, and how I'm doing now.



**When I was diagnosed,** I was very quiet because I was in so much pain and I had no energy to talk. I was also scared. If I could go back in time, I'd tell myself that things will get better. They will change.

**I remember the first time I was put on steroids.** Everyone was staring at me because the side effects made my face look puffy - and people treated me differently. They were just trying to be supportive, but I was still the same person inside.



**When I was diagnosed,** my mum's friend gave me a toy badger. She wanted me to take him on journeys, so I started bringing him into hospital! One time I was having some treatment in hospital and the nurses gave the badger a mask and a bandage on his hand. He's like my little friend.



**I started off doing sponsored walks, fashion shows, cake sales** and I was just trying my best to get awareness out about Crohn's and Colitis. And now that quite a few people know about it, they'll tell me "Oh, my friend has that. My cousin has that."

"I want to raise more awareness because not enough people know about these conditions."



**That's me at the Yorkshire Child of Courage awards ceremony.** I actually met the English football manager, Gareth Southgate. My dad, brother and uncle were really happy to see him! I'm also a big Leeds United fan, and I got to go onto the pitch as a mascot. That was amazing, I'll never forget it.



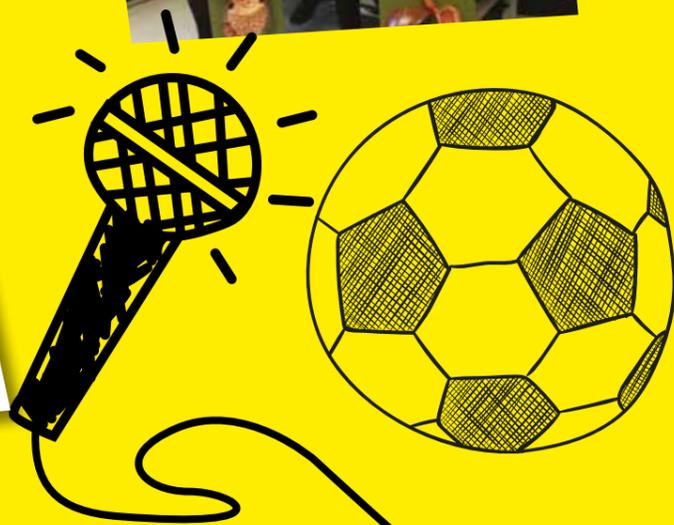
**It really makes me happy when people talk about Crohn's and Colitis because you should never be embarrassed to talk about it.** I actually worked with Leeds City Council to produce a guide about Crohn's and Colitis, and it was sent to all the schools in Leeds. It's better for everyone to know - instead of just keeping it hush hush.

Can you find a way through my crazy tummy maze?

Start



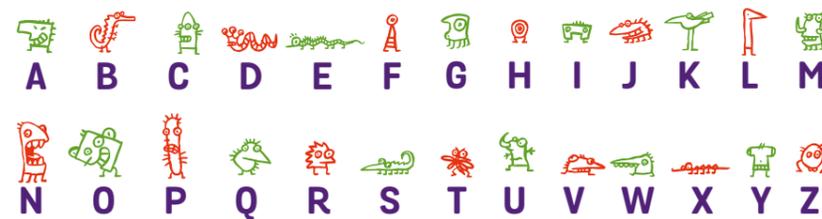
Finish



# A NEW NORMAL



Crack the code to reveal my special message to you!



Hi, I'm Aidan. My Colitis hasn't stopped me doing anything.

**I was diagnosed with Ulcerative Colitis on my 8th birthday.** This photo is me in the hospital bed on my birthday – and that's Ellie the elephant, my favourite cuddly toy.

The doctors and nurses were so lovely, they all sang Happy Birthday as I was walking down to have my treatment.

They made it as nice as possible. And we had a big birthday party the next year instead!



**I started at Cubs when I was in Year 3 and I love it.** We make stuff, play games, and get badges for doing things. I've been camping three times – we make fires, roast marshmallows, and learn to put tents up. I also love paddleboarding and archery.



**That's me raising money for charity.** I wanted to fundraise for Crohn's & Colitis UK to raise awareness, so mum signed me up for a 2km run in the Olympic Stadium. We set a goal of £200, but we actually raised over £1,100 which was amazing!



"I'm happy because I'm feeling healthy again and can do lots of things."

**I take Asacol tablets three times a day.**

I started on the liquid for a month, and it made me feel better in about a week. The tablets are quite big, so mum cuts them in half for me. The Asacol is working well, so I feel very lucky.

**My diagnosis hasn't changed me.** I do every activity I can, and I still go to my friends' houses. I had 100% attendance at school until I got the diagnosis, and the only reason I miss school now is to go to hospital appointments, which isn't too bad.



# TAKING CONTROL

I'm Aleesha, and I have Colitis. I was diagnosed in 2014 when I was doing my A-levels. I was rushed in for an emergency operation and life has been very different since. This is my story.

**It all still feels quite raw.** When I was diagnosed, my friends were about to go to university, and I had to take a year out. I needed an emergency operation and didn't know I'd be waking up with a stoma. (This is where doctors make a hole in your tummy for food to come out into a small bag, so it doesn't have to go through the poorly bit of your body.) I was only 18, and it was a big shock to accept the bag. It took me a lot of time to accept what was going on.

**I didn't know anything about Colitis or Crohn's.** The symptoms were weird, like my hair falling out, losing my appetite, or feeling fatigued all the time. But I knew it was serious when I couldn't control going to the toilet. I was really determined I'd get to university, but I had no control over my body.

**I took a year out to recover.** I did go back to college, but most of my friends had gone. And the people who had stayed behind thought that I'd been attention-seeking. None of my friends really understood what I'd gone through, and I felt quite alone for my last year. That was a tough time.



**When the nurse showed me my stoma** my initial thought was "Oh, it's not that bad." I thought it looked like a rose so I named it Rosie. Every year we celebrate Rosie's birthday - we get a cake and balloons for her! I think I'm just celebrating that I've had a second chance at life.



**I began posting pictures on Instagram and started a blog called Gutless Warrior.** It gives me a real sense of accomplishment. I've come across loads of Asian girls in particular who are finding it hard to adjust. There's a real stigma in the community. Connecting with them - and letting them know there are so many people going through the same thing - that's one of the best things I've done.

**I didn't realise I was strong until it was the only choice I had.** I didn't know I could get through so much in life. And I never actually let myself think that I was unwell. I just wanted to be normal.

"People started following me on Instagram and getting in touch. Now I get questions every day!"

**A few girls with stomas have asked me whether they'll ever be able to get into a relationship.** Well, I've been in a relationship for seven years - my boyfriend's been with me throughout all this. I think if you find the right person, they will love you no matter what.

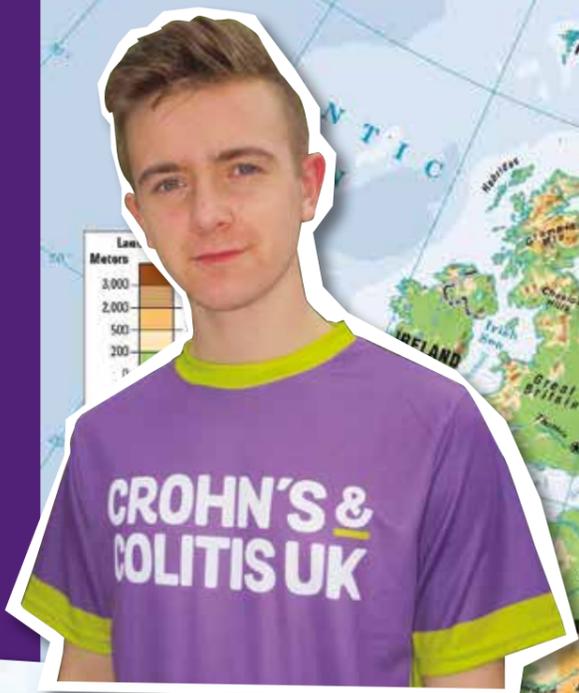
**Today I feel like I've got control over my body.** That's amazing. Before the operation, my body had control over me.



# LOOKING UP



Hi! I'm Charlie. I'm 17, and I was diagnosed with Crohn's Disease three years ago. I'm just about to start studying at the University of York. This is my experience of Crohn's so far.



## Before I was diagnosed I remember getting tummy pains.

At the start of my GCSEs, I was really ill. I was at home for four weeks in a row during my exams. I'd sit at home with textbooks and teach myself. I threw myself into revising and actually did really well!

**After I was diagnosed,** I was on 20 tablets a day – which sounds crazy – and they weren't really working. Now I take fewer medications and I have infliximab infusions every eight weeks. I don't know what goes in but it's like magic, it really works for me!



"I feel fit and healthy now. There are ups and downs, but I just enjoy the ups and make the most out of life."



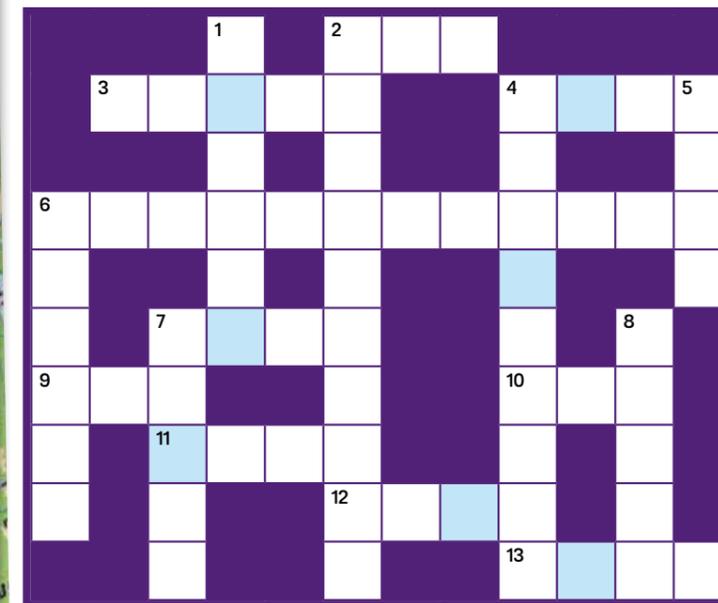
I've set you a crossword challenge. When you've completed it, the letters highlighted will form an anagram of a word. It's something we all need. Answers below.

### ACROSS

- Another name for Crohn's and Colitis (3)
- You think with it (5)
- Bravery (or your digestive system) (4)
- What I need to play badminton (12)
- The famous dinosaur from Jurassic Park (1-3)
- What we all breathe (3)
- The boy in Pokemon (3)
- What I took to get to college (4)
- A bridge (4)
- Where I'm going to university (4)

### DOWN

- Become an expert (6)
- The drug infusions I take (10)
- The science of the Earth's surface – what I'm studying (9)
- Not great, not bad (2-2)
- A good exercise for your legs (6)
- '\_' mill – what you run on in the gym (5)
- Somewhere to sit (5)



**That's me walking the Jurassic coastline to raise money for Crohn's & Colitis UK.** Ironically, I thought about it when I was in bed in hospital! The walk was 96 miles and we raised over £2,000.

**I started playing badminton at primary school.** At one point I was playing for the county! I had to take a break from it when I was ill. But I recently started it back up again and I'm going to play at university.

**My advice to a younger me? Don't give up.** Don't be so pessimistic. Look for the good things. Even when I was ill, I was still trying to enjoy everything – I think I got through a whole box set of *Friends* in a week! I've always tried not to worry about it as stress makes the symptoms worse. I often talk to younger kids at the hospital – and I always tell them it'll be okay and not to worry.

**ANSWERS**  
 Across: 2. IBD 3. Brain 4. Guts 6. Shuttlecocks 7. T-Rex 9. Air  
 10. Ash 11. Exam 12. Arch 14. York  
 Down: 1. Master  
 2. Influximab 4. Geography 5. So-so 6. Squats 7. Tread 8. Chair  
 Mystery word: COURAGE

# Being Rosie



I'm 10 and I've had Crohn's for the last year. I didn't know anything about the disease before I was diagnosed.



## This is a photo of me in hospital.

My school ran a competition to find the weirdest place you'd read a book – and this was my entry. I really love David Walliams' books.

## When I started on a liquid diet (Modulen), my mum asked me if I was ok to have it in the school dining room with the other children. I said yes because I really wanted to stay with my friends! The school told everyone why I needed it and they understood. Everyone saw me having my drink once, and they never thought about it again.



My drawings



I was on a liquid diet for six weeks, but I was also allowed to have chewing gum, jelly tots, boiled sweets and jelly. Gradually we replaced the drinks with food and before I knew it, I was eating normally again but – more importantly – I felt and looked better.

## Being diagnosed hasn't stopped me or changed my life much.

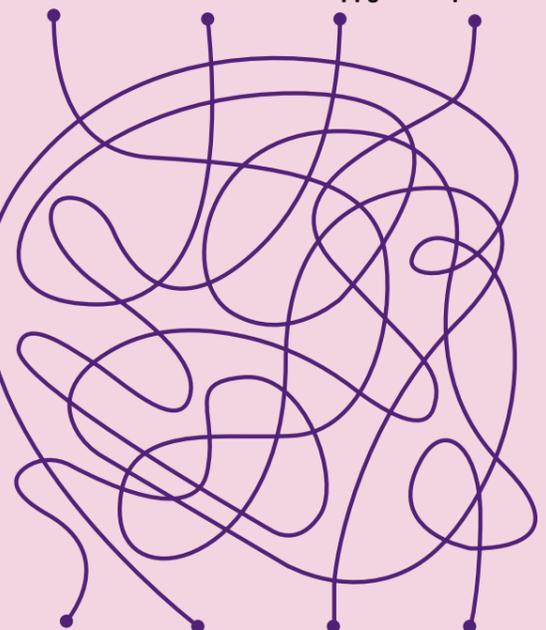
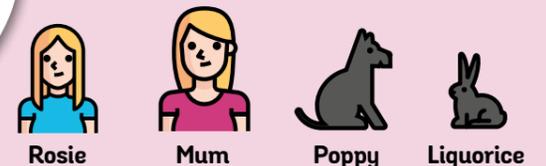
I still train six hours a week with my gymnastics team and have competed regularly. I love doing gymnastics – especially tumbling. This photo was taken just after I was diagnosed. I've always tried to just keep doing what I love.



I love to draw pictures of animals. My favourite animal to draw is a dog, and I actually have a Miniature Schnauzer dog called Poppy and a rabbit called Liquorice.



Only one line leads to the gold medal – whose will it be?



"Don't worry! Life becomes a bit different but it's really just about remembering to do a few more things, like taking your medication."

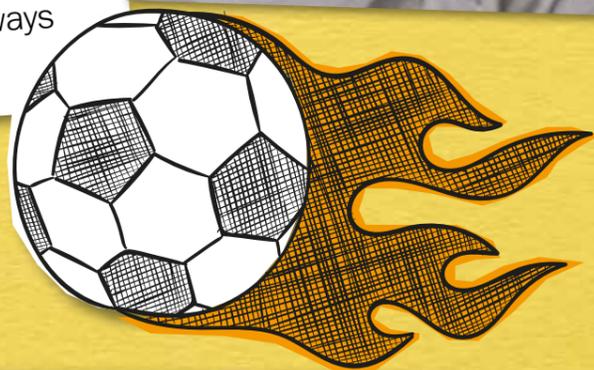
# MY NEW ADVENTURE



I'm Mason and I'm 17. I was diagnosed with Crohn's in my last year of school. After a tough couple of years I'm now looking forward to starting college.

## How do you feel about having Crohn's?

I don't like to be down about it. Sometimes I am but you can't let it affect you - because anything can happen in life, and it's always good to be positive.



## Have you talked about it at school?

Yes, we actually did a special assembly at school, where I gave a talk. We also had a teachers vs students football match to raise awareness, as most of the teachers didn't know what it was.

## Do people understand?

I wouldn't say my friends at school really know what I'm going through. I went to a friend's birthday last year when I had just been diagnosed. I was really ill but I wanted to go, and nobody could tell.

Can you find all the words in my special Wordsearch?

- COACH
- COLLEGE
- COOKING
- FATIGUE
- FOOTBALL
- FRIENDS
- FUNDRAISING
- INFLAMMATION
- INFLIXIMAB
- INFUSIONS
- MANCHESTERUTD
- MUM
- POSITIVE



## Is that why you like to help others?

Yes, I'm an ambassador at my school. And as part of that, I coach the younger kids on how to play football. I support Manchester United but I have a season ticket for Ipswich as they're my local team.



## So you love sports?

Definitely, I also really like tennis. This year, I went to Wimbledon Centre Court and saw Serena Williams play which was amazing. Yes, I had strawberries and cream!



## How does your Crohn's affect you?

The big thing for me is fatigue. The most pain I get is when I am anxious or stressed. I'm currently having infliximab infusions and it's going quite well. The doctors said the inflammation had gone down, which is good.

## What's next for you?

I'm about to start studying hospitality and catering at college. Because I'm on infliximab, I have to look after myself a bit more carefully. But that's okay. It won't stop me.



# IF YOU HAVE QUESTIONS

Having Crohn's or Colitis can sometimes feel a bit like being on a rollercoaster. There will be good times and tough times – but there will always be people to help you. Just ask...



Here are their top tips when things feel rough:

## If you feel alone

Just like Charlie, you can meet other people who know what you're going through at fun events like WALK IT or at special family days.

See: [crohnsandcolitis.org.uk/walkit](http://crohnsandcolitis.org.uk/walkit)  
[crohnsandcolitisuk.org/support/support-for-families](http://crohnsandcolitisuk.org/support/support-for-families)



## If you're feeling worried

Aidan had loads of questions when he was diagnosed. If you're worried about anything, talk to your parents first. If they don't know the answers, there's a free Helpline that they can call.

Call us on **0300 222 5700**  
or email: [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)



## If you want to learn more about Crohn's or Colitis

Evie thinks that everyone should know about Crohn's and Colitis. If you or your parents want to know more about the conditions, the Crohn's and Colitis Companion is a great place to start.

Find out more: [companion.crohnsandcolitis.org.uk](http://companion.crohnsandcolitis.org.uk)



## If you want to tell your school

Be like Mason and help everyone at your school understand more about Crohn's and Colitis. Download a free guide for your school here: [crohnsandcolitis.org.uk/schools](http://crohnsandcolitis.org.uk/schools)



## If you're worried about moving into adult care

Aleesha knows that transition can feel like a big change, but there's lots of great info out there that can help you.

See: [crohnsandcolitis.org.uk/transition](http://crohnsandcolitis.org.uk/transition) and watch our videos about transition: [crohnsandcolitis.org.uk/youngperson](http://crohnsandcolitis.org.uk/youngperson)



## If you have questions about your medication

Why do you have to take medicine when you're not well?

And why do you *still* have to take medication even when you're feeling better?

Rosie didn't know anything about the treatments and medications that she had to take. But she and her mum found lots of great factsheets on the Crohn's & Colitis UK website.

See: [crohnsandcolitis.org.uk/treatments](http://crohnsandcolitis.org.uk/treatments)



# WE'RE HERE FOR YOU

Every day, Crohn's & Colitis UK helps  
someone just like you.

The young people you'll meet in this booklet all  
have Crohn's or Colitis – and they want to share  
their stories with you.

Together, we helped them get through the tough times  
and start feeling like themselves again.

We can help you too.

Look inside to find out how.

it takes  
**guts**

to talk about  
Crohn's  
and Colitis