

# Inflammatory Bowel Disease (IBD) with Amy Kelly Crohn's & Colitis Ireland

## Speaker Key:

VO Voice Over

SC Scott Casson-Rennie

CB Chantal Boyle

AK Amy Kelly

00:00:00

VO

Welcome to the Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

SC

Welcome to the Sunflower Conversations with myself, Scott, and Chantal. Hi, Chantal.

CB

Hi, Scott. How are you?

SC

I'm very good. It's my first time leading this, so I feel like the master is in the room with you, because you've done this all the time.

CB

You're in the driving seat.

SC

And then I'm the trainee today, which is unusual, because on my own podcast I just crack on with it. So hopefully, we'll be fine. We'll be fine. And you'll no doubt, give me feedback afterwards if I'm not.

CB

I'll be learning from you, Scott.

00:01:03

SC

So, for anybody who doesn't know me, I work for a Hidden Disabilities Sunflower in Ireland, and I work on the communications side, social media, all that kind of stuff. And everybody will know you, Chantal, because they've all listened before. You work in the UK, just in case [overtalking].

CB

That's right, I'm in the UK, doing a similar role to you.

SC

But much better, it has to be said.

CB

Social media, working with new organisations that come on board to celebrate their launch from a communications perspective. The very exciting role of being one of the hosts on the Sunflower Conversations podcast, which is great, because that's when we get to speak to people, the end user, which is wonderful. But also, speaking to experts as well, and sharing and signposting for support, which is crucial.

SC

Yes, absolutely. Talking about guests, this episode we are joined by Amy Kelly. Amy is the Head of Communications and Fundraising raising at Crohn's and Colitis in Ireland. So we've got an Irish guest, which is lovely, obviously, for me. Amy lives with her husband in Galway, which is not too far from where I live. It's on the West Coast, for anybody who doesn't know the geography of Ireland. Amy was diagnosed with Crohn's disease at the age of 27. So, welcome, Amy.

00:02:30

AK

Thank you so much. Hello.

SC

Hello. And we were just saying before we started recording, you are also a podcaster, which we'll get into in a second, so there's three podcasters on this podcast. It could be a long one. Hopefully not. Hopefully we're professional enough not to go down that route.

CB

I hope not, because I've got to edit it. I'll be right, keep to time, everybody.

SC

Exactly. So, Amy, you're very welcome. As well as being head of communications and fundraising at Crohn's and Colitis Ireland, you're also the co-host or the host, actually, of the Gutcast podcast, which is an interesting name, which is the first podcast for people living with inflammatory bowel disease, or IBD in Ireland. And as we said, you live with Crohn's disease yourself. On 19 May is World IBD Awareness Day, so we thought it would be a really good opportunity to talk to you and for this podcast to go around that time. So you're very welcome, you're very well placed to talk about the subject, as well. So, welcome, thank you.

AK

Thank you so much for having me. It's great to be here to create awareness around inflammatory bowel disease. It's kind of the umbrella term and then underneath that, you have conditions like Crohn's disease, ulcerative colitis, Crohn's colitis, microscopic colitis. And it can be undefined, there's a few different variations, depending on where it is at for the patient. It's great to be here to share awareness on World IBD Day. Thank you for having me.

00:04:06

SC

You're welcome. That takes me into the first question then. Can you explain the difference between IBD, or inflammatory bowel disease, and Crohn's and colitis? Because obviously, the work you do is with two specific conditions, but how does that differ? What's the differences?

AK

If you think about it, so inflammatory bowel disease, IBD, is the umbrella term. And then under that, you can have variations of inflammatory bowel disease. As I said, there you can have things like Crohn's disease, ulcerative colitis, microscopic colitis, you can have undefined IBD, and so on.

I suppose the main thing in comparison to Crohn's disease and ulcerative colitis would be Crohn's disease affects anywhere along your digestive tract. That means from your mouth, all the way through to your anus, it can show signs of inflammation in variations, or in one part of those areas.

With ulcerative colitis, it is usually more localised to the large intestine, so you wouldn't have signs of inflammation in your mouth or your back passage, for example. With microscopic colitis, to be honest, the main difference between ulcerative colitis and microscopic colitis, microscopic colitis is only identified by a microscope. So, it's the same presentation of information, you may experience the same symptoms, but they can only detect it by a microscope, by a biopsy in the microscope.

00:05:36

Some people might be diagnosed with something like Crohn's colitis, and that's where the medical team are unsure at that time if it's Crohn's or colitis. And that was myself, because mine was a perforation in my intestine, so a hole burst and an abscess the other side. They'd done a colonoscopy, but they can only go up the large intestine, they couldn't get past my small intestine due to the inflammation, so there was no way of confirming that it was Crohn's disease for me at that time, but it was later then confirmed it.

It could be a mixture of the two for some people, depending. Inflammatory bowel disease is the umbrella term, so everyone with Crohn's or colitis can say I have IBD or I have inflammatory bowel disease. But there the difference, people can still present with very similar symptoms, regardless of what your inflammation is, What some people say, for example, mouth ulcers is something I get, so that would indicate Crohn's disease, because there's inflammation present at the start of my digestive tract.

Some people might have abscesses or tears in their back passage, and that could be external or just internal, and that would be obviously a sign of inflammation that it's just outside the exact small and large bowel.

CB

IBS, that is underneath that?

H

No. With IBS, this is the frustrating thing, I suppose, because IBD and IBS naturally sound exactly the same and naturally, they're both gut-related conditions. And the annoying thing is, as well, some symptoms overlap, and that can be frustrating for a few reasons. It can delay diagnosis for people and try to identify... So, I actually have IBS and IBD, just to add fuel to the...

And that would be quite common. When you're in times of remission with your IBD, so you will go through times of remission and flare, so times of inflammation, times of no inflammation, when you have it managed and under control. And that will fluctuate throughout your life, depending where it's at.

00:07:49

Whereas with IBS, it's really controlled by diet and exercise and those kind of factors. With IBS, so irritable bowel syndrome, you can see the difference when you expand out the names, inflammatory bowel disease and irritable bowel syndrome, they sound different when we spell them out that way. With irritable bowel syndrome there is no sign of inflammation present at all. There's no inflammation in the gut, there's no ulcers in the gut, there's no passing blood, not any of those symptoms, like the mouth ulcers.

I can go through the symptoms of Crohn's and colitis in more detail, but very different, but do have overlapping abdominal pain, bloating, those kind of symptoms. Some people might have diarrhoea, as well, with IBS, but there's no

sign of inflammation present. That's the main thing to understand between the two of them.

00:08:47

But what we do see is a lot of people might be diagnosed with IBS prior to being diagnosed with IBD. IBD can be quite difficult to identify and to diagnose. It typically takes around two years for somebody to get diagnosed with inflammatory bowel disease, which is quite a long time to be living in extreme pain. And depending on the severity, but it can affect people's working life, it can affect their ability to partake in society, a wide range of things. And they're suffering for quite some time.

But even the year before I was diagnosed, I was diagnosed with IBS, and then it kind of pushed Crohn's and colitis to the side. We all Google our symptoms, even though we shouldn't, but we do. And Crohn's disease did come up for me, but I, like a lot of people, just thought that Crohn's disease is just diarrhoea and that's it. And totally brushed aside, because that's not something I personally experience.

And I always say, once you've met one person with IBD, you have met one person with IBD, because it is a really complex condition in the sense that there's no rule book in regards to the way the condition presents and the way we get it treated. It's all very individual, and there can be some overlaps, but I've never met two people with the same story.

SC

I think that's the same for a lot of conditions, isn't it? Where you may have the same condition, but actually, your symptoms are very different.

CB

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00:10:19

SC

In terms of the numbers of people, Ireland and globally, how many people does this effect, roughly, exactly?

AK

In Ireland it's quite difficult to know, because we don't... Some European countries would have an IBD registry. Basically, IBD teams around the country would self-import data into that registry, and you'd have more accurate data. In Ireland, we don't have that. We're relying on various research and comparison to other European countries and globally, as well.

The figure that is used currently is around over 40,000 people in Ireland are living with IBD. But we are seeing an increase in that. That figure is going back since maybe 2011, so you can imagine, I would imagine that it's significantly higher than that. But we do see a 90% increase in children being diagnosed with IBD in Ireland, which is...

CB

90%, sorry?

AK

Yes, we see a rise in children. There's a mixture to that, obviously, environmental factors and so on. But also, you could put it down to better diagnostics, as well. But definitely outside of just the better diagnostics, there is a general globally massive increase in people being diagnosed. Globally, I think around 4.9 million people live with inflammatory bowel disease. It was kind of seen as higher in Western countries, but now we're seeing it increase massively everywhere, it doesn't really matter now where you live, unfortunately. We're seeing massive increases in many countries that never really had high prevalence of it before.

00:12:05

CB

So it's not it's not hereditary, then.

AK

There's a lot we don't know about IBD. We can't pinpoint exactly why people get diagnosed. It's in the family of an autoimmune condition. If you can imagine, the inflammation, essentially, it's our body seeing our intestines as a foreign body, and it attacks itself, so that's what happens to us.

If they're looking at a number of different factors, there in regards to hereditary being one of them. So we do see that, that some people may have a relation, whether that be a direct relation, like a parent or a child or a sibling. I actually have two second cousins on both sides that have it, so I don't know if that's just suppose, part and parcel of the increase that we're seeing in it. And so it can vary.

Environmental factors definitely do obviously affect it as well. People think that diet causes IBD, and there's evidence to show that it doesn't. It definitely has an effect on it, obviously we're passing food through our digestive tract. So if it's inflamed and unable to do its normal job, of course it's going to affect and cause us pain and difficulty, whether to process that food or whatever, but it's not necessarily. There's nothing, I always say to people, that you did wrong as a person.

CB

I think that's a really good point to raise, because quite often things related to our bowel, we assume that it's because of some damage that we've caused ourselves. And then the fact that it's actually autoimmune is significant.

00:13:42

AK

It really is. I think friends and family, in particular, try to be helpful, especially when you're diagnosed, from a diet perspective they're like, can you have that? Can you eat that? Can you do this? And it's coming from a place of love, but sometimes that can be incredibly frustrating. It's really putting it out there that it's something I did as somebody to get the condition. And that's just not the case. I eat quite healthily, even in my early 20s, in college. I remember my aunt was actually over one Sunday, even as I was going back to college, packing my suitcase. And she couldn't believe the amount of fruit and veg that I had gone back, that I was obviously robbing from my mam's purse. But I was getting all that good food.

Obviously, look, we all like our takeaways. It wasn't that I was on this clean diet that I never had a takeaway. Of course I did. But all of us can have a takeaway, that doesn't mean that we all get inflammatory bowel disease or any condition, once a week, or whenever it might have been. I wasn't, and still am not, a really big drinker, so it wasn't anything to do with that.

When I look back, my mam, when I was growing up as a child, made everything from scratch. That's just the way I was reared, I suppose. I can't say, well, I had a beige diet growing up, there's nothing like that. So I think we can sometimes look at ourselves and blame ourselves for something like this. And when you're diagnosed with a condition like this, it's so important not to do that. You're juggling so much, and don't self-blame, that's the main thing, it's important just to acknowledge.

00:15:11

And do what's right for you. Because sometimes, I kind of laugh, because before I got diagnosed, and especially the couple of months prior to that, I'd have my fruits and veg during the week or whatever. My fatigue levels were really bad, particularly at that time, so my now husband would go, say, maybe meet his friends on a Friday evening. We lived in Dublin so he might go meet his friends for a drink or two, and I just couldn't go out. So I used to use a Friday, get a McDonald's for myself, and go home and chill on the couch.

And I remember saying to him, God, I feel so much better after I have the McDonald's in comparison to the fruits and veg. But that was because I had active inflammation, so me trying to process high-fibre food was put my body under so much stress. Whereas the McDonald's, because there's obviously nothing in it, was... And it's not that it's good for [overtalking].

CB

That is really interesting. Because I have problems with my digestion and my bowel, and I took... They said do a food diary. And I did a food diary and it was all the things that were really healthy, like apples would literally be excruciating. Raw carrots, things like that. And I found that a lot of the healthy foods were incredibly difficult to digest and break down, and would leave me with, with pain. So that's quite an interesting spot there with how unhealthy the McDonald's is, because it's already been processed to...

AK

And, look, processed food isn't good for anybody. And I'm definitely, absolutely not recommending that. It's about working with your medical team to say... Because if you are in times of flare, you can't, sometimes you just cannot process those foods. So there might be an adjustment in your diet that you might have to do during that time. When you're in remission, you should be able to eat everything just fine.

00:16:56

I'm on a predominantly plant-based diet, so far from the McDonald's. I'm completely high fibre, high everything. But last year, I was in a flare and I was quite sick and a slice of toast was about the height that I could manage. Because at time of the flare, you might have things like nausea and vomiting and loss of appetite and stuff like that. I always say to people, I don't necessarily feel hungry myself. The way I look at food, I will wake up in the morning and I will say, it is breakfast time, I must have my breakfast. And I would eat my breakfast. And then at lunchtime, I'd be like, it is lunchtime, and I would eat my lunch. And at dinnertime, I'll be like, okay, I'll eat my dinner. And obviously I have a husband, so one of us is making the dinner, so I'll just sit down and eat it.

I don't have snacks, I don't have any kind of appetite in general. That would be just the way I would be. And again, somebody else might be totally different, but that's just something I've identified. I really have my meals like clockwork, just because of the time of the day, it's not necessarily because my stomach starts rumbling.

00:17:59

CB

Were you like that pre diagnosis or has it just always been your way?

AK

It's funny, I obviously was, because even my mam has told me that when I was a baby, I would wake up and she was like, it usually takes about an hour or an hour and a half in the morning before you'd have your first bottle after you woke up. So it probably was, to be honest, going back my whole life. I'd be a great eater,



it's not that I wouldn't be a great eater. I absolutely love my food. I'm more of a savoury tooth than a sweet tooth, I absolutely love my food.

Whenever we're going to a restaurant, I will, you bet, look at that menu before and think about what I'm going to have later on that evening. I am that kind of person. But at the same time, my three meals a day is enough for me. But then some people might have to have smaller meals throughout the day, just to give their digestive tract a break. It's really individual, particularly from a diet perspective.

Because I can have a cup of coffee because I don't have diarrhoea as a symptom, and I actually have constipation passing stool, so sometimes that cup of coffee actually helps me go in the morning and keeps me quite regular. But then other people can't have caffeine at all, some people can't have onions. It's really individual, which is so frustrating and difficult sometimes, because you'd only love, particularly when you're diagnosed with illness in the middle of it all, to be like, just give me the guidebook, and I will follow it. But it doesn't exist.

And that's why we work with dietitians and so on, to help support people from that perspective, along with other...

00:19:30

SC

I'm a person that's really into language and stuff. You used the terminology, remission. What does that mean when you're in...? I mean, we know what remission means, but does it have the same meaning in terms of your condition?

AK

Exactly, yes. Crohn's and colitis, like inflammatory bowel disease, is a lifelong condition. There is no cure for our condition currently. That means that we're going to have times when we're flaring, so the term flaring for when we have signs of inflammation present. That's when our condition is really active, really overactive. It's when we see all of the symptoms, perhaps blood, loads and loads of symptoms.

Just for example, the symptoms that you can present with are obviously persistent diarrhoea, fatigue, even a fever, night sweats, nausea, vomiting. You can have fissures, you could have cramps, abdominal pain, skin tags, weight loss, mouth ulcers. And growth can actually be affected in children, as well. You can have bleeding from your back passage on the toilet tissue or the toilet bowl. And so you can see the list goes on and they're quite varied, and can overlap with different conditions.

So prior to diagnosis, it's kind of hard to know. Other things you can experience are things like joint pain, some inflammatory arthritis. Some people might get that form of arthritis as part of their condition, and other organs can be affected as well, depending on your condition as well.

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Say if you're diagnosed when you're in times of flare, your medical team are trying to induce remission. Remission means that the inflammation has subsided. The difference with Crohn's and colitis, with colitis, it can reduce the inflammation completely. You can have surgery. Some people might go on medication, some people might have surgery for both conditions.

If you have surgery in regards to ulcerative colitis, which is, for example, a bowel resection. So that would be removing the inflamed part. You can have these in both, but in ulcerative colitis, removing that part can actually rid you of ulcerative colitis. Now might show back up again in another part, but it can remove it completely.

With Crohn's disease, because it affects all different parts of your digestive tract, you can't remove the inflammation fully from your system, which is really important to note. But surgery and medication is still very much there as a treatment plan for people, depending on where they're at. So your medical team are trying to induce remission, and they will work with you to find the best course of action for that.

It may take a few months. So people always think, it's like that mentality of when we have a condition or we have something wrong with us, we go to hospital, we get better, we walk out, and we move on with our lives. And unfortunately, that just sometimes doesn't happen with inflammatory bowel disease. So we're trying to introduce remission. Remission means that we're taking out the inflammation from our body.

What can happen, though, even after you have an induced remission, is you will have scar tissue due to the inflammation, and then that can cause problems for some people. For my own case, as a prime example, with the flare that I was in a few years ago and last year, I had seven centimetres of inflammation in my small bowel, and ulcers. And because of that being in my small bowel, it's narrowed thickened my small bowel through the scar tissue.

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So even though I have no inflammation, I have narrowing and thickening of my small bowel. And I have to be really careful with that now, because I can't have nuts, seeds, popcorn. Those things that we can't digest, that go in and out the same way, basically, I can't do anything with them. I need to be really careful, because if you can imagine, your intestine is supposed to like this, mine is now like this. I'm passing it through, so there can be a lot more pain when I'm eating in general because it's trying to push through a smaller space. And if I eat that kind of food, it can actually block my intestine and cause me to have a bowel obstruction, which would mean emergency surgery.

I'm probably going to have to have surgery. About 80% of patients with Crohn's disease, in particular, will have surgery perhaps at some point in their life. And

those that have surgery, 100% of them will probably have a repeat surgery. That can sound so scary for people, but it's important to know that your team will do it at a time when it's right for you. Some people might never have it, which is great. Medication is advancing every year, but it's a really important treatment plan, because for me, it could actually just take out that scar tissue or that aspect of inflammation, and then I can begin to heal.

00:24:00

Some people could be a lot in flares, so they might not necessarily have long times of remission or remission at all. So perhaps surgery might be the right course of action for them to remove that area of inflammation, to induce remission, if that makes sense. Remission is what we're all after.

CB

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How long is the bowel?

AK

Oh, God. It's really, really, really long.

CB

We can afford to remove sections of it, because there's so much of it.

AK

Exactly.

CB

And not replacing it with another tube, as such. They're just taking out that bit and slotting it together.

AK

There's different variations of surgery that people can have. So obviously, a bowel resection is one, which is obviously removing the inflamed area or the scar tissue area. And that can be quite common. As I say, not everyone has, and I'm really conscious of saying this for anyone who might be listening, it's totally individual. As much as it's a treatment plan, we are moving away from surgery, as well, as I say, with the medications that we have available to us, which is great. But it's important to note that it can be a very effective treatment plan, depending.

The other side of it, as well, some people will live with a stoma. Some people might have a permanent stoma, so that means that once they have the surgery, they will have a bag for life. Some people might have a reversible stoma, so some

people might need to give a part to their intestine a rest. So to stop anything passing through it, they will be given a stoma for a while to let that happen and let it re-heal and regain, and then have that reversed.

00:25:49

So it's completely, as I say, individual. There's so many treatment plans to be tailored to where you're at. And most people I know, when we hear stoma bags, it can be really daunting and scary and all of those things. But most people that I've spoken to who've had a stoma have gone through a real difficult journey, to be honest. Some people might have [inaudible] urgently, but some people might have it for quite some time and have them battling their condition for quite some time.

And so, many people never look back when they get a stoma bag because they have their life back. [Inaudible] ease inflammation, ease the pain and that kind of thing. And that's not to undermine how much of a life adjustment, of course it is, but it can really be a positive thing. And that's something I want to definitely get across in that regard.

**SCR**

I go down TikTok rabbit holes quite a bit. The algorithm shows you stuff that you've watched. I've watched the guy who has a stoma. I'm not sure why he has a stoma, but this guy is clearly comfortable with it. He knows his life, and he knows how it affects him and he knows his limitations or what he can and can't do.

00:26:52

And I think that for people who aren't informed, it's probably more scary to see somebody actually be confident and know what they're talking about, rather than somebody that's not. That's just my observations on somebody who maybe has that condition and has to live that life. And if it makes it easier for them, then why would you not?

But of course before you get to all that, you need to be diagnosed. So what is the process for being diagnosed with one of these conditions?

**AK**

Again, it's kind of [inaudible]. It can be quite traumatic, unfortunately, for a lot of people. As I said, it typically takes around two years for someone to get diagnosed with inflammatory bowel disease. In my own condition, I had symptoms for quite some time. They started to ramp up, and I started to make, not necessarily I made excuses for them, but I put them down to other things. I had started a new job, it was winter, so I was, I'm run down, or I'm just stressed with my job. When you start doing these kind of things naturally, like not making excuses, but just naturally, and putting it down to other things.

I used to refer to an area, my lower, just underneath my belly button, as my pouch, My stubborn little piece I can never lose weight on. Not that I was trying too hard, but it's just a little area that was just always very obviously popping out. I went to a GP, and unfortunately, it wasn't with my GP. I was living in Dublin, but I'm from Kildare, so it wasn't my own GP. It was a walk-in clinic, which sounds very dodge, but it was the only one, unfortunately, that I could get access to.

And I'd done a couple of urine samples and stuff, but nothing really showed up, and sent off with some painkillers. And then I just start to think everything was in my head, and then pushed on for further a couple of weeks. At this point I couldn't put on my shoes. I could feel everything in my abdomen if I was driving the car, when I was pressing the pedals, turning, lifting my seat up. All like all of these small things that we don't even think about doing, were massive challenges for me in my daily life.

00:28:54

And so then we were actually at a weekend away in Liverpool. My husband was going over to collect a car. It was very exciting, obviously you're trying to be happy for him, but I was in excruciating pain, particularly on the last day. And we went straight off the ferry, our first trip at 12 o'clock at night, off the ferry [unclear] to A&E. I went to A&E and presented, so I had a perforation in my intestine, as I said earlier, which is essentially just burst a hole in your intestine and an abscess either side and fluid leaking.

And so I was really, really unwell. I was told I was the sickest person in A&E that night. And I, looked, to be honest, no different than I look here sitting before you. I didn't have makeup on at 12 o'clock at night, but that's about it, really. That was the only difference, you wouldn't have been able to tell what was happening internally. So, for a lot of people, we do see that they are presenting at A&E prior to their diagnosis, and perhaps a few times, depending on the severity of it.

00:29:52

Some people, it might just come on all of a sudden, as I say, and they might need urgent treatment straight away. It's really individual. We'd done a survey recently, and about 47% presented to A&E prior to their diagnosis, and then some of them presented more than five times in the year or two before their diagnosis. So, A&E, I think is a big one.

GPs do refer for colonoscopies as well, so if you are experiencing some symptoms and want to get an investigation, colonoscopies, endoscopies, all those are obviously the way that they diagnose you. So even if you present at A&E you will have these tests, MRIs, CTs, whatever is needed at the time, depending on how you present, obviously, they will do it and that's how you get diagnosed with it. So they might take a biopsy or they might be able to see the act of inflammation or whatever it might be. And so that's the route.

CB

Amy, can I just clarify, that's the route globally or just in Ireland? Are other A&E offering the colonoscopies?

AK

When I went to A&E, I was admitted then as an inpatient, and it was the next day as an inpatient that I had all this done. So you're an inpatient, more so than... But as I say, it totally depends on what you're presenting as. Some people may be experiencing symptoms, but might not... Mine just had got to a head.

Your bloods, for example, your CRP levels are supposed to be between zero and eight, so any sign of an infection is like ten and above or something, in that space. My bloods were showing 124, so I was really on the [overtalking].

00:31:39

CB

Blimey.

SC

Wow.

AK

I was really sick.

SC

Jeez, that's massive. Between a zero and eight and you're 124.

AK

I remember being in hospital, I was in hospital for ten days after. I remember when the consultant would come in and be like, your bloods are now showing 86. And then the next day it 50. It was gradually going down. And I was like, what does that mean? And after I realised, and I was like, oh my God.

CB

Is part of it, can I ask, because you said you experience constipation as opposed to diarrhoea. Is part of that because your body is retaining all of the toxins? Is that the reason why you're...?

AK

Just due to the inflammation, really, and ability to pass. The constipation I would have, most days I would go. Some people with constipation might obviously not go for a week or two, or something like that. Mine was never like that. Mine might be a couple of days, but when I pass, it's absolutely rock hard. Sometimes

it would be like passing a pane of glass to be quite honest with you. That would be the level of pain that I would... I'm moving in the seat, it takes a while, I'm deep breathing, all this kind of stuff. And then sometimes you're passing blood.

00:32:55

So, particularly here, I'd pass my stool and there'd be blood all over the toilet bowl, or there'd be blood on the tissue when I wiped, those kind of things. That's the constipation, the way it would affect me. Now I'm literally watching like a hawk my bowel movements. I am the kind of person that celebrates a bowel movement, I tell everybody. I'm like, just had the best bowel movement. I have no shame, because I just know that it's a great thing. Me and my husband, he won't mind me saying it, but we give each other high fives if we make a good one [inaudible] the house we live in.

Because I know the importance of it, and I know our poo tells a really important story of what's happening internally, regardless of if you have inflammatory bowel disease or not. And to ensure that you, as a person, have the right consistency, that you are going every day. It should nearly be like clockwork. You should nearly be going more or less first thing in the morning, that's just the way. As soon as you start eating in the morning, you should have an urgency. Not urgency, but a need to go to the toilet from the day before. That's the way it should be. But for most of us, we know that that's not the case anyway.

CB

What is a healthy poo? What should a healthy poo look like and feel like?

AK

It should kind of look like a bit of a snake kind of shape, a light brownie kind of colour. It should absolutely be not painful at all when passing. Or if you find that they're a little bit pebbly or a little bit rough or painful or whatever, there could be signs of constipation. And obviously then on the runnier side, obviously it's diarrhoea.

It's important to even just to keep check of your bowel habits. If you find that there's blood inside it, or when you wipe or in the toilet bowl. And that's actually really important to highlight another difference, as I said earlier, the fact that IBS and IBD. So IBD will show the signs of infection, but what some people might say, I have a bit of IBS and sometimes I might have a bit of blood. If you have signs of blood, that is not IBS. If you have signs of blood in your bowel movement, you need absolutely to get that checked or talk to your GP.

00:35:03

There's no excuse to be made for it. You should not be bleeding from your back passage. And that's not to scare anyone. It could be anything. It could be like myself, having a bit of constipation. There could be a tear there and every time

you're passing your stool, you're reopening that tear, for example. But you need to have something, you need to have some sort of treatment to get that rectified.

That's really the main thing, because we'd done a survey last year as part of our Poo Taboo campaign. It was a public awareness campaign, just to get understanding of what the public would do.

CB

Sorry, what's it called?

AK

Poo Taboo, obviously the stigma around... Because people don't like talking about their bowel movements, but we're trying to empower people to do so, because it's important to do it.

00:35:52

So around two in five people would do nothing and adopt a wait-and-see approach if they're seeing blood in their toilet bowl or if they're seeing symptoms. We don't need that. We actually had a symptom checker as part of that campaign last year, and around 13,000 people filled that symptom checker in, and around 93% were told to go and speak to their GP based on the symptoms they're experiencing, that could be signs of Chron's or colitis, but definitely to speak to their GP.

So there's so many people suffering in silence with symptoms and just not knowing where to go or what to do about them, so that's a really, really big thing.

SC

It's massive, isn't it? I mean, I live in the house with five boys, and there's no such thing as poo taboo when you live in a house lots of males it has to be said.

CB

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SC

So talking about the survey that you did there, because that's my next question, really. You're organisation, Crohn's and Colitis Ireland, recently surveyed your members. And obviously as surveys and that contributes to research for the country. But what were the main things that stood out for you as an organisation when you were analysing the responses in that?

00:37:05

AK



We've had over 1,500 responses, which is fantastic. We ask a series of around, I think it was 93 or 96 questions, so we really get a good understanding of the person living with IBD pre-diagnosis, current treatment of care, and then just external factors to that, as well. I have a couple of the figures in front of me. For example, in regards to work, if you are in times of flare, sometimes people can't work and sometimes people might need to reduce work or might initiate a change in... Just those variations of any condition of effects that that might have.

Only 45% of people say that they work full time with IBD. Some people might have to change to work part time, and that could be for a number of reasons. 23% of people have said that they haven't told their employer about their condition. And the reason being for that is fear, they might be new to the role. They don't want it to affect them going for any work opportunities. But that fear of what will this mean for me, definitely comes up for people.

And 47% of people will not go for a promotion or more responsibilities in work due to their IBD, which I think is really, really sad, because when we get to a point when we can get our condition into remission, we can live well, and we can participate in society just as much as everybody else. But it's quite sad to hear that in regards to people.

And we asked, as well, do you find that IBD affects your working life? And 69% of people said it does affect their working life. We asked if people changed their working conditions due to their IBD and what those reasons might be. And 42% said that the change is due to the fatigue that they experience in regards to the condition, and 14% said in regards to mental health. And then there was about 22% that had other reasons, but it was IBD related as well.

00:38:54

That was staggering, I thought, because a lot of people think the diarrhoea is the most difficult symptom of inflammatory bowel disease, but it's the things like abdominal pain, cramping, fatigue, and obviously then diarrhoea will be the top three areas that come up quite consistently as the top three symptoms that people experience.

There were 62% of people who said that IBD adds a financial burden to their life, which is quite big. So, we're not recognised as a disability or a life-long illness in Ireland. In Ireland, we have a thing called the Long-Term Illness Scheme, and there are a number of conditions. It hasn't been updated since the 1970s, and there are a number of conditions that get access to medical care and financial supports and so on if their condition is named. You don't have to apply for anything, but when you're diagnosed with it, you get these supports.

And that's not part of Crohn's and Colitis, so that's something that we really are trying to advocate for as a charity. We have another kind of couple of things here. I asked as well, in regards to do people experience stigma or unfair treatment in regards to their IBD? 30% of people say they occasionally

experience stigma or unfair treatment in regards to their IBD. 54% say that they're worried about their future, which is a staggering number as well.

And then we asked have you found it hard to cope in the past 12 months with living with your IBD? 48% say occasionally, 27% say regularly, and 10% say most of the time. So that's really staggering to think. I always say to people that even at times of being well or not well, I say about 70% of the thoughts in my head in a day are related to my IBD. So as soon as you wake up in the morning, you're there and you're like, okay, body scan, how am I feeling? Okay, grand. And you're watching for the bowel movement. Have I had enough water today? How was that bowel movement? That pain there in my tummy, is that part of that now?

00:40:51

It could be a number of things. The fatigue as well, I'm managing my fatigue so managing... If I exercise today or whatever it might be, I have somebody coming over this evening, so I went to bed really early last night, so I'd have the energy for that socialisation. These kind of things are all part of your IBD diagnosis.

In regards to Sunflower and having access to toilets publicly, we asked do you think that shops and public spaces should do more? And 86% of people said yes, and everybody came back and said toilet access being number one in Ireland. It's very, very poor in this country. We try to do a lot of work, and obviously that's why we partner with Sunflower as well, to create that awareness and gain that access when people are out.

Because when people go out in public with a condition like IBD, you urgently might need to go to the toilet. And there has been loads of incidents, unfortunately, when people have been denied access to a toilet, just by simply not understanding and appreciating their condition, especially because it's an invisible illness. So we look well on the outside, people don't have an appreciation for what could be happening internally, so there's a lot to do in that space.

00:41:58

The other side of things, as I said, in regards to the symptoms that I mentioned, but just in regards to other supports, like diet, 46% don't have access to any diet supports. But overall, 66% don't have or never even get asked around diet supports that they may need. In clinic they don't get asked 68% of people don't get ask around areas of fatigue.

83% of people don't get asked about their mental health and the impact it might have and how to manage that. That's so significant, because it really does take a mental toll. You're juggling so much, you're exhausted, and you're processing this condition. So it really needs to improve in that space.

And 67% aren't asked about external gut conditions. Like I was saying there, the mouth ulcers, the joint pain, the variety of other symptoms you might be

experiencing as well. So there's loads that's come out of our survey. I could go on, but I won't. You could do a whole episode alone on [inaudible]. That's just to give an idea of what it's really like for people. We're celebrating our 40th anniversary this year, and that was... We'd done a survey a couple of years ago, and it's obviously a review of that survey, but also to find out what it's like for people living in 2024, living with this condition. And we've still a really long way to go.

SC

I think when you first started to talk there, I was thinking to myself, some of the responses, is it because people aren't sharing it? But actually, I guess it's like anything, isn't it? Any condition that you potentially feel a little bit embarrassed or scared to mention. And, of course, you're not going to, because you're scared of being judged, scared of perhaps schoolyard kind of behaviour about, because it's about your gut and about the things that are going on there.

00:43:48

But to me, it sounds more like I know this survey was just done in Ireland, but it sounds like a lot of this could be seen same around the world, maybe.

AK

Yes. I know our counterparts in Chron's & Colitis UK, for example, they had done a similar survey. And I was just looking at one from a few years ago, they've done one just last year, so the one prior to that say there's definitely similarities in some of our results in comparison to that one. And that was a few years ago, so it'd be interesting to see their results in regards to their newest ones, to see they've seen improvements. And are we just typically, like we always are, a little bit behind in the UK? Or whatever might be.

It's good to be able to... We do work with our counterparts in other countries just to see what improvements or are there similarities or areas. In some countries there's better support. So, for example, in Holland, we actually had a patient day just last week, and there was an Irish guy who moved over to Holland to study in there, and he actually got diagnosed over there in Holland. And he has tremendous support and access to support.

His consultant currently is meeting him every two weeks. He has a dietitian every two weeks that he's liaising with, and he has all his medication covered, and it arrives at his door whenever he needs it. So that, in itself is a massive gap in comparison to the service that we're providing here in Ireland.

00:45:13

We do have a great IBD... Like most hospitals would have an IBD nurse, but the multidisciplinary team that somebody needs living with a condition like IBD is really, really lacking. We don't have access to psychologists, we don't have access to dietitians. Everyone who's diagnosed needs to meet these people, and

thereafter, at different times of their condition. We just don't have access to them, everyone has to go privately. So that's not good enough.

**CB**

No, it's not good enough, is it? That's the problem. It's a lot of people out there who clearly need a lot of support from your statistics that you've run through. I'm just wondering, for you personally, what impact did it have on your health? Or your health, rather, have on your family, your work, and your social life? Because you said on a Friday your husband would go out for a drink, but you'd go home because you were tired. You said that 54% of people are worried about their future. How has your health journey...? It sounds to me like you've obviously turned it positive because of the work you're doing now, but up until this point, how have you managed?

**AK**

I was diagnosed in 2019, and when I got diagnosed, I remember being really positive about it and being relieved, and you have an answer. And I know I'm not alone. Most people who live with IBD would say that at time of diagnosis, because they may have been suffering for quite some time, and now they know what it is, so they can start to manage it.

A few months after my diagnosis, it was this weekend just gone, my anniversary, around this time in 2019 I was in hospital. I remember a few months after, I'd just couldn't stop crying all the time. I was using regular medication and I would have been someone who just wouldn't have taken a painkiller for a headache. And that's not like a badge of honour, just wouldn't have been me. And then all of a sudden, I was on this regular medication as a 27-year-old, and that was scary and a lot to process.

00:47:12

I was lucky, there was funding available in my clinic at the time, and they had funding for a psychologist. So I was able to access a psychologist and do cognitive behavioural therapy for three months to really process what I had been through, because it was quite traumatic. And it was only for a couple of months after you're like, I'm processing that and now I'm processing I have to deal with this for the rest of my life. The mental impact was huge, definitely, regardless of if you're a positive person or not, it takes a big toll.

I still do counselling now to try and help with my stress levels and just keep myself well and keep in tune with myself, just to do all I can. I wasn't able to really socialise particularly when I was really sick. I had to step back and just rest. I used to use the weekends just to do nothing, because I just had nothing in me. The thought of having to do something was just huge for me. And then the days after, I would be just totally wiped.

00:48:10

I changed my work environment for two reasons. One, I was working as a TV researcher for a few years, and I enjoyed it, but I never really kind of... I was about two or three years into it, and I was like, I don't think I actually want to do this forever. So I was having a career change thinking anyway.

And then COVID hit and production stopped, so I used that time to reassess, what do I actually want from life, and what do I want to work as? I was actually quite involved in the shoot and movement in third level college for a few years. I really liked that. I enjoyed that work of working with people and helping people. So then that led me on this journey and get into the role that I'm in now. And so it definitely did play a role in, obviously, I work in the area with Crohn's and Colitis Ireland, and so it definitely did derail it in that way.

But the other side, then diet for me, I started doing Meatless Mondays and started to notice that suited me quite well. My tummy wasn't in as much pain. And it's really individual, it's just what worked for me. So then during COVID just experimented and played around with a plant-based diet. I'm predominately plant based now and have a bit of fish, kind of a more Mediterranean diet, I would say, would be where I'm at now. Just no meat at all. So, pescatarian, even though I feel like that sounds very pretentious, I never like saying that word.

**CB**

But did you get dietary advice? Because I know that you said that in the statistics, that some people haven't had any dietary support. Is this is something that you've just had to sort of navigate and find out for yourself?

00:49:39

**AK**

100%, yes, exactly. I was referred, I asked to be referred, but that was around the time COVID hit. So naturally, the health system, everything went out the door. And my name on a waiting list is somewhere in the hospital. But, no, just unfortunately never happened for me. I've been just managing things myself. Now, I am going to go to a dietitian. We've actually partnered with Lorraine Cooney, who's a dietitian, who's given a discount to Crohn's & Colitis Ireland members for her service, which is great.

We're trying to do little things like that as much as we can for our members, to get some level of support currently, those kind of things. And then last year in particular, just up until my last flare, we had a really lovely, exciting year. We built a house, and we were moving in last February, and then we got married last May, which is obviously so exciting. But for when you're living with a chronic condition, it's just the time that it loves to rear its head. And unfortunately, that was the time when I wasn't well. But I was trying to get things investigated as early as mid-2022.

Because I knew what the kind of year I was going to have. I had just started working with Crohn's and Colitis, so in the same year I had just left a job, started working this job, built a house, got married, and there was something else. So I had massive life changes happening all at once. So I was really trying to prepare myself, as much as I had control over it. I went back to counselling, done a lot of the stuff to manage my stress levels. And it just wasn't enough, because, as I said earlier, had started a good few months.

00:51:12

It was not as an effect of what I was going through last year, it was just that obviously was rearing its head. I remember even things like not looking forward to shopping for my wedding dress because all I wanted was something that I would feel comfortable in. That would have space if I'm cramping or if I'm bloating or whatever, and I could just not feel uncomfortable. There were things like that, that it affected me on.

Two days before the wedding, I was put on... I was on steroids from January last year until August. But two days before the wedding in particular, I was put on really strong steroids, because I was just getting so sick, to get me through the wedding. So these are the things that it affects. And my wedding weekend, you never would have any idea what I was going through because the steroids worked an absolute treat for that time. But you're constantly trying to...

It used to frustrate me massively when people would be like, you're stressed about the wedding. And I'd be like, no, I just want to be well, I want to be there. We had a great day, we had a lovely day, but I didn't do the small, intricate details that probably some other people might, like this dress or the DIYs and everything. Because I done a couple of things. I like design, so I designed my menus, designed things, but they were quite simple to do, done them. But other than that, I just didn't put the pressure on myself. I just wanted to be there and enjoy it.

00:52:29

So I experienced hair loss, especially in the lead-up to the wedding. So that was just [overtalking].

CB

Oh dear, you really went through it, didn't you?

AK

Yes. And that's the thing, there's loads of things that can go on because your body is under stress. I remember my IBD nurse explained it to me really well when I was in clinic in the lead-up to the wedding. She was like, it's because you're under stress. And I remember being like, I'm not stressed about the fecking wedding. But she explained it so well. She's like, no, Amy, it's not that your mind is stressed, your body is under stressed. That sentence really hit a

chord with me for an appreciation of whenever I do feel fatigue or I do feel pain, for me just to take that step back and sit on the couch or go to bed or take that rest.

Because I'm like, that's actually more important to my body, and it's what it needs right now, than me, I didn't get out for my walk today, or I need to go to the gym, I haven't exercised. Sometimes your body's just not able for that and resting is something... I think it's a mind shift that we have to do, you're not lazy. And I used to think I was lazy when I was resting, but it was actually just what my body needs.

SC

As human beings, I think we sometimes do struggle to realise that actually, there's two different stresses for us, isn't there. There is the mind stress of I've got so much to do for this event, for this wedding or this party or whatever. But actually, your body can be impacted by other stuff as well at the same time. I think that you're right. I think back to something that I experienced a couple of years ago, when I came out hospital and I felt guilty about resting my body.

00:54:03

It wasn't about my brain resting. I could sit and watch Netflix, but just lie on the sofa for hours upon hours. But eventually, I felt bad for doing that. But actually, sometimes your body needs time to heal and recover and to get rid of all that kind of negative stuff that's gone on for it. I think as human beings, we can sometimes struggle to do that.

AK

Yes, 100%. It's so important, rest is just as important as anything else. And striking the balance, especially when you have any type of chronic condition, just understanding that your body does need times of rest, and you're not lazy, you're actually being really, really productive to do that. Because you are not borrowing energy from tomorrow, overdoing it today. You're preparing, you're acknowledging your body, and you're in tune with your body.

CB

The spoons theory.

AK

Yes, exactly, the spoons theory. We always use the spoons theory. We have a psychologist who does write pieces for us, and she wrote a piece for us recently, quite a few months ago. And even my husband would say to me, did you use up all your spoons today? It's actually really handy to even help friends and family understand your limitations sometimes, or how much energy going for a shower can take, the simple things. Yes, it's really good.

SC

Briefly covered this with one of the suggestions that you made about how Crohn's and Colitis support members, but with the dietician's discount. But what other services do Crohn's and Colitis Ireland provide, and how can people find you?

AK

Yeah sure.

SC

Google.

AK

Yes, Google us. [Chronscolitis.ie](https://www.chronscolitis.ie) is our website, and we have a range of information up there that people can access. We share patient stories as well, which I also think is nice. I always loved hearing other people's journeys with IBD. Can I find similarities? We have a helpline as well. So it's just a number, you can call us, we can have a chat with you about any questions in regards to your IBD diagnosis and anything you want to go through. We don't recommend, obviously, medications or treatment, that's obviously discuss with your clinician, but talking about anything like that, we can definitely support on work, relationships, anything that you might want information on.

We run events as well, so we have patient days around the country. We have a support meeting online. We do awareness campaigns, and we do advocacy as well, so working with our politicians to try and better improve the supports for people with IBD. We work very closely with clinicians around the country as well, to provide information.

We're a membership organisation, so we're not government funded, so we're completely fundraised. And then if you join to be a member, that's obviously part to cover the cost of having the organisation present as well, and you get a no-wait card, which we have our Sunflower logo on as well. And that obviously to help if you are in urgent situation in public, you can present that and hopefully people will support you getting access to a toilet.

00:57:11

We have a wide range of things that we have there for people. And we're always saying this charity is for people with IBD. If there's something you don't see that we're doing or that we haven't done yet, we often covered, tell us and we will do so. Because every situation can be different, and patient journey can be different. So there might be information that somebody is looking for, but they don't see, so let us know. We've medical teams that are there, that volunteer with us and so on, so we can definitely get that information for them. We're there to support, we're there to let people know that they're not alone.



We've been through it, myself and Karen are the staff members in Crohn's & Colitis Ireland. We both have Crohn's disease. We totally get it. Karen has it since she was very young, I obviously in the past number of years. I always call Karen, in particular, she looks after our helpline, she's like an encyclopaedia of IBD. She knows every intricate detail, she knows all the medications. She knows the health system and the available financial support, everything. We're there, as I say, just to let you know that you're not alone, and you will live well, and we're there to help you get there.

SC

And sometimes peer support can be just amazing for people going through that, we all know that. Finally, Amy, this is a question about the Sunflower because obviously, if we didn't cover the Sunflower specifically, then we wouldn't be doing our job right. It seems a silly question because I think I know the answer, but do you think the Sunflower is a valuable tool and, if so, why? Where have you found it useful?

AK

Yes, yes, and yes. Absolutely, of course it is. From our perspective, the reason we got involved, obviously we had a no-wait card, as I mentioned there, that people present when out and about. I think collaborating with the Sunflower programme, because it's not only based in Ireland, but globally. So when people travel abroad and they can see the Sunflower programme, it helps people just get that support.

I think it's important to have an umbrella group all working on the same mission. We've definitely spoken with other charities in Ireland who have a similar card for their conditions, and it's great to have an umbrella organisation that it doesn't matter what condition you have, you just get support. We all need support and the thing I think around toilet access in particular, we look at it as some sort of luxury in Ireland when we're out and about. We have access to public parks and loads of public amenities, but for some reason, we stop at public toilets, and it's the basic necessity that we all need.

It's not too much to ask, regardless of the condition or not. And I think working in the meantime, until we have more access to public spaces in Ireland, working with organisations like Sunflower to bring in more companies and organisations to understand the need to access toilets in particular, is hugely beneficial. So it's great to work collaboratively on this, is what I think.

01:00:16

SC

Well, Amy, you've really opened my mind up to this, because I've known people in the past who've said they've suffered from a condition, and I didn't really do much in terms of find out more about it. So, thank you for sharing so much. It

has been really eye opening for me. Chantal, I don't know about you, but I found it really interesting.

CB

Yes, it has been really interesting, and I think your final sentence there about collaboratively working together really makes sense. Together we've got a wider reach, and therefore, a bigger impact. Because it's not just reaching the people who are experiencing IBD, it's letting other people know what it's like for somebody who is living with this. So together, we can help create more of an understanding society. And make adjustments and to give a little bit of equity and make the journey for who is experiencing it a little bit easier, a bit less painful.

SC

Thank you, Amy.

AK

No problem. Thank you so much for your time, it was lovely talking to you.

CB

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VO

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