

BILE ACID DIARRHOEA SUPPORT

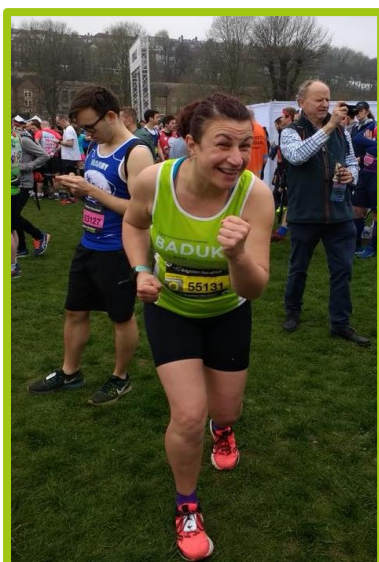
**BADUK**Making **BAD** days better

# What's News

## We're back with a BIG BANG! ....and a RE-BRAND!

We're so pleased to be back! We're back with our quarterly newsletters to update you with our Charity News. Formally BAM Support UK has been re-branded as **BAD UK** due to 'Malabsorption' not always being the reason for having BAM. In fact patients are often not investigated for BAM due to not having the symptoms of malabsorption, as most people who have BAD actually gain weight and having chronic diarrhoea is the main symptom of this condition. Therefore BAD is how the condition is being referred to by Gastroenterologists and the BMJ. So this is our reason to change our name and fall in line with the current guidelines of the British Society of Gastroenterology.

Next was the launch of our video campaign 'A BAD Story'. It was posted on our social media pages and online. It looks at the day and life of someone living with BAD. We encourage you to share this with your family and friends to help raise awareness and understanding of this condition. It is estimated that it affects 1 in 100 people, and currently, the condition is not very well known due to a general lack of awareness resulting in people having undiagnosed symptoms for many years.



The start of re-branding was made in April on our Facebook page due to one of our wonderful members Karen Slade, who raised over £1126 for our charity, by running the Brighton Marathon 2018 for BAD UK. She finished with an amazing time of 4:27.27. **Well Done Karen!** See her full story on Page 4.

We then launched our new website in July. We hope you have visited at [www.BAD-UK.org](http://www.BAD-UK.org). We are really proud of all the hard work from our designers getting it ready and for Lawrance Kelman who will be looking after it for us going forward.



With this we launched our personal story from our very own BAD UK Committee team Michelle O'Conner and Alex Hardwick along with a very brave member of BAD UK, Cathy. We thank you all so much for doing this. Check out these stories at; [www.abadstory.com/video/bile-acid-diarrhoea](http://www.abadstory.com/video/bile-acid-diarrhoea)

Finally, the launch of our BAD UK Shop was in September. Here you can purchase RADAR Keys, Pill Holders and our new look Toilet Card, also new is leaflet pack for you to hand out in your area.

Visit our shop now at;

[www.bad-uk.org/online-store/](http://www.bad-uk.org/online-store/)

# BAD, Anxiety & Cognitive Behavioural Therapy (CBT)

A story by Laura Gentles

I was diagnosed with Anxiety in 2015, and severe BAD in December 2017, eighteen years after my symptoms started.

My story starts at the age of 12 where I was misdiagnosed with IBS – D, I was prescribed Mebeverine and told to eat healthy. As you can imagine this didn't work, and school was a nightmare. That is the time I started with anxiety. I would try to avoid going to school so I didn't have to use a public bathroom as I was so embarrassed. I decided not to go to college because it was too much to take. Throughout my teens and 20s, I would arrange a night out, get ready to leave and cancel because I was too frightened to go out.

"What if I need the toilet and there isn't one free?", "What if they hear me when I'm using the toilet?"

The constant questions in my head were exhausting, but I couldn't stop. It builds and builds, and of course anxiety then presents physical symptoms. One of the common ones being the need to empty your bowels and having BAD I don't need any encouragement! On the rare occasion I did manage to make it out of the door, the anxiety got worse, I wouldn't go anywhere there wasn't a toilet. I made a list of situations I wouldn't put myself in due to BAD related anxiety; - Public Transport - Flying - Visiting other people's houses - The beach - Camping - walking anywhere without toilet on route - Car journeys over 20 minutes - Overnight stays with anyone that wasn't a close friend or family, I was too embarrassed to go on holiday with a group of friends and share a room - Working anywhere that had limited facilities, or if a toilet was in close proximity to others. The list goes on!

One day it all came to a head in 2016 when I was on the tube on my way to work. My anxiety had started almost as soon as I opened my eyes as usual. I was on the train with thoughts still crushing my brain.

"Only 10 more stops. Only 9 more stops. Oh no, I need the toilet. If you need to get off, there's a toilet at Earls Court. You can't make it, you're going to have an accident." This was my every day morning commute. That was my life, and my brain and me had had enough!

I got off at the next station, I found a bathroom. I called my boss and said I wouldn't be in work that day. Despite how ill I was, that was something I never did. I had dealt with BAD related anxiety for 16 years at that point, and something in me just snapped.

I went home and went to my GP the same day who signed me off work for two weeks, my anxiety was crippling, I ended up signed off for four weeks.

She also recommended I try Cognitive Behavioural Therapy (CBT) and referred me. I was sceptical to say the least. I really didn't understand how any kind of therapist/therapy was going to take away the real-life problem I had, because how can you not be anxious about something that's REAL?

The waiting list was around 12 weeks, and I still remember my first appointment. I felt like we did nothing, I went away feeling deflated and even more sceptical. I realise now is my therapist was working out how best to treat me, and what techniques to use. I had 12 sessions over 12 weeks, and each week we looked at my fears, my safety behaviours, responses, coping techniques and so on.

We all have safety behaviours, whether that's carrying a spare pair of underwear, or making sure you have a packet of tissues with you, or maybe it's toilet mapping. I learnt that while we think these behaviours are healthy and preventing us from anxiety, sometimes they work in the opposite way we intended, it can make us worse!

I learnt how to change my thoughts and I kept an anxiety diary. I wrote about times where I felt anxious, how anxious I felt, what the thought was, what I did with the thought, how anxious I felt after I used my coping techniques.

"What's the worst thing that could happen?" This was a question I was asked a lot in therapy. My answer was, "Having an accident in a public place, particularly somewhere crowded or somewhere I can't remove myself from, like a train." In one of my sessions near the end of my course, my therapist told me she was going to show me 'my' worst thing that could happen. She bought out a jar of Nutella and smeared it on the back of her skirt. I mean a whole lot of it, it looked real. She even asked me if it looked real! She asked me to come outside with her, just to observe people's reactions. At this point my anxiety was through the roof for her, as this was my biggest fear! I went outside, I was so nervous, I followed her down a street in South London, trying to concentrate on other people's reactions. We'd been outside around 3 minutes and I realised no one had noticed. We went into a supermarket where she started to shop. She was really trying to make herself seen by stretching to reach things and spending a long time in there. I stood and watched, and 9 out of 10 people didn't even notice. One girl who worked there pulled a face and one guy just looked confused. But the point was, nothing bad happened!

Hardly anyone noticed and the ones who did didn't say or do anything. I realised from that experiment

that my fear was down to other people. Other people's perceptions and how they would react. Once I saw how people reacted or barely reacted as the case was, it was a whole new story. If I did have an accident, well that was my business and probably no one would notice. If they did, so what? That feeling was really liberating.

Over time my anxious thoughts slowly disappeared. I don't have to use techniques like the anxiety diary to calm myself down, because the thoughts aren't appearing anymore.

CBT completely changed my life, and I owe it to the wonderful therapist I had with the NHS. I was so sceptical, but it blew me away. Of course, my BAD is still there and I still have bad days anxiety wise, but I've been given the tools to change my thinking. I get on the train without a second thought and I go for long walks. I went to Jamaica, New York, Brussels and Venice last year, after years of not getting on a plane! I go to friends' houses and go to places with only one toilet.

Could I still need the toilet urgently? Of course! but how I deal with it is different. I don't go into a place with that thought already there.

I still have a fear that I want to conquer – a trip on the London eye (no toilets and no way to get off). I feel if I can do that, I can do anything! I'm making it one of my main goals for this year.

I've come a long way from finding it almost impossible to step out of my front door, to travelling halfway around the world.

Cognitive Behavioural Therapy changed my life, it could change yours.

Such an inspirational story Laura, thank you so much for sharing it with us. If you would like some more info about CBT and what it involves, visit;

**[www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt](http://www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt)**

## Research and Surveys Updates

**Research Priority Survey** - We would like to say a big Thank You to everyone who participated and for all your responses. We are currently analysing the responses and will share findings over the next few months.

*Thank You!*

### **2nd Patient Reported Outcomes Survey –**

Building on the success of the first survey being published in the British Medical Journal for Gastroenterology and growing interest in our work from the clinical professionals we will be undertaking the 2nd Survey soon.

**Collaboration with Academic Organisations** - We are in discussion with an academic institution to undertake further studies into the impact BAD has on a person's life pre and post diagnosis.

## A BAD place in the 2019 Marathon

More great news for BAD UK, from Ella a doctor specialising in gastrointestinal disorders.

'I have come across too many patients who have suffered for years with BAD but without a diagnosis. This can lead to social isolation and depression. Earlier recognition of this treatable condition is achieved by raising awareness.

This is one of the primary aims of BAD UK, and it is vital.

By running the London marathon in aid of BAD UK, I hope to help this fantastic charity continue to support and educate patients and health professionals'.

Good Luck Ella! We will post more info soon on how you can help support Ella raise her funds.



Find us on  
**Facebook**

If you're not already following us on Facebook, find us! We have the best members who support one another whenever you have a question or are just feeling low. We will also keep you up to date with new news. Search for;

**BAD UK – Bile acid Diarrhoea**



## My BAD Marathon Journey

by Karen Slade

*'I will never be in front, I will never be fast, but I will be there.'*

My BAD journey started a long time before my marathon journey was ever a thought. Friends can recall witnessing episodes since my mid-teens and I constantly had a jippy tummy, 'food poisoning', 'gastroenteritis' 'gastritis' and more.

Roll forwards to my late 20s and rushing to the loo was a constant daily reality, receiving a diagnosis of IBS and advised to 'not eat chicken' and take lots of fybogel. Well in case anyone is wondering, it was not useful advice. It was about this time that a friend suggested that we do a run for charity and so I started running. Very slowly, with masses of doubt but with the determination that we would make it and raise the money, and we did.

Roll forward another 10 years and probably hundreds of tests, three exploratory operations, MRIs, CT scans and more. I tried to keep running but had to give in to regular long 'lie-downs' when I felt totally exhausted by the draining symptoms and a busy full-time job. Although it was always hard to start again, I persisted, and would come back to running even if it was a little 10 min jog/walk around the block. The fresh air and the freedom helped repair my psyche and keep the weight down. I also discovered parkrun, a 5k free jog or walk at 100s of local parks all over the UK. It was also a great way to meet new friends in a city I was new to, they easily accepted my irregular running patterns and found I could teach them a thing or two about managing a jippy tummy! I was the lady with loo roll, hand wash and Lucozade in her running pouch, a handy 'toilet finder' phone app and a RADAR key which opened the loos on the riverfront.

Through 2015 I was a regular attendee at A&E and for the first time, medically advised to completely stop activity. For 5 months I stopped running, but after yet another operation which found nothing, I was determined to take back control. I was not going to be defined by illness and my tummy could just get in line. I was going to run a marathon, for charity, by hook or by crook.

For all the powerful words, it was hard and had times of massive doubt. The pain, tiredness and toilet trips made training quite the challenge and I have come back from runs with tears in my eyes after feeling unable to move one-foot in front of the other. But I had made a pact with myself that I would run on every day I could, unless it was a physically impossibility and so this sporadic, inconsistent

running plan was ticked off, still managing around one-third of what I wanted.

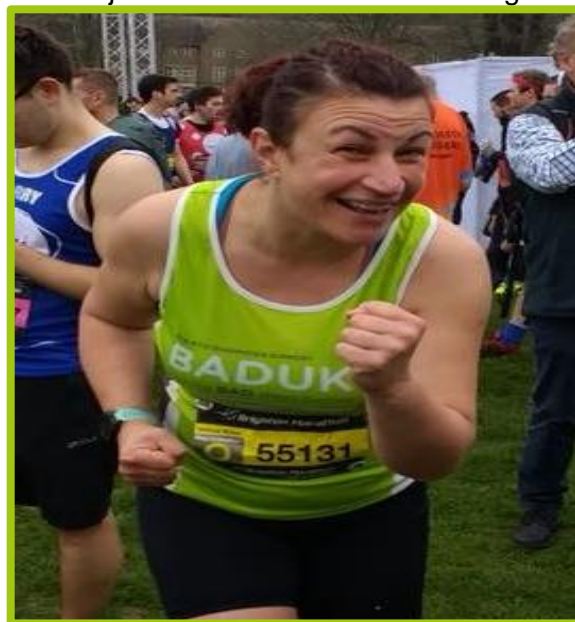
**March 2016 – SeHCAT test.**

**April 2016 – BAD diagnosis.**

That day, my life changed forever. Since then I have been on colesevalam and I have not needed more than a few days off running at a time due to BAD. I still have to plan, I still use the loo roll, I still use the key, I still use the app, but I can run with less exhaustion, I can run with my friends, I can run about three-quarters of what I would like, but that's enough.

15 April 2018 - Brighton seafront.

Me, a BAD-UK singlet and a few hundred other runners. Friends and family had travelled to be there. I thoroughly enjoyed every moment of that marathon, even the last couple of miles where I wasn't sure I could feel my legs. Everyone was there at 26 miles cheering, clapping and shouting. I cried but with a huge smile as I crossed the line, BAD could just do one. I was back in charge.



BAD is tough, it brings challenges, but it doesn't need to stop us from being active or achieving things we thought were beyond us. Running with BAD takes planning, advice from others and it takes courage but it also brings with it a sense of achievement and control, new friends (who are very used to me being smelly), weight stabilisation (although it seems I will never be slim) and a resilience to dealing with the symptoms that nothing else does. When I have a flare up or other issues, I recall that marathon day and it always makes me smile. I will never be in front, I will never be fast, but I will be there!

We have more info on our website about exercise and running with BAD. Have a look;

**[www.bad-uk.org/exercise-and-bad](http://www.bad-uk.org/exercise-and-bad)**



## Have you heard about...

'There are no catches or hidden charges and BAD UK will be really grateful for your donations'



**easyfundraising.org.uk**  
feel good shopping

# A Big Thank You!

Thanks to all our lovely supporters so far we have raised £650.00 from your online shopping sales. Our next target is £1000.00, can you help us reach this? Here's how.....

## Do you shop online?

Did you know that whenever you buy anything online - from your weekly shop to your annual holiday - you could be collecting free donations for BAD UK? Donate while you shop with [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk), its **free** and will not cost you a penny, with over 3000 stores taking part, raise money for BAD UK every time you shop. **It's That Easy!**

## How does it work?

### Step 1: Head over to

<https://new.easyfundraising.org.uk/causes/bamsupportuk> and join for free. Don't forget to download the App.

### Step 2: Every time you shop online

Go to easyfundraising **first** or log on the app, find the site you want and start shopping.

### Step 3: After you've checked out

The retailer will make a donation to **BAM Support UK** for no extra cost whatsoever!

## BAD UK Coventry and London Meetings Support Group

We don't currently have any dates for the next meetings in Coventry and London as we would firstly like to get you options on the meeting we have previously held.

If you have previously attended a meeting at Coventry or London, or are from this area and thinking about coming along, we would like to ask you to drop us an e-mail at

**coventrymeetings@bad-uk.org**  
**londonmeetings@bad-uk.org**

with answers to the following questions and any improvements you would like to see.

- ✓ What would you expect to learn from coming to these meetings?
- ✓ What would you like to see more of at the meetings?
- ✓ Is there any particular evening which would be better for you?

## Receiving our Newsletter

If you would like to receive this newsletter quarterly by e-mail, then please send an e-mail request to **contact@bad-uk.org**.

We can then include you in our mailing list.

We want your story! We are looking for people to write an article or tell us their story that we can post on our website and feature in our newsletter. We would like people to share their experience of BAD and how a proper diagnosis and medication has helped, we know

from attending the meeting and hearing other people's stories really helped others when they were first diagnosed with BAD, so can you help us help others?

If you are interested in helping me with this, please e-mail me and together we can create your story.

**Please send your e-mail to;**  
**admin@bad-uk.org**