

EATING, BODY &amp; DIGESTIVE HEALTH &gt; INFLAMMATORY BOWEL DISEASE (IBD)

# Inflammatory Bowel Disease (IBD)

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## 1. IBD - Treatment options to manage IBD including infusions

Can you explain the different types of treatment for Crohn's, and now I am on infusions, will I need to take them for the rest of my life? Well, first of all, with Crohn's disease or ulcerative colitis, none of the treatments that we have cure it, make it go away and never come back. Yeah. So the treatments are focused upon settling down the inflammation, and then the second phase of treatment or the different types of treatments, longer term treatments, are keeping it controlled so it doesn't come back. So it's, and I may well have said to you in the past, but I often say we want it to sit in the corner and behave itself and not be a problem.

And the types of treatments that we can use to settle down the inflammation or get it under control. Include antibiotics, sometimes having just drinks in terms of a liquid diet, sometimes having medicines like steroids, and then sometimes medicines like your infusion that can be used to settle down or to get control. And then the other sorts of medicines that we can use to keep control differ a little bit from person to person, but some of those medicines help to stop the immune system. We can use the infusions, like your infusion as an ongoing thing to keep control, and there's a whole lot of different medicines in both of those groups, and some of them are a bit more, some of those treatments are more useful for Crohn's disease, some of them are more useful for ulcerative colitis, but a chunk of them can work for both, regardless of which type we call it.

And with infusions, with that sort of treatment, generally we'd see it as a long-term treatment, not necessarily forever and ever and ever. In some people that have infusions like that, the benefit can wear off over time and then stops working, and we need to think of

something else. In some situations, people can do really, really well, and then we have to have a discussion in terms of, do we stop, do we continue, what else do we do to keep things controlled? So remembering that they don't cure things, but they're there to help keep control. Everyone's a little bit different, and it needs to be a discussion for that person, so it may not be the same choice for a different person.

What is an infusion? So. The infusion that you have is something called infliximab, and infliximab's one of the medicines that we call, that can be termed a biologic, so it's sort of an antibody-based medicine, and it's given over a period of time, so whether that be one hour or two hours or whatever, and it's given intermittently. So for you, it's given every eight weeks, and it goes over two hours or whatever. One hour? Yeah. Yep. One hour? Yeah. And that's an antibody that then binds to one of the proteins that is involved in inflammation, and stops that inflammatory process. Yeah. And there's a number of different biologic medicines that we have in New Zealand, there's now four that we have in New Zealand, two of them are given as infusions, like the infliximab that we just talked about.

Yeah. Two of them are mainly given as injections. Okay. And that's under the skin. Yeah. But they work in terms of different, affecting different processes that are involved in inflammation in the gut. Yeah. And some of them are used for things that aren't inflammatory bowel disease as well. Yeah. So they're not just for IBD. Oh. And there's a whole lot of other biologic medicines that are available internationally, or they're being assessed and evaluated in terms of what might be effective for inflammatory bowel disease. Yeah. And some of those are infusions. Some of them are oral medicines or tablets.

Yeah. Okay.

## 2. IBD - About IBD, Crohns & Ulcerative Colitis

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Hi, I'm Kendal and I have Crohn's. Hi, I'm Micah, I'm Kendal's mum. I'm Andrew Day, I'm a paediatric gastroenterologist. What is inflammatory bowel disease and how is it caused? So inflammatory bowel disease is a group of conditions where there's inflammation, which is a great big long word, in different parts of the gut. And inflammation means the body's responding to something, and typically that means the area that's inflamed is thickened or swollen, and there's other changes that go along with that as well. And inflammation in the bowel, we don't know all of the things in terms of why some people get it and some people don't, but the really key things that are important are different genes, and there's more than 250 genes that are linked in with protecting the surface of the gut, so changes in those genes are important.

What goes through the gut is important, or what lives in the gut in terms of the bacteria, and how they might be changed or different from one person to another. And then the immune system is also really important. So in essence, something happens in the gut in terms of an irritation, the immune system comes along and responds to that, and normally, just like the fireman coming along and putting out a fire, then everything's over. But in someone with inflammatory bowel disease, instead of that process being over, then the immune system continues to attack and continues to attack, and it goes on and on and on and can't switch itself off.

Does that sort of make sense? Yeah. What is the difference between Crohn's disease and ulcerative colitis disease? Can you be diagnosed with both at the same time? No, you can't be diagnosed with both, because that group of conditions called inflammatory bowel disease, there's two main types. One is called Crohn's disease, and the other is called ulcerative colitis. And ulcerative colitis is characterised or involves the large bowel predominantly, mainly, and has a different appearance when we look at it under the microscope. Yeah. Crohn's disease can be anywhere through the gut, from the mouth to the bottom and all the different parts of the gut.

Yeah. And again, there's some features that when we look at under the microscope that are different between Crohn's disease and ulcerative colitis. Yeah. The inflammation, some of the pattern of inflammation is the same. Yeah. But the distribution, the parts of the gut that are involved, and then some other details can be different. So no, we don't, we never think in terms of both of them happening at the same time. Yeah. Sometimes we can't decide, or there's not enough information to be able to say which type of inflammation it is. Yeah. And then we use a term called IBDU. Yeah. Or IBD unclassified, where we know it's IBD, but we can't decide at that point in time whether it's Crohn's disease or ulcerative colitis.

Yeah. But usually with time it becomes more clear for that sort of situation. Is there a typical age to get IBD? Absolutely, sure. So it's a really important question. So in the first two decades, so in children and adolescents, it's more common in the second decade than it is in the first decade. Yeah. So it's more common when someone is 11, 12, 13, 14, 15 than if you're 4 or 5 or 6. Yeah. If we look at the whole age range, there's sort of peaks between 15 and 35, but also in the 50s as well. So it can be any age when it can begin. Yeah. But it's more common in some age groups. In children, in the children that I look after, so there'll be more children that are diagnosed when they're 12, 13, 14 or thereabouts than in younger children.

But regularly there'll be children that are infants, so less than one or two or three or four or five. So right through the age groups in terms of children as well. Yeah.

### 3. IBD - Diet, vitamins and lifestyle changes

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Should I change my diet, take vitamins and supplements, or make any other lifestyle changes? Sure. So some of the important things in terms of lifestyle and diet for inflammatory bowel disease. So first of all, we know that, and I know this doesn't apply to you, but we know that people that have Crohn's disease, if they smoke at the same time, that tends to make their Crohn's disease much worse. So that's one lifestyle thing that would be really important for not smoking. In terms of diet and eating and food, generally we'd encourage people to have whole foods. So foods that we can recognise in terms of this is a carrot or this is a corn, some corn or whatever.

And steering away from highly processed. Highly processed foods. But especially for kids, but also for adults, there also needs to be sometimes foods. In terms of whether that means a birthday party or Christmas or whatever, there always needs to be special occasion things as well. So it's not like only having fruits and veggies all the time and not having anything else. But steering towards whole foods is probably a good thing. Yeah. There's also a number of different diet changes, or diet treatments that are being evaluated and looked at. And some of those involve taking out a number of foods from the diet.

That may have effects on making more inflammation. Some of those are still being worked out or still being evaluated and what their role might be is unclear. But generally it's really important, especially in children that are growing, not to start taking things out of the diet unless it's with supervision or with the support of a dietitian. Because as soon as we start taking things out of the diet for kids, that potentially interferes with their growth and development. And potentially means that they're not getting some of the goodies that they need in their food. For most kids, we wouldn't see a reason to have lots of extra vitamins or lots of extra supplements.

Yeah. We will check things like iron and vitamin D and so on. And some of those things do need extra treatment to correct low levels of vitamin D, for example. Especially at this time of the year when there's not much sunshine. Yeah. And sometimes we do use extra vitamins, but usually it's for that individual person, not something that everybody needs. Yeah. Oftentimes also we'll use special drinks in addition to ordinary eating. Yeah. And that can help people to grow, but can also help in terms of keeping the inflammation under control. Yeah. In terms of IBD effects on individuals and the requirements of medication, can IBD be managed by diet and a natural approach alone?

So there's a range of different treatments and there's a range of severity for children or for adults with Crohn's disease and ulcerative colitis. So some people can have more severe disease that's harder to control and might need two or three or four medicines to keep things under control. And sometimes in that setting also treatment might mean an operation to help. Yeah. But other people will have very mild symptoms or very mild inflammation and not need treatment or medicines. And they may do really well with some of those dietary things that we mentioned earlier. So having a whole food-based diet, avoiding preservatives, additives, processed foods, or having other dietary changes that might be helpful.

So it's really important to think of what's right for that person, for that person's inflammatory bowel disease. And it's not like everybody gets the same cookie cutter approach in terms of diet. Exactly the same things. Yeah.

### 4. IBD - Energy levels and fatigue

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Fatigue and managing energy levels have been quite an issue with Kendal. Is there anything you can suggest to help her with this? So low energy levels and fatigue is something that's fairly common with inflammatory bowel disease, especially when there's times where the disease is more active, when there's more inflammation going on. Part of energy and that inflammatory process, when there's more of that, can impact negatively upon energy, particularly if there's also a reduction in if people aren't eating as well, or if they're not gaining weight and not growing. That's another thing that can impact upon energy and well-being.

And a number of different parts of food. Iron, the blood count, being anemic, low vitamin B12. There's a number of things that are really important in terms of what children eat and what their micronutrient levels are doing that might contribute to being tired as well. So the first thing with evaluating is, is there active disease or not? And if there's active disease, then getting that under control better. The second thing is looking at the micronutrient levels in terms of things like anemia or low iron levels. But some people, even if their disease is perfectly well controlled, and all of those micronutrient levels look good, some people can still be tired.

And still have fatigue and interfere with getting to school or interfering with playing football or horse riding or whatever. Maybe nothing interferes with horse riding. Horse riding's a target for it. And the reasons for that are, horse riding's a target for it. Horse riding's a target for it. And the reasons for that are, aren't too clear. There's a lot of work ongoing at the moment. And there's a whole lot of studies in the UK that I'm aware of, for an example, looking at the powerhouses of ourselves, the mitochondria, that, and trying to see, are there changes within some of those inherent processes that are altered or interfered with because of Crohn's disease or because of inflammation.

And the general things that can help with fatigue in that setting are having routines, sometimes linking in with a psychologist, thinking of mindfulness, and a number of different aspects like that can be helpful.

## 5. IBD - Flares and remission

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We hear a lot about flares and remission. Can you please explain these? So the terms flares and remission, so inflammatory bowel disease, whether it's Crohn's disease or ulcerative colitis, can have times where there's more activity, more inflammation. So typically when people are diagnosed, there's lots of inflammation happening because things are uncontrolled, and that's leading to symptoms and leading to changes on the surface of the gut and changes in blood tests and so on. And the idea with the initial treatments, those treatments that help to settle down inflammation, is to get people into remission.

And by that we mean there's different levels of remission, so that can mean getting rid of symptoms in terms of diarrhoea or tummy pain. It can mean getting the inflammatory tests back to the normal range. But... perhaps more importantly, it can mean getting the ulcers on the surface of the bowel, the changes that are more visible, healed. And by remission, we really mean that all of those things are doing okay. So for a child, that means not having symptoms, growing normally, getting taller, getting into puberty. It means that the blood tests and the poo tests are all back to where we want them to be.

And ideally, that things are doing well on the inside in terms of healing. But unfortunately, with Crohn's disease and ulcerative colitis, things can be well for a period, and then people can have an increase in inflammation and then an increase in symptoms. And we can call that a flare or an exacerbation, where things are building up again and coming back to the surface. So in Kendall's case, would you say at the moment she's in a remission as such? Once she's controlled under medication? Yes. Yes. So some people can go up and down a little bit just by themselves without treatment. But for most cases, it's different treatments or interventions to settle things down and then to keep things controlled.

Yeah.

## 6. IBD - When is an operation required

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What are some of the operations? So for Crohn's disease, first of all, operations can be helpful in terms of, I'll say that again, operations for Crohn's disease don't cure Crohn's disease. So they're typically for when things are really, really active and not settling with medicines, sometimes taking out that problem part of the bowel can help. Similarly for Crohn's disease, it's when there's a complication of the inflammation. So one of the things that can happen with ongoing inflammation or particularly with cycles of inflammation getting bad and going up and down is developing scars, which lead on to a narrowing in the bowel.

Sometimes also the inflammation can erode through the wall of the bowel and then get a false canal or a false passage that goes to another part of the bowel. Sometimes to the skin or to the bladder, different parts of the body. And that's called a fistula. So with most people that have an operation for Crohn's disease, it's fixing that particular problem. So if there's a narrowing in the small bowel, it might be taking that part of the bowel out and then joining things back together. There's different operations in different ways, but usually for Crohn's disease, it's because there's a complication.

Yeah. Yeah. So a big reason for someone with Crohn's disease to have an operation is where there's Crohn's disease around the bottom, and again, there can be canals or fistulas or abscesses related to that. And so operations to help that particular part of Crohn's disease can be another reason. Some people with ulcerative colitis need to have all of their large bowel taken out. And that's again, typically when things aren't controllable, or things just very, very severe, or if there's a complication related to the large bowel. And that would usually, having the large bowel taken out would usually be something that would happen for someone with ulcerative colitis, not Crohn's disease.

Yeah. Do you find now that there's more medications and treatments available in New Zealand? Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. I think there is a greater chance for people with ulcerative colitis in New Zealand than there was, say, 10 years ago, that the need for operations is less. That's what we would expect, but there's been some variable studies internationally. Some of them haven't shown a reduction in rates of surgery. Some studies have shown some reduction in rates of surgery. Yeah.

But perhaps even more importantly in terms of whatever treatment, or with no treatment, new treatments it's getting really good control so as we said earlier it's getting remission and particularly getting the surface of the bowel healed getting the ulcers gone and keeping that controlled and that's the really important thing in terms of avoiding a complication or avoiding a need for an operation so the medicine itself is part of that but it's the effect of the medicine and monitoring and making sure that the medicine is doing the job that we want it to do and although we have a range of different medicines and there's new medicines that are on the horizon and so on again none of those medicines are cures for Crohn's disease all of them help in different ways in terms of managing the inflammation

## 7. IBD - The difference between IBD and IBS

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Is there a difference between IBS and IBD? Yes. Yes, there is. So, Kendall, IBS stands for something called irritable bowel syndrome, whereas IBD stands for something inflammatory bowel disease. And lots of people get them mixed up, and sometimes even in the newspaper or whatever, people get them mixed up. Inflammatory bowel disease is where there's inflammation, and the two main types being Crohn's disease or ulcerative colitis, affecting different parts of the gut, where there's inflammation, and that can lead to typical symptoms of diarrhoea, tummy pain, interfering with eating and so on. Irritable bowel syndrome is a condition where, if you like, people can feel things moving around every corner of the bowel.

It affects more... It affects more in terms of how things work and how people feel things moving through the gut. Irritable bowel syndrome is really common, a bit more so in women than in men. And it relates more to the control of the gut and the interactions between the gut and the nerves. So many people with irritable bowel syndrome will have more symptoms when they're stressed or when they're worried. Or have symptoms that relate to spicy foods or some other trigger in terms of what they're eating or drinking. The tricky part is that people with inflammatory bowel disease, over time, they have an increased rate of also getting irritable bowel syndrome.

So sometimes we see children where all their blood tests are perfect, repeating their scope tests. Everything's perfect, but they're still getting tummy pain or still getting diarrhoea, and then it's managing the irritable bowel that's there alongside the inflammatory bowel disease. Yeah. And thinking of ways to do that. But that's a really important question in terms of the distinction or the differences between those two things. Yeah. They sound the same, but they're not the same. Yeah. Good.

## 8. IBD - Increasing incidence with IBD

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Do you need to cover it being an autoimmune disease? I can touch on that, and there's a couple of other things I was going to mention as well. So when we talk about inflammatory bowel disease, and we talked in terms of Crohn's disease and ulcerative colitis affecting different parts of the gut, so ulcerative colitis being rather large bowel, Crohn's disease being any different part of the gut, and we're talking mainly in terms of inflammation in the gut, leading to symptoms that might be diarrhoea or tummy pain or not wanting to eat, and tiredness and so on. But a number of people with inflammatory bowel disease can also have things affecting different parts of the body.

And some of the common things are getting sore knees or sore ankles or sore joints, getting rashes on the skin, interfering with how the liver works, and even affecting the eyes. And there's other things that affect different parts of the body beyond that, but those are some of the most common things. And sometimes we'll see children who present with a rash. They don't have any tummy pain or diarrhoea, and then over time they develop symptoms related to their gut. Yeah. They are presenting with or getting sore knees or sore joints, Yeah. and then going on to have inflammatory bowel disease as well.

Okay. So oftentimes we'll ask, have you had any rashes, have you had any sore knees or sore joints? Yeah. Because it's an important part in terms of understanding not just what's happening in the gut, but around the whole of the body as well. Yeah. Okay? Yeah. Okay. Yeah. Okay. Okay. Okay. Okay. Okay. Okay. I was just going to say one, so we talked a little earlier in terms of some of the things that are related to people developing inflammatory bowel disease. Yeah. The genes, the bugs that live in the gut. Yeah. And changes within them and the environment in the immune system...? Yeah. over the last years, there's lots of studies showing increasing rates of inflammatory bowel disease.

So more and more people being diagnosed. diagnosed. Yeah. Especially in children. Yeah. And also lots of observations of people that have moved from one part of the world to another part of the world. Yeah. And when they are in their new country, they tend to get increased rates or increased risk of also having inflammatory bowel disease. Yeah. So for example, people moving from India or Pakistan or Nepal. Yeah. To New Zealand or Australia or Canada or US or UK. Yeah. They tend in there to have higher rates of inflammatory bowel disease in their children and their grandchildren. Yeah. Than what their families do back home in their country that they've come from.

Yeah. And but even within New Zealand. Yeah. And they tend to have higher rates of inflammatory bowel disease. Yeah. And we've seen that. And in New Zealand in terms of people that have lived in New Zealand, we're seeing more and more children being diagnosed. Yeah. And some of the reasons that are likely behind that include things in the environment. Perhaps diet. Yeah. Is likely to be a factor. Yeah. We don't know all of the different factors but when one moves from one part of the world to another part of the world particularly from a less developed to a more developed country. Yeah. They tend to have higher rates developed country, hygiene, diet, the environmental things are likely to be big factors.

## 9. IBD - Symptoms that parents need to be aware of

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Although Kendall's symptoms were incredibly severe when she was diagnosed first with Crohn's, what would parents be on the lookout for if they thought there may possibly be an issue with inflammatory bowel disease? Sure, that's a really good question. So certainly some children, some young people can have very rapid onset of symptoms in terms of lots of diarrhea and lots of blood, maybe belly pain, becoming really tired and so on very quickly within a few weeks. Most children though will have a longer period of symptoms or a gradual onset of symptoms. Typically with inflammatory bowel disease, there'll be changes that happen.

It'll happen beneath the surface in the gut where there's a little bit of inflammation related to some of those processes in terms of why some people get IBD. So there's a little bit of inflammation and then it builds up to a point where people start to get symptoms. So typical symptoms in children will be having diarrhea, maybe having to get up at night to go to the bathroom, particularly concerning when there's blood mixed in with the poo as well, having diarrhea, having belly pain, sometimes with stalling, with going to the bathroom, sometimes following meals, especially when there's pain that wakes people overnight from sleep.

Not having as much appetite, not eating as much, losing weight, again, is a really concerning thing. And for some children it's just not having the energy. Not being able to get to school, not being able to play football, or go horse riding, or whatever. So on some occasions it's all of those things happening together in terms of getting belly pain and diarrhea, and losing weight and losing appetite. Some children will present with things outside the bowel, in terms of getting joint symptoms or getting rashes. Sometimes children will present with having lots of ulcers in their mouth or changes around their mouth in terms of getting splits on the side or getting swelling of the lips, other changes there as well.

So the really key thing is when there's things that are, regardless of what the symptoms are, it's really important to look out for those, particularly if they're persisting, and to get checked out early in terms of, could these be features of inflammatory bowel disease? And that's even more of an issue, or more of something to be looked out for, when there's other people in the family that also have inflammatory bowel disease. Because with genes being important in terms of why some people get IBD, and some people don't, it's more common for a number of people within a family to get IBD. Not necessarily within the same immediate family, but I'm meaning a grandparent or a parent or a child, or even an uncle or an aunt or something as well.

One other thing, Kendall, and as you get older, at some point it'll be time to think about leaving the paediatric part of the hospital, and going to the adult part of the hospital. And that's just an important part of growing up and developing and so on as well. But here in Christchurch we have what we call a transition clinic, where it's myself plus one of the adult gastroenterologists, and we see young people together, and then eventually that young person moves on to the main adult clinics. And as we're leading up to that time, we're to think about making sure that people are ready. And how are they remembering to take their tablets?

How are they thinking about their inflammatory bowel disease? Do they know what's happening? And taking charge. What age do you normally go into the adult part? Normally sometime after 16.

## 10. IBD - Responding to diagnosis and IBD camp

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So Kendall, when you were diagnosed about 18 months ago or so, how did you feel, how did you manage that time when you were really sick and before you were diagnosed and just afterwards? When I was diagnosed, it was quite scary when I first started showing symptoms of being very sick because I didn't know what to do and I didn't like, I didn't want to like tell everyone. I sort of just wanted to keep it to myself and then I found out it was better letting mum and dad know so they could help me and like even though it's scary, you just have to push through it because you know that it's going to be really good on the other end, even though it's bad at the start.

Cool, yep. Kendall, what do you know about IBD camp? Um, it's a camp where there's, um, you fundraise and then you go on a camp and a lot of different people with IBD and different situations with IBD go to it and then like you can talk to other people and make friends and stuff. Mm-hmm. Yeah. So we've had camps in New Zealand since 2015. Yeah. And they occur once a year in January. And they rotate around Auckland, Christchurch, Wellington. And usually we aim for about 80 young people with inflammatory bowel disease, with Crohn's or colitis to come along. Yeah. Um, and it's an activity-based camp so it's doing lots of active things, flying foxes or...

Horses? Sorry? Horses? Um, there have been camps where there's been horses, yes. There should be horses in every camp because horses are amazing. So all sorts of things, but, and then most of the leaders on camp as well also have inflammatory bowel disease. Yeah. So it's a pretty cool thing. Yeah. I met someone at horse riding a couple of weeks ago, um, and she had Crohn's too. I forgot her name, but she was one of the, I think she owned a horse and she was, she had Crohn's too. Oh, okay. Yeah. Cool. Yeah. Was she talking about cancer? Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah.

Yeah. Uh, no, I just could, she was talking about Crohn's and then I said, oh, do you have Crohn's? And she said, oh yeah, I do. And I, and then I said, oh, I have it, I have it too and yeah, random. But, yeah. So sometimes it's really helpful to know that you're not the only person in the world that has Crohn's disease. Yeah. And to share experiences and to... Yeah. Compare notes with people. Yeah. That's also really important for mums and dads as well. And as well as the camps, we also have parent seminars, where parents come along and learn a bit about inflammatory bowel disease, but as well as learning, they also get an opportunity to chat to other parents that have been in the same situation and helping to learn from each other.

Where's the camp this year? The camp in January next year will be in Auckland. Ooh, you can stay on the boat and not go to the camp. So it's at Camp Adair, which is near the Hunua Falls, just half an hour or so away from the airport in Auckland, 40 minutes away from the airport, and somewhere we've been before for camp. What are the dates this year? It's from the 15th to the 20th of January. Do you have to go for the whole five-day course, or can you go for the whole five-day course? We'd aim for campers to be there for the whole time. Most by the end of the camp, some people are getting tired and ready to go home, but lots of times people say, why can't we stay for another two days, or why can't we stay longer?

Because they have so much fun.

## 11. IBD - Google & Facebook - Overwhelming initially

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Oh look, I did a lot of instant doctor googling and going on Facebook support groups and everything and I actually found it too overwhelming initially. I found that I didn't have enough information to decipher what I was looking at and it was quite daunting knowing that it's your child. But after a bit of time and a bit of research then I was able to go back to those resources, the Facebook books and have more of an understanding of what Kendall was going through and I find them quite helpful now. Definitely more helpful than they were in those very initial stages because I think initially, initially, initially, initially, you just want the questions of what is this and what are we dealing with answered and then we get more into the medications and how to manage it and lifestyle and what the future might hold.

I remember those first few nights when we'd met you but she hadn't been diagnosed but we thought that's where we were heading and we thought that's where we were heading. Of going online and I think quite often in those Facebook groups and things people put their bad stories and their terrifying stories and then as a parent that is really hard to read. You almost have to take a step back and then look at just the basic questions, answer the basic questions, and then look at just the basic questions, answer the basic questions, and then progress. And then now when I go back and I read I think, oh okay well I understand that and I understand these situations but yes it is, it's quite a hard thing to read.

Especially because we had no genetic links in the family so we don't have, we had no pre-exposure to IBD. So it was really, really new for us. And I found hospital like at the start I thought it was really scary and I'd always like tried to act like I was fine when the doctors came in so I could get out and I did end up getting out but I had to come back and I actually figured out that it's better to stay and get better than running away. And maybe just to add to that discussion Crohn's Colitis New Zealand has really good website lots of resources and there's various ways that they help to educate and support, answer questions and so on too.

There's lots of other good websites internationally but there are lots of nonsense shall we say things on the internet as well where as you said there's very extreme points of view or very radical treatments that might have worked for that individual person but are unlikely or uncommon to work for others. A really common one which is why I asked the question before that I've got in the two years that Kendall's a year and a half since Kendall's been diagnosed is people will say oh if you just have a healthy diet or if you just go gluten free that that will manage it and and that happened for my auntie or that happened for my brother or you know and that's certainly not the case for Kendall.

Like a lot of people see me eating stuff and then they'll go oh that has gluten in it why is she not gluten free and then it's a bit awkward trying to explain I have to be gluten free and stuff.

## 12. IBD - Key messages

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Thank you, Andrew. It's been really great having this information today and it's really good to know and to learn that each patient is individual and it's not a one-size-fits-all and certainly in Kendall's case there's been a few ups and downs but it's really great to see her treatments working well for her and her getting her sparkle back. It's been really good today and it's good to know that we have support through the hospital and stuff and that I'm not the only person who has it and that there's other people I can talk to and stuff. And I guess, Kendall, I'll just add to that that inflammatory bowel disease has different ways that it can present. Yeah. Different ways that it can affect kids and young people. Yeah. But the really important things in terms of managing it is identifying it early, getting on top of the inflammation with different treatments that might suit that person. Yeah. And then keeping on top of the inflammation and

making sure that kids grow and develop and get to school and go horse riding and do karate or whatever works for them. And also supporting them along the way. Yeah. And things like the IBD camp can be one really important way in terms of doing that. But giving people opportunity to learn, to ask questions. Yeah. All of those things are really important. Yeah.