A conversation with a Gastroenterologist

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1. Talking to a Gastroenterologist - What triggers Coeliac disease, why do people respond differently_

Hi, I'm Katie, and I have coeliac disease. Hi, I'm Tom, and I have coeliac disease. Hi, I'm Professor Andrew Day, and I'm a paediatric gastroenterologist, and I look after and diagnose children and adolescents with coeliac disease. And I'm also a member of, or actually chair, the Medical Advisory Committee for Coeliac New Zealand. So what triggers coeliac disease? So coeliac disease is where the cereal proteins get through, or the toxic parts, the bad parts of those cereal proteins, can get through the lining of the gut, and then trigger the immune system to cause damage to the gut. So sometimes that change can be triggered after an infection.

So sometimes I've seen kids that are completely well, and then they have a tummy bug, and then that starts the process rolling, and then things happen from there. But also for that process to happen, people need to have the right, be at risk of having coeliac disease. So there's some genes that are really important in terms of why some people get coeliac, and some people don't. And when there's genes involved, things can run through the family. Why do people with coeliac disease respond differently? So there's a whole lot of different things that coeliac disease can lead to in terms of, so some people can have diarrhoea, some people can have tummy pain, some people can have mouth ulcers, some people can have none of those, and not have any symptoms.

It's very rare, very rare, very variable. So there's a big range in terms of that. It's not exactly sure, clear, why there's so much difference in terms of symptoms. So some people can have the same amount of damage in their gut, but some people can have diarrhoea, and

some people don't. And it's not really clear why. But the really important thing is that lots of things can be manifestations or the ways that coeliac disease comes to the surface. And that's what I talk about with young doctors and people that are looking out for coeliac disease. It's really important to think broadly in terms of, yes, we worry about people with tummy pain or diarrhoea, but there's also a whole lot of other things that can be signs of coeliac disease as well.

Which food brands are coeliac friendly? So when starting a gluten-free diet, so the key treatment, the only treatment, we have at the moment is having a gluten-free diet. And with starting a gluten-free diet, it's really important to learn what foods are gluten-free and what aren't. And there's a number of manufacturers that make gluten-free foods, and that's one of their sort of main products. But there's other people or other manufacturers that might make, one, a food that's gluten-containing, and another variant of that, like Weet-Bix as an example. The really key thing when you're learning to have a gluten-free diet and learning how to manage it is to know what to read on the labels, to know what to look for.

Sometimes manufacturers are also a little bit sneaky, if you like. Sometimes their product can be gluten-free for a while, and then something changes, and now there's gluten in their food. And that's why it's really important to not just look at the label at the beginning, but just recheck over time as well. Sometimes those sort of changes, Coeliac New Zealand can be really helpful for making people aware.

2. Talking to a Gastroenterologist - How much gluten is too much and how is testing done_

Why are there different levels of gluten testing in different countries? That's a really good question. That was one of my questions, because I'm really interested in that. So there's an international sort of understanding in terms of 20 parts per million that something below that is gluten-free. And that was established many years ago. And since then, there's been much better ways of testing and looking for gluten. So that's looking at a food, breaking it down, digesting it in a laboratory, and getting an idea of how much gluten is present. And now those tests can detect down to three or four parts per billion, parts per million, I should say.

So they can detect even really small amounts of gluten. And the legislation in Australia and New Zealand means that if a product is labelled as gluten-free, that there's no detection. There's no detectable gluten present. So it might be that that food is okay in Europe, because there's 15 parts per million. But because it's a different testing platform and a different legal arrangement in New Zealand and Australia, things are labelled differently. And the testing platforms and the ability to detect smaller and smaller amounts of gluten sort of hasn't kept up with some of those other things. So why have countries not, why have other countries not kept up with the, I mean, if the testing is available to bring it down to three or four parts per million, why are other countries not managing to keep up with that?

Is it just not part of the legislation, I guess? I think that's part of it. The other part to that equation is also how much is safe for people with coeliac disease. Is... Is three parts per million safe for someone with coeliac disease? And there's a study that's ongoing across the ditch in Australia at the moment, in adults, that are trying to assess very small amounts of gluten. Are they safe in people with coeliac disease or not? So challenging people with coeliac disease with an amount of gluten. I think it's five, maybe it's five or ten. I can't quite remember offhand, but... Parts per million.

Parts per million. Right. And trying to get an idea, is that actually appropriate to restrict that or to be that strict or not? So there's some evidence, there's some studies, but there's not a lot of evidence worldwide. There's a study from Italy that looked, I think it was 15 parts per million. But there's not a lot of good evidence at the moment in terms of trying to guide, now that we can detect more, is that being over strict or is that appropriate to be that strict? I don't know. I think it would be really useful to know that. But at the moment, it's no detectable gluten is the limitation of the...

Related to the restriction of the testing platforms. How is food tested for gluten? So it's tested in a laboratory, and then so it's a... There's different platforms, but one's called an ELISA, which is looking... So it's using antibodies to detect that protein. And then... And then seeing whether or not... Or to try and quantify how much of that protein is present. So yes, so the food's digested in a certain way in the laboratory and then analysed and put through that test ELISA platform in terms of coming up with the answer in terms of quantifying it. Is it quite an easy test? Is it quite an easy process?

Well, there are home testing things as well. So people can test. They can do it themselves at home, but it's a slightly simpler process. I'm not sure exactly how many laboratories do do gluten testing in New Zealand, but it's not a large number, and I mean, those sort of ELISA tests are relatively straightforward and then can be used to detect all sorts of different proteins and quantify how much of different proteins are present. But all sorts of things. Not just gluten. Not just gluten. Not just gluten. Right. So there's a lot more information about gluten. Right. So we'll fix this one.

3. Talking to a Gastroenterologist - The history of Coeliac disease

What's the history of coeliac disease?

So coeliac disease has probably been around for a long long time and in the late 1800s people started to put together the connections between serials and symptoms but it wasn't really until the early 50s or late 40s early 50s 1940s 1950s in the aftermath of world war ii a paediatrician from the Netherlands put things very clearly or closely together in terms of cereals or foods and cereals and the connection and there was a time I understand where there was lots of restrictions on foods and some of the European countries had bread drops so they didn't have access to bread for periods of time and then bread would be delivered from an airplane and then so they'd noticed that people got sick when they had exposure to bread and then they got better when they weren't having the bread for example and they started to put those things together and at that point access to checking the surface of the bowel wasn't available and prior to those sort of dietary changes or establishing those connections coeliac disease could be a very nasty condition sometimes the medicine's a little bit of a pain in the neck sometimes the medicine's a little bit of a pain in the neck like steroids were used to treat it sometimes it was even fatal in terms of the nutritional consequences and then but with the work through the early 50s then started to move to a gluten-free diet and then testing platforms in terms of being able to look at the surface of the bowel evolved with endoscopic techniques in the 60s and 70s but from that time there's been a whole series of different antibodies that have been available and used in terms of trying to detect um antibody responses in someone with coeliac disease the blood tests right and one of the tests that was done initially even before endoscopy was called a crosby capsule which was sort of swallowing a little device on the on a um on a string and then it that little capsule was activated and moved to the small bowel and then it took a little bite and then you pull the capsule back up again oh that sounds horrific i'd never um so some of my colleagues some of my the people i started working with when i finished my training had been doing that for years in terms of a way to look for coeliac disease but that very quickly became outdated with endoscopy and been able to look at the surface of the drug directly and take focused biopsies um so the biopsy itself is taken as a way to measure the villi, is that?

And that's what the Crosby capsules did as well, they took a little sample. Yes, so the idea is to look at the surface of the bowel, so we know the normal structure has lots of little fingers sticking up like a really thick shag pile carpet, and they help to give lots of surface area, lots of area for the goodies to be absorbed from our foods, as well as lots of other functions as well. But with coeliac disease, typically those villi are short or stunted, and there's other changes beneath the surface. So with the biopsy, one can look at the structure, is it normal, is it altered, are there features that go along with coeliac disease?

And that can be graded in terms of the severity of damage, so how much, whether those villi are completely absent or whether they're just abbreviated or shortened. And obviously also making sure that there's no other processes that are going along as well. Thank you. So what are the things that can be done that can help with coeliac disease? Well, there's a lot of different kinds of diseases that we can look at. So the first one is a small bowel. It's a small bowel that could sometimes contribute to damage in the small bowel that might look like coeliac disease. So Giardia is an example, or allergy that might lead to some parts of that damage that could look a bit like coeliac disease.

meaning is it's not just, I mean, is the small bowel not normal? Does it look like coeliac disease? Or could there be other things going on instead that could be contributing to that person's symptoms?

4. Talking to a Gastroenterologist - Managing Coeliac disease – Diet and possible future alternative

What new drugs are in development for Coeliac disease? So at the moment, the only thing that we have to manage someone with Coeliac disease is a gluten-free diet. It's a strict gluten-free diet from the time of diagnosis for the rest of that person's life. And that's the only treatment that we have at the moment. For some people, for most people, that is perfect and things get recovered and things work normally thereafter in terms of the small bowel. But some people inadvertently get exposed to gluten or don't adhere to the gluten-free diet. So it doesn't always, for everybody, lead to the outcomes that we want.

And there's a whole lot of other treatments that are being evaluated and looked at. And some of those break down those toxic parts of the cereals. In the small bowel, so that they're no longer toxic. So they break them down into smaller chunks so that then they don't trigger the immune response. There's one that works a bit like a sponge in terms of holding onto those toxic parts and then taking it further down the gut so it can't trigger changes. There's one drug that helps the lining cells of the gut get closer together so the toxic parts can't get through. And then there's a series of drugs that we're looking at now.

So there's a series of drugs that we're looking at that work on some of the immune responses and some of the things that happen in the surface of the gut to try and halt that. There was a vaccine that was being developed, but unfortunately, although the initial results look promising, the subsequent results weren't. So that program's been halted. But I believe in New Zealand there's currently three or

four studies that are ongoing. They're looking at adults at the moment, so not kids at the moment, just like you, Tom, and they're evaluating some of those different treatments. It's not clear at the moment whether that will mean that someone with coeliac disease doesn't have to have a gluten-free diet.

It might mean that one of those treatments mean that you could go out to a restaurant and not worry so much if the chef doesn't know what gluten-free means, and have that treatment at that time. So, yeah, that's a big question. And probably the ones that are closest to being ready, or ready for use, so to speak, are the medicines that break down those peptides in the surface of it, within the gut, so that they don't trigger the responses. But probably in the next five to 10 years there's going to be one or more different treatments that will be available. So by the time you're grown up, they'll very likely be available.

So, yeah. So, by the time you're grown up, they'll very likely be available. So, yeah. There could be other treatments. But as I said at the moment, we don't know exactly whether that means that you can have a gluten-containing diet, or whether these are additional treatments in addition to a gluten-free diet. So how they, what their role will be and how we use them isn't clear yet.

5. Talking to a Gastroenterologist - Can your gut fully recover from undiagnosed coeliac disease_

I just had actually an extra question. When you talked before about recovery by being on it when you're diagnosed coeliac, can your villi completely recover if you stay gluten-free? Are you expected to make a full, your small intestine expected to fully recover? Yes. So nowadays we don't always, well, it would be infrequent to repeat the scope test or so on to look at the small bowel after recovery. But some of the previous studies, some of the previous experience is that most children by 12 months, 90% or so by 12 months after getting onto a gluten-free diet, have complete recovery. So the villi come back to normal.

That figures a bit. A bit lower in adults, and it's probably somewhere around about 40% by 12 months. And that probably reflects that most adults with coeliac disease at the time of diagnosis have had the damage for a much longer period of time. It might be more extensive or more expansive around the small bowel. But it takes longer for things to recover. But in time, the other people would still be expected to have recovery if they were being fully adherent to a strict recovery. And that's not necessarily what they're actually expecting. So it's good to have enough work for you. That's a good question.

And so I'll be sure to try and answer your questions. Thank you so much. No, no, no, you're welcome. I would hope so. Thank you. And so hopefully, you've been able to get a sense of what is happening with your donor. I'm sure you've received training. Thank you. And so hopefully, it's something that you want to expand on. Thank you. And so hopefully, you're able to expand on the next step of finding out if there's anything potentially important that you want to talk about. Thank you. Thank you so much. Thank you. And if you could tell us what was a major issue for you in terms of your diet or health or anything like that.

You're welcome.

6. Talking to a Gastroenterologist - Knowing what foods to eat and other triggers

How do I know which glucose syrups are okay to eat? So one of the really key things in terms of managing a gluten-free diet is knowing what foods are safe and what foods aren't and reading labels, knowing what to look for in the labels. And that's one of the key things that, so I know a whole lot about coeliac disease, but I also work in very closely with my dietitians who are also experts in terms of those things. And so having a discussion with the dietitian and working through some of those things in terms of what to look for and what is safe and what isn't safe is a really key thing. And sometimes it's helpful to talk, not just at the beginning, but subsequently also to a dietitian and to get their input and expertise with that as well.

So it really should be a team, in terms of looking after people with coeliac disease and having overlapping areas of expertise. With makeup, which is something that can have glusion in it, is there an easy way of finding out which makeups, foundations, lipsticks, have glusion in them? Because you tend not to be able to read the ingredient list. Sure. So there has been some studies looking at, makeup, looking at toothpaste and so on, in terms of whether it's safe or not. And there's been a couple of case reports, or a very small number of reports internationally, in terms of people that have had their coeliac disease has been impacted.

For most people, it's probably not an issue. Lipstick might be more of an issue in terms of licking and... and then ingesting small amounts. But some other products, probably not so much of an issue, because it's more exposure of the gut to those proteins. I think if there's any question that it's really important, any question about a product, whether it's a makeup product or a food or whatever, then it's really important to talk to a dietitian or see their New Zealand and then get... and then sometimes it's either directly or via Coeliac New Zealand speaking to the manufacturer in terms of could that product, or does that product contain gluten or not.

So that's something Coeliac New Zealand could help with? Yes. We could ask the question. Great.

7. Talking to a Gastroenterologist - Diagnosing Coeliac disease and the role of genes

So Andrew, are there any other methods at the moment of diagnosing coeliac disease, or is it just biopsy? So traditionally, the way to diagnose coeliac disease has been looking in somebody who might have symptoms, or be thinking that they could have coeliac disease, doing some blood tests that point in the right direction, and then moving ahead to an endoscopy and looking at the surface of the bowel for the confirmation. And largely, that is still certainly a diagnostic approach, a journey that we take very often. But over the last years, beginning in Europe with some guidelines, there's now what we can call a serology-based or no-biopsy-based approach to considering the diagnosis of coeliac disease.

And so in a child... That presents with symptoms, that has abnormal or high antibody levels on their blood tests, we can consider making a diagnosis without a biopsy when there's more than one antibody test. So I would do that a second time, so that it's not just a lab error, so that it's real. And the level of the antibody needs to be a certain amount, so 10 times what the blood test needs to be, so that it's not just a lab error, so that it's not just a lab error. And so in that context, in somebody with symptoms, their initial blood test looks very much pointing towards coeliac disease, and the height of their antibody test is sufficient, then I would often have a discussion and suggest, let's consider this approach, we'll do a second blood test, and if that all matches, then we move ahead with the diagnosis of coeliac disease without a biopsy.

Right. Do they still have coeliac disease? Do they still have to be eating gluten to be able to get those diagnoses? Absolutely, yes, that's really important. So whenever we're thinking in terms of making a diagnosis of coeliac disease, it's really important that that person continues to have gluten in their diet until the diagnosis is confirmed, whether that's with a biopsy or whether that's with serology, with the antibodies. Taking away the gluten too soon can compromise those steps, can modify the antibodies or the biopsy and make things into a grey zone that we want to avoid. So we're still making a decision that is a lifetime decision, and it's really important to get the right information to help make that decision right at the beginning.

So Tom, your mum was just mentioning that a number of people in her family also have coeliac disease, and obviously you do as well. Yes. So we talked earlier in terms of genes being important, in terms of why some people get coeliac disease and some people don't, but if we looked across Christchurch, we'd probably find half of Christchurch. Or maybe even two thirds of people in Christchurch have one or other of those genes. So lots of people have the genes, but that doesn't mean that they'll ever go on to get coeliac disease. And it's probably more like one and a half, at least one percent, probably even more than one percent of people in Christchurch do have coeliac disease.

So lots of people that do have the gene don't ever get coeliac disease. So what are the chances that the rest of our family will get coeliac disease or have the gene? Within a family, usually the risk is somewhere like 10 percent with a first-degree family member, so a sibling of someone with coeliac disease. What about a twin? So when it's a non-identical twin, it's probably about 30 percent, and with an identical twin it's something like 70 percent. That they'll have the gene or that they'll get coeliac disease? That they will get coeliac disease. Right. The chances, do you know what the percentage is that they have the gene?

Will everyone in my family have the gene? All of my children? All of my children have the coeliac gene. Not necessarily, no. Okay. But the chances are higher of having the gene probably than if I didn't have coeliac disease. I'm getting myself confused. So I had heard that if, so I've got four children. I have coeliac disease and obviously have the gene. My children all have the gene. We've tested them all and they all have the gene. Because I've actually got coeliac disease. And they've got the gene. Does that make it a higher, is there a higher chance that they will get coeliac disease? Because I've got coeliac disease, regardless of the gene situation?

I don't think so, no. Okay. So the switching on of the coeliac disease gene doesn't necessarily mean it'll switch on in my children any more than it would if they had a mother without coeliac disease. Because there's other factors, I mean bugs or other environmental factors or genes that can trigger the onset of those changes. So some people will have a higher risk of developing those changes, but they'd still be on an individual basis. There are other factors. Okay. So I'm going to stop there. I think we're almost there. Thank you. Thanks. Thank you. Thank you. Thank you. Thank you. Thank you.

Thank you. Thank you. Thank you. Thank you. Thank you. Thank you. Thank you.

8. Talking to a Gastroenterologist - Managing as a child – parties, school camps, dining out

So, Tom, how did you feel when you were first diagnosed with coeliac disease? Do you remember? No, I don't remember. I guess you were only three. Yeah, something like that. Quite a long time ago. How is it now when you have coeliac disease, when you're at a friend's house? Generally it's fine. Most of my friend's parents know that I have coeliac disease, and generally I just don't eat any food

at my friend's house. Hopefully you eat some food. Yeah, I eat some food. Just not any gluten-free food or anything else. How about going on school camps? Because that could sometimes be a challenge, huh?

Yeah, usually they take notice. Some of the gluten-free food is fine. Others aren't. Other tastes like very processed meat. So it doesn't taste very good? Is that what you're saying? Yeah, some of the gluten-free food. Some of it tastes nice. How about with sleepovers? You go to one of your mates' place for a sleepover? It's usually fine. I usually know them long enough when I go for a sleepover, and they'll know, and they'll prepare and get some. It's definitely been a thing though, hasn't it, Tom? Because there's some times that maybe we might not have had a sleepover or gone and done something because we're not 100% sure that there's going to be food that you can eat.

And on the school camps they tend to go along, the first few anyway, just to make sure that all the food was safe from cross-contamination. So it's definitely an added extra for us, which is why there's that disability allowance, I think, as well, that's usually available. Birthday parties might be another challenge? Yeah, usually there are. Usually there's at least some food or drinks, and sometimes Mum or Dad or something will bring some form of gluten-free food. So some of it's planning ahead, huh? Yeah. Thinking about it in advance. Yeah, in the early days when Tom was quite young, I used to go and buy one of the cupcakes from the gluten-free bakery, a special gluten-free cupcake that was a special treat, you know, one of those great big ones with masses of icing on it.

And Tom would take that along to birthday parties so that he didn't have to worry about the birthday cake, because that was often a thing. Parents would often, the parents of the child who was having the birthday, would make a birthday cake, but we weren't 100% sure that it was going to, even if they said it was gluten-free, we didn't. No, generally when I go to a friend's house for a birthday, usually they don't bother, because I'm the only person that's not gluten-free, there's probably some other. So we just make sure there's a really special treat that goes along with them in a wee container for that situation, just so he doesn't feel left out.

There's one birthday party that you went to, do you remember where the parents did the entire birthday gluten-free? Everything that was there. I don't remember. Sorry. One thing I hear about sometimes is well-meaning grandparents that bring along some food that they think might be gluten-free, but it isn't really, because they haven't quite understood it. Because they haven't quite understood things properly? No, it's been pretty good. Usually when a grown-up comes around and brings some food, it's usually just the same brand, and what we all know is gluten-free, we've had it before. Right. Yeah.

But there is definitely that aspect of it, is helping their wider family to understand what it means. We're very lucky with my mother, she now has two grandchildren who are coeliac, and a sister who's coeliac, and a daughter who's coeliac, so she's not coeliac herself, but she's very good at understanding what the requirements are. And Gran, as you said, always brings down gluten-free goodies. The prepackaged gluten-free, made by a gluten-free manufacturer. Yeah. How about going out to a restaurant, or going out for a birthday dinner to celebrate something? Usually it's pretty good. Usually we decide we are going to go to a definitely gluten-free restaurant, just a restaurant we know is pretty good.

We haven't been there before, but it's been recommended by one of Mum's coeliac friends. And usually it's pretty good. Most restaurants are very careful, and if I'm not able to have it, I just have something else. It can be quite depressing sometimes, don't you think? It can. Yeah, when you see something on the menu, and it says gluten-free, and then you ask the question of the restaurant, and they say, oh no, actually it's been cooked in the same fryer, and there's something that's got gluten in it, and I say, I'm sorry Tom, but you're not going to be able to have that. So it can be quite depressing.

Which is why I'm annoyed at going to some places, like we're going to get some fries, and then it's like, oh, it's cooked in the same fryer. But what we do is identify, we've got a set of restaurants and cafes and Christchurch that we have identified that we've been to numerous times that have not made either of us sick, and therefore we know that we can go there. But we still ask every time, don't we Tom? Yeah, most times at, usually we go to like Riverside or something, because they have good food, they have humble goldmine, they have shake-a-bows and they've got...

9. Talking to a Gastroenterologist - Messaging - Coeliac not gluten free

was one thing that we work really hard to do Tom and I is to make sure we use the word coeliac rather than just Gluten-free if we use the word coeliac people know it's actually a medical condition Not just us with our dietary thinking that we decided we want to go gluten-free because it might make us feel better So the more often that we use the word coeliac and the more often people with coeliac disease use the word coeliac disease The better off it is I think for the coeliacs of this world to be able to be helped and when in hospitality And sometimes people in hospitality approach those things differently don't they?

Absolutely, they do. There's a few again a handful of restaurants that we go to in Christchurch When I say I go there often But I say and I'm a coeliac and they have a little note on their computer which actually says coeliac So even though the thing I've ordered says gluten-free On the menu when I didn't say coeliac they put in coeliac and it gives that added They can never they always say to us we

can't be a hundred percent sure and I say I know but if I know that you've gone, you know as You've been as careful as you can Yeah, that's an awesome fish and chip shop, yeah So some of the other websites you were talking about there is one that I found an app recently called find me GF I think it's based in the UK.

I don't even know where it is. But what's valuable about that is that You can look up people's comments about a particular place So people might have been somewhere anywhere around New Zealand and they've actually added a comment and the more people that comment on that the more you can then make it a Choice about whether you would then choose to eat there or not and so finally GF obviously see New Zealand is as helpful as they can possibly be but they can't put restaurants and cafes on their website or Promote them and these they've been through the dining out program Which is what's difficult?

10. Talking to a Gastroenterologist - Key messages

So my key messages around coeliac disease are that it is a medical condition not a dietary choice and that when I want to eat out I want to make sure and do the research first to make sure the place I'm going to eat out is going to be able to cater for me and also that I don't want to be made a fuss hole actually I don't want people to necessarily go to extra effort to cater for like talking about friends and family to cater for me because very often even if they've gone to extra effort I still don't know whether what they produced is going to be 100% gluten free what would be super helpful is if they had one packet of crackers or one thing of that is still packaged that I can then eat and and I do love it when people do if it's a meal if they have cooked for me and if I ask them what they agree or they tell me what the ingredients were for even thank you.

My key messages probably be very careful around coeliac disease and um if you're a waiter or something when someone asks to be coeliac disease don't as Mum said don't make it a big deal just make it you know just pretend it's in normal order just in everyday order but make the point that it's to the kitchen that it's definitely coeliac but not to the table of people that you're sitting at don't is that what you're saying? yeah yeah just don't be like here's a everyone, this person's coeliac, will you just be very careful what you're talking about? I remember when I was first diagnosed with coeliac, I went to a restaurant and I walked in and they took, and I'd said on the phone before I went that I was coeliac and the waiter came up to me and said in front of everyone, ah, you're my coeliac, come on over here and I'll show you what I've got.

And actually it did make me feel quite special at the time, but in hindsight it probably wasn't ideal. Some of my key messages would be the real importance in terms of establishing the diagnosis at the beginning, because it's a lifetime thing. That the key day-to-day thing is the strict gluten-free diet and managing that within the realms of normal life and we've talked about restaurants and going to school camps and so on and so forth and all of those things need to fit in with that. But also that there is a whole lot of new therapies that are coming, we just don't know exactly where. When and how they might be used.

So there's a whole lot of promise around the corner in terms of potentially other ways of managing coeliac disease. And also with coeliac disease it's better to eat at home to make homemade food, because you know it's gluten-free, then eat out. Or buy a definitely gluten-free packaged food or something.

11. Talking to a Gastroenterologist - Coeliac NZ

One of my other key messages is to join Coeliac New Zealand. Should have thought of that before. Because Coeliac New Zealand is a resource, but they're also an organisation who will help spearhead some changes for people with coeliac disease, and even the volunteer network that they've got throughout New Zealand who help organise events like the one you just talked about, Tom. I think that it's very worthwhile. It's not a massive fee every year, and every donation that we make to Coeliac New Zealand is helping all of those of us with coeliac disease to lead a better, gluten-free life. Coeliac New Zealand is really important for support, education, resources, information, advocacy.

It's the advocacy. That's the word I was missing. Also, find somewhere to find out the sponsors of Coeliac New Zealand because they're the most likely to find. Some companies that are good for... Do you know, on their website, they have a whole page of all of the sponsors of Coeliac New Zealand and all of the people who are part of the gluten-free dying out programme and the blue tick. And that's all on their website, and if you buy those products, then it's helping support. So do that. Particularly when you're diagnosed when you're three, it's really important that you get to understand, understand about coeliac disease yourself.

Yes. And read about it, learn about it, talk about it with your mum and dad. All of those things are really important. Coeliac New Zealand has lots of different resources. They do have kids clubs and other things where you can chat with other people who also have coeliac disease. I remember there used to be these big things who would go out somewhere, like go to the garden, or go somewhere and sit with mums, and then all these people that are awesome people out there, like Coeliac New Zealand. Coeliac and Christchurch, and they'd all come together, bring some food, and just be like a family. And you knew that you could eat anything on the table.

That was the best thing in the world, hey? Even the table. Even the table!