A conversation with Dietitians

Full transcript · 13 video clips · generated 22 September 2026

> **About this transcript.** This transcript was produced automatically from the video audio. It has not been checked by a person, so names, place names, te reo Māori and medical terms may be wrong in places. The video is the record. If something here reads oddly, please check it against the video.

Watch the series: **listeningtofamilies.co.nz/coeliac-disease/a-conversation-with-dietitians**

IN THIS TRANSCRIPT

1. A conversation with Dietitians - What can Coeliac disease look like_
2. A conversation with Dietitians - The genetic role - black sheep
3. A conversation with Dietitians - Managing as a family
4. A conversation with Dietitians - Newly diagnosed
5. A conversation with Dietitians - Managing day to day
6. A conversation with Dietitians - How strict
7. A conversation with Dietitians - Getting a formal diagnosis
8. A conversation with Dietitians - Continuing to enjoy life
9. A conversation with Dietitians - Language
10. A conversation with Dietitians - Support
11. A conversation with Dietitians - Referral pathway
12. A conversation with Dietitians - Diagnosis - Having gluten for 8 weeks
13. A conversation with Dietitians - Key Messages

1. A conversation with Dietitians - What can Coeliac disease look like_

Hi, I'm Sam, or Samantha. We are sitting in offices in Auckland, and we've got my mum Anna and Sophie, they'll introduce themselves in a tick. I have been coeliac for about 10 years now, used to work in the corporate space, but I'm currently concentrating on mum life. I've got two little boys with a third on the way due any day, but that's a little bit about me. Sophie. Hi, I'm Sophie. I'm a paediatric dietitian down in Christchurch, and I'm currently doing my PhD looking predominantly at children with coeliac disease and how they are managed in New Zealand. Anna. Hi, I'm Anna Richards. I've been a dietitian for probably over 40 years now, and I work predominantly in allergy and detoxification.

I work in the health and tolerance and also in gastroenterology. I work, I'm a curious beast. I work with both children and adults. So I see coeliac disease at all life stages, right from the littlies. And I think the oldest patient I've seen newly diagnosed has been 83. So I see the full gambit. Very good. Well, let's, let's get cracking. So question for both of you, I guess, to start with was what can coeliac disease. Actually look like, because coeliac disease is a curious beast and it can look very different and in different people. So maybe Anna, do you want to get us started? What, what different presentations or what, what can coeliac disease look like for different people?

Coeliac disease can be a very tricky one because we get everything right from when you look back at the old medical books and we'd see children with very wasted little limbs. And great big bellies that didn't thrive and often died early. In all honesty, we don't actually see that very often these days. So, um, I might let Sophie to do the more paediatric side of things. And from the adult perspective, um, the sort of presentations that we have, honestly, we have everything from those that think that they have severe IBS to those that are completely asymptomatic and we turn up a diagnosis of coeliac disease for other reasons.

So I might have. I've had a lot of patients who are having fertility issues, um, chronic low iron low B12 symptoms that they've just put down to IBS. My 83 year old client was quite convinced that she was going gaga. She was needing Nana naps every, every morning and every afternoon. She had chronically low iron. She had a fuzzy head. Her memory, um, was poor and post-diagnosis and exclusion of gluten. She was often ready. To go again, had a new lease on life, a new lease on life. So, um, I think the presentation can be very, very wide and buried, which is often why it's missed. So if you do want to talk a little bit more about the paediatric perspective.

Yeah, I think I agree with you. I think it's completely the same in children. You have the whole spectrum of, um, presentations from the traditional gastrointestinal, uh, presentations to things through mood changes, fatigue, difficulty, concentrating at school. Um, skin, um, presentations, dental and animal defects, the whole growth, slow growth, growth, delay, puberty, delays in puberty, and it's, yeah, it's a very sort of subtle, often quite subtle symptoms that, yeah, like you say, do get missed.

2. A conversation with Dietitians - The genetic role - black sheep

An important point to add in here is there is obviously a significant genetic role that gets played in coeliac disease, but is it possible to have a situation where you have a black sheep? So for example, I am the black sheep of my family. As far as we are aware, we cannot find the genetic link where I might have got the coeliac gene from. What are you guys seeing? Is that common to have a black sheep? Is there a genetic link? What does that look like in practice? Sometimes we can be going through a couple of generations, and the reality is your brother is HLA positive for HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. HLA-positive. She doesn't be the highest at risk combination. doesn't mean he will develop coeliac disease. It does mean he has to keep it on his radar. In reality, there is a potential of developing coeliac disease in the first degree relative.

3. A conversation with Dietitians - Managing as a family

which probably leads me on to the you know in a in a household do we completely exclude gluten for everyone or do we not and you know there are pros and cons both ways and when we're looking at potential risk for other household members we're never going to know if they don't keep eating gluten comment Sophie that's absolutely a very valid point if we're wanting to get diagnosis for other members of the household to exclude or diagnose they need to be having sufficient amounts of gluten and that can be really challenging if more than one member of the household actually does have coeliac and because it's quite a it's quite a decent amount two to four slices as you were saying earlier two to four slices of bread a day for eight weeks is required for the how do you manage it in your household so at home we you before children we ran a completely gluten-free house my husband very kindly committed to a gluten-free house at home which was great we had the single-use toaster we didn't need to think about it or worry about it in any way shape or form and when my beautiful boys arrived we made the decision that actually the best protective strategy we could have for them on a go-forward basis in terms of coeliac and if they were ever going to develop it or not was actually to feed them gluten so what we did initially was that we said right whenever you go to your grandparent's house grandparents it's up to you to feed my children as much gluten as you possibly can and and they were very willing participants which we're very grateful for so that's how it started and then slowly as I've got more confidentiality that I'll be able to chort out the nudge they'll start Chandler is who's a great example of the fact that the knows so much about why children spend most their time making healthy pills and I started asking him for a whole lot of places on how are we nice to see because I would be making an amount of take affects if we ever terms of how I can manage gluten in a way that I feel safe and comfortable because I'm very symptomatic um which is helpful uh and some of that's been the expense of very hungry two and a half and four and a half year olds yes my boys I'm very worried for when my boys uh are teenagers because the amount that they consume at two and four is horrifying and if they consume that much when they're proportionately that much when they're 18 I'm very concerned um but yeah with with how expensive everything is and how expensive gluten-free products are these days it's amazing that they're on the market and I love them and I don't fault them but when your kids are eating a loaf of bread a day you don't want to be paying the nine dollars for the gluten-free loaf you'd rather buy them the the standard the standard so I guess from my perspective it kind of comes down to what you're comfort levels are okay one one of my um hot tips for families to help with their initial stages of whether the family's um going to to some of the family members consume gluten-free products and some not and I often suggest getting a box of red dots and a box of green dots go through the pantry the fridge the fruit bowl the veggie bin and identify which products are gluten-free and which products are gluten-containing which allows the cop really to be able to get the right amount of gluten-free products and which products are gluten-free and which diets would be best suited for gluten-free fasting but I

know how important gluten has to be you don't just take out certain products and snap theueny to put it in a drop bag that way you can really show that you know that's you- you're chasing those giant effects of gluten in your diet just reading the minute label is really easy you're not reading the minute label every time you're cooking but also it's really positive for the newly diagnosed coeliac and that they open the fridge they open the pantry they see the fruit bowl and they see the sea of green dots in front of them and it just reminds them that actually there are more things in the world that don't contain gluten than there are that do contain if gluten is good there's sure grabbing gluten for the finger that represents my recommend gluten or gluten.

gluten-containing breadcrumbs um so it's it's one way that it just makes it really easy for families and and let's face it in most households dinner's always going to be sort of a shared meal that's gluten-free but there's no reason why other family members can't continue to eat gluten at other meals and and we've got a wee holiday house and with a very very small kitchen and certainly that's the way that we manage it there and to date I don't think we've poisoned you um and and shared dinners are always gluten-free the majority of lunch is gluten-free we'll have regular bread and yes if it's a windy day we leave the gluten-containing bread on the bench inside for people to get what they want so that we don't risk crumbs outside but breakfast and things we're each doing our individual um gluten-free or gluten-containing there's lots of different options or ways in which you can kind of structure having the both gluten uh consumers and gluten non-consumers in your house and there's a way to have them both

4. A conversation with Dietitians - Newly diagnosed

move on to maybe the next question is Sophie do you want to take this one if you from your paediatric perspective how long do you kind of expect symptoms to last when you've got a newly diagnosed coeliac like how long is it going to take them to kind of feel like themselves again again it's a huge spectrum depending on the person but some it's generally weeks we know about half of people newly diagnosed with coeliac improve have some full symptom resolution by about six months but it can be any spectrum between days and weeks getting those initial symptom improving from those initial symptoms and about or 30 percent might need a bit more work sort of in terms of looking at hidden sources of gluten but what was your experience if you asked me after say three months I would have told you like wow I feel amazing like this is so good I didn't actually realize how unwell I was feeling before that's so common and then after six months I was like wow who is this person like this is amazing and so I think it probably took me a year yeah to feel properly like myself and it was a year to kind of I guess also so I was diagnosed in my early 20s so it was also the took me a year to mourn the loss of my beloved gluten in my diet and what that was actually going to mean and obviously uh when you're looking at gluten-free products compared to gluten-containing products gluten plays this really lovely role in our food it makes it delicious and the bread soft and squishy so you're you know technically you're not going to be able to eat gluten-free products but you're you know culturally and taste-wise in your food it tastes quite different so it I feel like a year sets you up really well in terms of expectation to to know that once you've hit the year mark things are significantly going to improve and just get easier from that point well there's so much you're navigating you're navigating the green dots and the red dots and um what you know when you're going socially I think food has such an integral play into your diet and it's so part in our social lives and we definitely found that amongst the particular teenagers i guess early 20s um where food plays yeah such a key role in socialization and a significant number it's you do have to mourn that loss of feeling fully included in all of those things but it's also also really important that we get the message up for children um as well as teens and 20s any to advocate for themselves and one of the biggest things i really push is using that word coeliac and not gluten-free so i'll often say anyone can be gluten-free but only a coeliac can be a coeliac and and um as young as the child can comprehend that they're starting to say that for themselves ask the question every time i mean like and we obviously talk about coeliac disease at home but like my kids so two and four they understand the we talk about it in age-appropriate terms with them but they understand the fundamental concepts of mommy can't eat the same things as everybody else and mommy's body works differently and and yeah i don't share my drink bottle with my children but i don't want any of your gluten in my drink bottle thank you very much he has the hot pink mommy only drink bottle um they're banned from using it but like i mean it's just proof of that even really young kids can get the basics of coeliac disease and it is different and you do have to modify your diet and you do have to modify how you're doing it and what you're doing but it's all it's all doable and i know i guess speaking to like the people that will watch the video is that everything gets easier when you are first diagnosed your room just shrinks like nobody's business and the world feels empty and you're not able to do anything about it and so i think it's a different thing i think it's a different thing i think it's a different thing i think it's a different very small and very daunting and it's very overwhelming but every new day is another step forward and now I wouldn't have it any other way like it's just not even worth eating the gluten it's just not like there's no temptation left at all and now it's easy so it it gets easier there is a light at the end of the tunnel

5. A conversation with Dietitians - Managing day to day

but then it's having that support crew around you you were very fortunate with a very good group of friends fortunately a number of them were medical who were your advocates and and who look after you and put that safety net around you well I had a friend once we went to we I was pregnant with my number two and we went out for lunch and um I was concentrating so hard on getting my meal

prepared so that it was pregnancy friendly I totally forgot about being coeliac like I just genuinely forgot like it was just not front of mind and I was like okay so I'm pregnant so can I please have my eggs and can I have them well done and da da da da and she said oh and I'm sorry she's actually coeliac can you just make sure that it comes on gluten-free bread please but um like it's amazing to I guess have that support network around you so that if you are being a dodo that you know you've got people there that are prepared to um um to advocate for you and and have those conversations and I guess you don't have family members and close friends who have that knowledge around coeliac support groups like coeliac new zealand totally local local groups kids clubs and they have that sort of local first-hand knowledge of foods foods and um restaurants and things that you can go to that and feel confident about ordering safe food definitely I mean just thinking of the that uh something that I always find really helpful to do is um I will call a restaurant if it's somewhere I haven't been before and I want to know that I'm going to be safe I'll first of all look at their website to see if they mention gluten-free in their menu um and then I'll often give them a call and let me tell you you can work out in about 10 seconds whether it's going to be an establishment that is safe or not safe so you'll see that I'm going to be able to do that something like you could say um like hi I'm I've been looking at your menu online I see you do gluten-free I'm a coeliac uh can you cater to me if I was to come and eat with you and that if they um and are and kind of say oh uh oh yeah no just that one's gone sorry friends move on to the next one um but if they come back um um you know they're really positive and they're like yes coeliac totally we've got lots of things on the menu we can do this we can do that we can do the other thing it's often just that level of reassurance that um that they get it and that they understand it um we are really lucky in that the longer time goes uh establishments are getting so much better with coeliac disease and with their offerings and with their understandings and I know that coeliac New Zealand has done a whole lot of work in terms of like trying to improve the standards um around catering for coeliacs they did a big dining out program a couple of years ago uh and so the message is getting out there and it will continue to get easier but yeah certainly calling places ahead of time is a really good way to just gauge which does take some of the spontaneity out of it I mean Sophie can you add something in terms of how families can cope when you can't just sort of drop in somewhere when you're on the road yeah and we did a survey in 2012 looking at how the impact of these sort of things on families and about 80 80 percent of families said most or all the time they brought back up they brought gluten-free foods just to make sure that they had an option available and especially with the littlies who get hangry very quickly you need to have those well even Samantha's baby's due in a few weeks time so your your grab bag is full of food options isn't it yeah I mean for me when I go into hospital normally after you have a baby they bring you some beautiful hot buttered toast and after you've delivered your baby in the hospital and in a cup of tea they don't have any options for a coeliac none whatsoever so my bag before I run out the door has like all kinds of gluten-free treats so that if I'm starving I've just got I've got options and basically no matter where I go I always have something in the bottom of my handbag just in case just in case and I I mean I used to work corporately and when I when I was first diagnosed and um if you went to events where they were doing passing around like whatever they're called my brain doesn't work today um if they're passing around food and you didn't I mean I didn't always particularly feel comfortable asking in that environment excuse me does that little whatever have gluten in it because it would start a whole conversation with people at a work function that you didn't really know about your the innermost workings of your body which for me would ultimately end up being talking about bowels and other things and it's just conversations you just don't want to have with those kinds of people so I would often eat before I went in those situations just because I knew I was fed if there happened to be a gluten-free option that I felt comfortable with great if I didn't I wasn't going to go hungry and and things and you know one of my little hot tips for families on the move is a banana and a carton of chocolate milk that you can pick up at any corner dairy your chocolate milk's got a label on it you don't need to read the label on a banana and they're safe they're packaged you don't get sticky fingers you don't need to use your fingers and it's available wherever you are so just having a few of those up your sleeve too definitely

6. A conversation with Dietitians - How strict

um sophie maybe do you want to talk to this one um what would you say to a family who has an asymptomatic child like how strict do you actually have to be with coeliac disease um i suppose going back to looking at what coeliac is so it's an autoimmune condition where your um your system mistakes gluten for something that's harmful and causes inflammation and damage that those billi in our small bowels so you're either coeliac or you're not so even if you're asymptomatic and actually like you said when you were first diagnosed you didn't realize how well you felt until you that one year down the track and you were completely gluten-free i think it's the same even things like concentrating at school mood growth all of these things that are sort of hard to see in the day-to-day but they can all be uh symptoms of uh coeliac yeah have a massive impact on a on a long term absolutely yeah and i often i think we were talking about it earlier i often will say to patients actually coeliac disease is like pregnancy you're not a little bit pregnant you're not a little bit coeliac and you either are or you aren't so i guess the message that i'm hearing from both of you then is that regardless of your symptoms it's something that really does need to be taken quite seriously and people do need to adhere to that diet because regardless of what is happening symptomatically the same damage is still going to be happening inside even if you have no symptoms at all there can be that that damage is still happening and it will affect absorption of nutrients so you're not going to see a reduction in bone density in a few days that's uh it's an additive effect

7. A conversation with Dietitians - Getting a formal diagnosis

Sophie, could you maybe give us a little bit of information around, you've got a diagnosis of coeliac disease from your GP, the numbers have come back, everything's feeling daunting. What might the next step look like? So generally down here in Canterbury, there are two main pathways. There's either, well, you would get through, you'd get referred through to your gastroenterologist first and foremost, a paediatric gastroenterologist if you're a child. And then you would either go down the pathway of, if your results were high enough, you could do a non-biopsy pathway with a diagnosis, or then you may need to have a biopsy, your child may need to have a biopsy to confirm that diagnosis.

But the first port of call would always be your GP. And what, I mean, for both of you, what is the, or maybe mum, you can handle this one, what's the gold standard in terms of the biopsy? Root versus non-biopsy, just with the blood work results. Like, is there one option that is maybe better than the others? What does that look like? In adults, we would always go down the biopsy route. In children, depending on what your blood work returned, we'd always repeat that again, just to make sure that we're getting the same results again. And there is a threshold whereby with, with certain factors that we're looking at, that the probability of coeliac disease is so high that with confidence, we can go down that non-biopsy route.

But that's not a call that a GP can make. So that's a paediatric gastroenterologist or a paediatrician who makes that call. But what's really important is that families still go down that route. I have a lot of families very fearful of, you know, biopsy, and they'll just decide we're just going to exclude gluten from the diet. And I always worry that those patients without a formal diagnosis, you know, when your 15 year old looks you in the eye and says, is this for real? We're not going to know.

And potentially, you know, potentially it might mean that some of the doors for other interventions further down the track, once science catches up with coeliac disease, I worry that potentially say if there's any drug available that will either block the action of, of gluten or, or whatever, wherever we end up, that won't be available to everybody who thinks they feel better on a gluten free diet. And that likely, I mean, correct me, Sophie and your perspective, too, likely that would be available to those with a formal diagnosis. No, I completely agree with you.

And on the rare occasion, where there's a very high dose, of such a high dose, it might be masking something else so it's nice to really know that actually it's the gluten that's the problem you've got it rubber stamped and you don't want to have to go down that no crumbs in the butter no crumbs in the jam if you don't need you don't have to absolutely yeah

8. A conversation with Dietitians - Continuing to enjoy life

bit of a bizarre one for you sophie um but do you have any recommendations that you make in your practice uh to a family newly diagnosed coeliac child my child has gone and eaten a loaf of bread what on earth do i do now what can i do help gosh i guess can you do anything not really i guess it's all supportive care isn't it because they're not gonna well chances are they're not gonna feel very well are they so it's it's just a matter of some oh yeah no supportive care really isn't it yeah ondansetron can be useful in terms of that extreme nausea and vomiting um but it's time yeah so you've just got to wait for it so there's and i guess from my perspective like slip-ups do happen you can't control everything and you've got to it's finding the balance absolutely between living and being out in the world and being a member of society um and but also protecting yourself and you could be the safest person in the world you could follow all the rules you could leave like live in a complete bubble but mistakes happen and accidents happen because we're all human um so yeah one slip-up is not going to destroy your child forever it will all be okay with time is the message i'm getting from you guys i did i did some work quite a number of years ago with one of the adult gastroenterologists looking at our cohort with those who had had coeliac disease for at least 10 years and we accessed that cohort through lab tests and we were looking at a variety of measures with them in terms of quality of life and some of the stories were absolutely heartbreaking because there was one end of the spectrum where i recall one woman who was in her 70s in a new relationship and she ate gluten-free when she was at home and she didn't when she was with her partner because she didn't want to be a burden right to the other end of the spectrum where some patients only trusted themselves to prepare food for themselves and that gets back to your point sam that it it's just not living and so it's creating that safety that knowledge that support network but still living yeah fine and and often it's a challenge i'll say family's a little challenge actually go and eat out eat out somewhere once a week get get a few runs on the board um feel as though you can do it and certainly from my perspective when i was first diagnosed i um my world was very very small and i just wanted to get myself feeling better as quickly as i possibly could so to start with predominantly i only trusted myself and just that's how i felt safest and uh and i didn't want to be having those conversations like oh i don't want to tell people i've got coeliac disease like that's it's weird and it's awkward and i don't want to be the weird awkward person i just want to be me and so i did really limit myself and then as you i guess get older as you get more confident as you um you know get more runs on the board and i just wanted to be able to be myself and i just wanted to be myself in terms of positive experiences out all of those conversations become easier and um and and also i guess like i didn't want to be coeliac and i didn't want to be weird and awkward but there's nothing weird and awkward about coeliac disease it's just a fact of life

and there's nothing to be like ashamed of with that and people most people are totally happy for you to you know tell people when you're sick and you're sick and you're sick and you're sick and you're out uh oh one quick thing that just popped into my head so very quickly tip for if you're out with colleagues and you don't want to mention coeliac disease in front of them but you're at an event um i would sometimes sneak off and have a conversation with the um with a member of staff at the restaurant and just quietly tell them on my own so that i didn't have to have like a public discussion at the table surrounded by well i worked in an industry that was predominantly men so it was me at a table with a whole lot of men and i didn't need to look about my gastro issues so i just quietly slip away and um and have those conversations so there are you can kind of be a bit tactical if you need to be

9. A conversation with Dietitians - Language

And I think, Anna, you had a point where if you're feeling confident enough using the word coeliac disease rather than gluten-free, because there has been an increase. There's a big difference. Yeah, there's a huge difference between being gluten-free out of choice and having coeliac disease. It's really important to differentiate that. And I guess the power that the two different, the words can have is, you know, coeliac disease is not something to be joked about and it needs to be taken seriously versus the just being gluten-free.

10. A conversation with Dietitians - Support

Sophie, do you have any maybe ideas about like around self-advocacy, like what could families maybe be, yeah, what could families be doing to advocate for their child with coeliac disease? Maybe any hot tips? Gosh, I think using, again, using the word coeliac disease when they're asking about gluten-free foods when out and about, there are some resources that coeliac have to support families and talking about coeliac disease at schools, with the schools, not really, it's a sort of a journey of building confidence, I guess, and like you said, and being able to talk about it. What about, I was going to ask you your perspective from the non-paediatric side of things, if you're seeing a, you know, late teens, early adults, what, do you have any hot tips in terms of?

Well, I think sometimes the Coeliac Facebook page can be really useful and member-to-member, it's not run or monitored by Coeliac New Zealand, it's just a member-to-member forum. And look, I must say, sometimes. There's some pretty interesting advice that goes between members, but most of the time, there's a pretty quick response. So you'll get help, my child's just been diagnosed, I'm standing in front of the crackers at the supermarket and my eyes are glazing over, and I've read every packet and I'm confused, and what would you recommend? And from member-to-member support, often you get pretty quick feedback.

Well, my child's going on a school camp. Has anybody got some good ideas of how I can? So I always support the Coeliac Facebook page with a little bit of a parameter. It's definitely a grain of salt. Around it as well. And if and don't check with Coeliac New Zealand. I've also had a young patient who was about 10, I think, and she did a presentation in class on Coeliac disease and what it was and what it meant. And her presentation was so amazing that they asked her to do it in assembly. And then she stood up in assembly and taught the whole school about Coeliac disease and what it is and what it's meant.

So I think in terms of advocacy and confidence, it's turning it into something that you can cope with. Turning it into a superpower rather than a hindrance. Do you know what I mean? Like framing it in a positive way for. The child or the adult or the whoever's in your life that's got Coeliac disease. And it's not about what I can't eat. Look at all of these other things that I can eat. And I guess if you're feeling isolated, there are lots of Coeliac disease, not rare. And there are lots of other people out there who are going through the same journey as you are. And places like Coeliac New Zealand, the Facebook groups, the kids clubs, they've all got really great places for support and that community feel.

And it's quite interesting because as soon as you start. Talking about it, chances are in your community of people that you already know, you're going to find several other people that are also feeling the same way, but they have Coeliac disease and they haven't been able to have those conversations yet. But all of a sudden you've got a bigger cohort than you thought you did just by, you know, having some of those more challenging conversations to start with. But again, they'll all get easier with time. And I think, look, I know it's hard for some patients in some areas. Of the country and one of our concerns in in terms of, you know, the Coeliac medical panel is sort of equitable access to medical care throughout the country.

But if you possibly can, I'd say get an early appointment with a dietitian rather than just trying to wade your way through all the information yourself. It means that you start with a clean slate, you get the right information and you can move forward from them far more easily.

11. A conversation with Dietitians - Referral pathway

so i guess a question for both of you in terms of pathways so you've been diagnosed by your gp and they refer you to your paediatric paediatric gastroenterologist or your normal gastro and you might get a biopsy or not what who can refer you on to a dietitian do you need to go back to your gp do you what's the next step so you've seen your gastro you've got coeliac disease now what in the public system that would have to go through your gp okay in private you can self-refer okay so it's always useful to have some of those results so that we've got them on file and and i encourage patients to be monitored annually choose a date your birthday the date at which you were diagnosed just so that we keep a little bit of a check on what's going on so you in private you can self-refer in public that would be your gp or your gastroenterologist referring you through to the public system and sophie is there anywhere that people can go uh to find out what dietitians specialize in coeliac disease because i know that different dietitians will focus on different areas of health and they'll kind of each have their own pockets so is it important to find a dietitian that knows what they're talking about in terms of coeliac disease and then also is there a way that they can how can they access those individuals yeah in canterbury it's a sort of a one package one stop shop you get knows you refer to your gastroenterologist and paediatric gastroenterologist and then you see a dietitian as part of that review so it's right um but yes uh if you're going through the private route dietitians new zealand has a page that um you can see all the different dietitians available and they're all available and they're all available and they're all areas of interest and specialty and they'll have a blurb so it's a great place for people to maybe start if they want to go down the dietetic route um and see someone that way they can they've got access to that yeah

12. A conversation with Dietitians - Diagnosis - Having gluten for 8 weeks

coeliac disease has been flagged and I need to get my child tested for coeliac disease but what does that actually mean so what what do I need to do to get my child tested for coeliac disease what's the first point of call and then also are there any things I need to make sure that I've I check off to to confirm a diagnosis I guess you need to go through your GP for that initial they're initially the gatekeepers for getting those tests done but you would if it's if your child is already on a gluten-free diet they really really need to have that gluten back in the diet and sufficient amounts of gluten in order for those tests to be worthwhile doing and to actually because I guess coeliac disease like it's it's the one autoimmune disorder that you can cure entirely by eating a gluten-free diet so if you're not eating gluten those tests are never going to be accurate and now we're looking at around about eight weeks and depending on the eight weeks in the leader eight weeks of consuming a reasonable amount of gluten so we'd say around about four slices of bread but but obviously we'll we wouldn't expect a two-year-old although you're two-year-old without without any problem at all um but we're we're talking about a reasonable gluten load and we do know in those that have gastrointestinal symptoms that if we grade that up a little bit more slowly that the tolerance is better and some so sorry what do you mean by that so if you wouldn't go straight from eating no gluten to eating four slices of two dollar from the supermarket bread which actually gives a lot of people gastrointestinal symptoms anyway we might grade that up with crackers or some plain sweet biscuits or um including some wheat bix for breakfast so we just grade that up and relatively slow lead in time gives enough time to get the gut nice and full of all that beautiful gluten goodness so that it comes up positive and i always temper that with patients if you get to the point where you absolutely can't take it anymore let me know and we'll do the bloods anyway and there are there is a small percentage of those with coeliac disease um who will be who will have what we call seronegative coeliac disease so they will have coeliac disease but their serology or their blood work will always return negatively so there is a cohort of patients and i see it in my adult world that we would look to go straight to gastroscopy and that must be really hard and sort of if it looks smell looks and smells and sounds like coeliac disease and the history is really really hard and i think that's a really supportive and they can't tolerate um maybe maybe going through that eight weeks or only get part way through it we will choose to go straight to gastroscopy and i work with um and some of the absolutely amazing gastroenterologists here at mcmurray who are very supportive of that that dietary um review and that dietary recommendation and we turn up a handful every year and so i guess that can be the benefit as well and i think that's a really good point and i think that's a really good point as well of um you know going to see a dietitian to discuss all of your gastrointestinal issues so that they can be across it and they can kind of help to make those calls so it's not left for you and for your gp to to decide on because i mean gps are amazing and they do such great jobs but they're jacks of all trades um and they have 10 minutes and and um you know the the dietitian can like be your specialized well sometimes too given given the you know vast array of presentations of coeliac disease i recall one adult patient who pretty much had all the sort of the weird and wonderful nondescript symptoms that and she'd been to all sorts of specialists all over her life but because they'd been very sort of diverse symptoms it had been really hard to pull all of that together and um so sometimes it's sort of really looking outside the box but trying to get that diagnosis

13. A conversation with Dietitians - Key Messages

In that summary, reflecting back on everything that we've talked about, some key takeaways that I've got from the family point of view is that coeliac disease does need to be taken seriously. You either are or you aren't, and regardless of your symptoms or your child's symptoms or your family member's symptoms, it is something that really needs to be taken seriously, and you do need to abide by that

gluten-free diet, and it is tricky, but it gets easier, so that's probably my biggest takeaway, Sophie. And if you have any suspicions or concerns that you or your child has coeliac, going to your GP, getting checked, it's a straightforward blood test to usually to test for coeliac. And I would add to that, Sophie, I think we were talking earlier about a patient of mine, a little girl. We had gone from negative serology in December one year, with mum with coeliac disease, negative serology in the December to off the Richter scale by May, and it was through the mum advocating and the child being retested that we got that diagnosis. And also, just because you've tested negative for coeliac disease today doesn't mean that it's going to be negative next month or next year, and I get an awful lot of patients in who are saying, I was tested five years ago, I didn't have it, I don't have it. So leaving that diagnosis open, also a takeaway from my perspective is learning to use that word coeliac, and not just gluten-free. Anyone can be gluten-free, but coeliacs are special.