OCD

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1. The basics of childhood OCD

Hello, I'm Sarah. I'm a parent of three children, two of which are autistic and one has OCD. And we're going to be talking about OCD and it's going to be a series. Hi, I'm Emma. I'm a child psychologist. I'm also the clinical lead of Open Closed Doors, which is a charity that's bringing accessible treatment for OCD to New Zealand. And I am looking forward to chatting to you about OCD. Emma, are you able to tell me what OCD is? Sure. OCD is, it's sort of in the name really. The O part is obsession and that's an intrusive thought or a sticky thought. It can also be an intrusive image, intrusive sensation, intrusive urge.

And it's something that the person can't let go of, their brain keeps wanting to think about it. And it brings up for people an uncomfortable feeling or a distressing feeling or anxiety. The C part of OCD is the compulsion. And that's actually the key to OCD. That's why OCD is OCD, is that there is a compulsion part. Sometimes those compulsions can be really easy to see to anyone. So for example, someone might be flicking light switches, something like that. And sometimes they're mental compulsions. And they can be a lot harder for whānau to pick up on or therapists to pick up on or even the person themselves sometimes.

And they can be things like thought stopping. They can be mentally revising or checking things in their mind. And that's sometimes where diagnosis for OCD and things like that can be a little bit trickier. The D part of OCD is also very important, which is the disturbance to a person's day or their whānau's day, which is taken up with intrusive thoughts, images, that type of thing, and the compulsions. Because we can all have intrusive thoughts. That's just a human nature thing to have kind of thoughts that come to us and we go, oh, I don't really like that or don't really know what that is. But the compulsion part and how much that takes up of the day is why you'd get a diagnosis of OCD.

Okay. So you covered then that it's not always about, say, neatness or flicking light switches. What are the common myths about OCD? Yeah, well, there's actually quite a few common myths. One that you'll hear all the time, people say, I'm so OCD because I like my room

clean and tidy and things like that. People don't like OCD. You do not like having OCD. It's not a positive feeling. Those of us that like the aesthetic of things and that brings a positive feeling, that is not OCD. One of the other things is that these are rituals and routines that are unpleasant. So it's not actually OCD if you are enjoying those rituals or routines, which can sometimes happen in things like autism.

Where actually a ritual or routine is a self-soothing type situation. Okay. So how are anxiety and OCD related or not related, I guess? What's the differences and the similarities? Yeah. So there's similar feelings, like there's anxiety feelings in both. And in fact, a lot of people have both anxiety and OCD. Yeah. The main difference is that anxiety is usually about real world situations. So for example, you might have anxiety about speaking in public, social situations, things like that, fear of flying type things. And once that experience has passed, so once you've gone out to the social situation or you've spoken in front of the class, the anxiety goes.

For OCD, we don't actually focus on the anxiety as such. We look at what the compulsions are for that. So you have something that sort of triggers you off for a certain, which will be an intrusive thought or something like that. And then the anxiety will rise or the distress will rise because of that. And then you do a compulsion to bring that distress down. And by doing that, even though it alleviates some of that distress or alleviates that anxiety, it's very short term, like it's a temporary thing. And it will come back again quite quickly. So that a person becomes in the cycle of maintaining OCD, where they have the intrusive thought, they do the compulsion, it reduces the anxiety, and then unfortunately, it will come back up again.

Yeah. Is it a parent's or anyone's fault that a child or a person has OCD? No, not at all. In fact, what we do know is that we could all somewhat develop OCD. Like we all have sort of things of you don't step on a crack because you'd marry a rat or I'll just park in my favourite car park because it's going to give me a good day. And we all have these kinds of things that come into our brains to do that are somehow going to alleviate some kind of anxiety. The difference between me who doesn't have OCD, and people that develop OCD, is that they are so hardworking at keeping up that routine or that ritual, that compulsion.

It's very hard actually to have OCD. Like it's very hard. It's very hard to keep going and going and going at that same thing, especially when you sort of know. You know 0.00001% likelihood that the thing would actually happen. However, you can't chance it. So you keep at that thing over and over and over again. So yes, it's parents' fault if they have genes of hardworking. And it's also parents' fault if they have genes of creativity because you cannot have OCD without being highly creative. I mean the ideas that OCD can have of how a person is to go about a compulsion is, I mean it can be mind-blowing what people can come up with.

So hardworking, creative genes are sort of really important. Another really important thing is kindness. So if you have really kind values in your family and things like that, then people often develop OCD because they're trying to keep people safe, trying to keep themselves safe, trying to be a good person, trying to be so hardworking that they don't fail at life, those types of things. So yes and no, it's your fault as a parent that you've got it. You can maintain it just like the child can maintain it. But I, or we suggest that actually that's because of a lot of positive strengths that you've got that are just being sort of kidnapped by OCD.

You mentioned about it but having been quite hard work for a child or a person to have, my child was very exhausted and couldn't attend school, and it really affected their day-to-day life. Is that what you're meaning by that? Absolutely, yeah. So they can, again I suppose it goes back to the question you asked before around the myths about OCD is because it isn't fun. It can be highly distressing and highly disabling and that's why we're really trying to work on getting as many children sort of diagnosed and under some kind of intervention because developmentally what children are going through, and avoiding or not being able to be part of socially, education-wise, even whānau and how it's disrupting whānau and whānau's lives.

It's really a myth that OCD is just a bit of OCD here and there. We see just whole lives being destroyed. Okay, thank you. Do children recover from OCD? Yes, well that is one of the very exciting things is OCD, you do not actually need to have OCD. It's not a disorder that you're born with and once you get on top of it and once you can manage it, it can actually be that you have shifted so much of giving weight to those thoughts and urges that they just sort of like fly off you. They come in just like they would for us, or those of us that don't have OCD, and we're able to go, well that's a weird thought, and then just move on.

What we do know is that a lot of people go undiagnosed for a very long time, so around eight years, and a lot of people are not getting the correct support, which keeps it going, or maintains it, You can absolutely get on top of it, you just need the correct support, and know that it's something that you don't have to keep managing, and know also your stressors that come up for you, because often OCD, it likes to, it's very cunning in the way that it gives you these kind of reasons why it's needed. So for example, you've got exam stress coming up, kind of whispers in people's ear, well you're really stressed, so why don't you come this way and do a couple of these compulsions, and I'll, you know, soothe you through this.

Or when you're really tired, just do this one last little thing, and then I'll leave you alone type thing. So we do know that in times of stress, it can get a bit louder, but once people know that, and once they're, we call it, they're broken up with OCD, then it's not a problem. Okay, thank you. So in terms of the recovery, what are the treatment options available currently in New Zealand for OCD? Yeah, so the number one treatment for OCD is ERP, and that is exposure response prevention. So essentially you expose yourself to whatever the intrusive thought is coming, building the anxiety in and things like that.

And response prevention is the not doing the compulsion that OCD tells you to do. That's where having a diagnosis of OCD over anxiety is very important, because if you are working on just anxiety, you actually do a lot of challenging of the thoughts, grounding, and really looking at reducing the anxiety part. ERP and OCD, it's not looking at challenging the thought, because the thoughts aren't important. We don't need to know about those, and we don't need to try and challenge them in any way. And we also don't need to even look at reducing the anxiety. The key part is that the person doesn't do the compulsions.

So ERP works on not doing the compulsions. And at the same time, anxiety and things do decrease. However, the important part is the person actually doing what they want to do and living by their rules over what OCD is telling them to do.

2. Family accommodation

Emma, can you tell me what causes OCD if there is such a thing?

yeah yeah, well I mean there's been lots and lots of studies done on what causes OCD, and there are things that can kind of cause it like genetics and different things like that, however there is a lot of different ways into OCD and what brings on OCD can be for a lot of people quite an insignificant thing that happens, and for others it's much more significant so for example an insignificant thing a child once told me is she vividly remembers being in her grandmother's car and her grandmother had a woman's day magazine must have been quite a few years ago woman's day magazine on the back seat and it read about there being somebody prowling around taking washing off a clothesline so there was this headline that she remembers and she thinks she was around five or six and from there on she knew that she started doing compulsions to make sure that that her and her family were safe not necessarily from the prowler that was taking the washing, but it was like oh this could happen, so the likelihood of it happening she knew was like 0.00001% however because her family's safety and her own was so important she started doing all these compulsions and the compulsions were often really nothing to do with safety so for example they were she had a special rock that she'd found she needed to hold that rock and not breathe for around one minute and so we go well like how does someone go from wanting to protect their family, to holding on to this rock and not breathing?

Like those two things don't kind of fit and yet that's what happens with OCD, is yes some of the compulsions are very much tied to what this sort of theme is and a lot of them aren't as well. Yeah. Okay should we talk about accommodations that families might make that unintentionally maintain OCD? I know for our family it was quite tricky to work out as I mentioned earlier that our child had OCD . Yeah. They asked a lot of reassuring questions, apart from because they didn't start with what if, and they're particularly clever the questions were very clever it took a long time to work out that they were actually seeking reassurance.

And I think we were keeping the cycle going so I was just wondering if you can talk about that a little bit? Yeah for sure. So OCD is very good at recruiting whānau and caregivers as well, almost in the same way that it does for the person that has it, so it comes in quite sneakily and asks things of the person and of the whānau and the whānau don't kind of know that they're necessarily answering to OCD at the time what we do know is that the accommodation cycle mirrors the OCD cycle.

So there will be some form of distress or sort of heightened anxiety in the child and they will want the parent to do an accommodation and that will be like the child doing a compulsion and that will sort of temporarily make the child feel a little bit better or the household even feel a bit calmer and things like that but it won't be long until it's needed again and there becomes this reassurance on the parent to essentially help in regulating the child through the OCD cycle so that's a really good way to go through that cycle I know for our family as I just said about reassurance being the accommodation, but sometimes we could be up till midnight offering that reassurance.

Yeah, yeah, and i mean i implore any parent or caregiver who sees their child exhausted, in distress, unable to sleep, eat, go to school, that type of thing not to actually do accommodation it's like it's part of the attachment system we kind of have different systems for regulating, one is sort of self-soothing you know we're born with developing our own self-soothing, and the other is an attachment system.

Which is a child when concerned about things or stressed looks to their parent to actually help them regulate, and in normal attachment a parent would of course reassure, or give protection, like that's just a normal part of the way that we move through life what happens with when there's high anxiety, or ocd, that gets stunted for a little bit where the the child doesn't continue to learn that yes their parent will give them some reassurance, but also they need to develop independently some of that. And so that can be stunted for a little bit until people get on to it, or it can actually go on for a very long time for families.

Okay what other accommodations? What are some other examples I mean I've given our example but for other families. So we have we have what are called active accommodations so they're the ones that you can see they would be ones where you're listening to say confessions and things like that, or you are actually doing some of a ritual for a child, they might also be stopping a child doing compulsions sometimes you jump in there and and try and do that passive ones are more sometimes harder to spot kind of like the mental compulsions where you just stop avoiding going out at night because your child would get so distressed if you did, you avoid

people coming around, or for some people they take separate family holidays because the child can't be with their sibling for whatever reason because their sibling might be contaminated in some way.

So there's those two types of accommodations and it's very interesting once you start working with families on mapping out that accommodation or sort of diarying it where they start having this realization that OCDs actually recruited them to do a lot more than they thought that they were doing. And the other really important part to that is that OCD can be a very isolating shameful experience for children, and so actually some children don't have their parents or caregivers doing any accommodations it can be that it's quite invisible that that's happening. And is that because they haven't told the parents because they're shameful about it so it's all just kept to themselves and they just go about their life yeah.

managing it themselves. Yes, and they also just may not know that they've got OCD, you know? I have so many young people that come into the office and they're like “I just thought I was going crazy” or, “I just thought I was actually going to harm someone” or, “I was not doing enough study to be a good person” and once they understand it it's a lot easier then to pull apart what accommodations a parent might be doing. But yeah often at the point that I see people they don't know they've got OCD, and the parents don't know that they're accommodating, or the parents aren't accommodating anything because the child's just not speaking about any of it.

Yeah could it be that the child just thinks what they're experiencing everyone experiences? No it's the opposite, they just think there's something very very wrong with them normally. Yeah, very concerning. We're very lucky these days that, lucky and not lucky that there is the technology and the media are out there and that a lot of OCD advocates are very you know are really out there, and saying what it is so yeah. Almost to say making awareness of it. Making awareness of it, yeah.

And so these days I mean even in the last few years that's been so different so people won't necessarily have discussed it with their whānau at all, but they'll come in and they'll say I've seen this person and I'm sure this is what I've got, and often that will be around things like harm themed ocd, or sexual themed ocd, where it's just it's taboo subjects that make them feel shameful and that they're hard to actually discuss with your whānau to begin until you actually understand what they are. Yeah that's that's fair. So how does a family go about reducing accommodations, or how does that support recovery for ocd?

yeah so what we know is family accommodations maintain ocd for the majority of the time they maintain ocd, and they can actually exacerbate it. And if you think about kind of the attachment system and a child sort of looking to you for reassurance, if you're then saying “yeah like this ocd we need to actually make sure that we are helping regulate you because this is real and this is a real stress for you” then it's giving the child a message that they can't cope with it, that they can't handle it, and that also what ocd is saying could actually be sort of quite true so we know that accommodations keep that up it doesn't help build the child's sort of resilience or their belief in themselves that they can they can handle it.

Yeah yeah you’re often, well we're always talking about whānau helping, like accommodating the OCD, does this help not happen or would schools not be accommodating, or is it that the child sort of masks at school, or how does OCD come? Is it only in the evenings or at home that OCD presents? yeah yeah good point, some OCD is specific to locations, however there will often be a way of neutralising whatever that's been. So for example some children just won't have it at school and part of that is that they then have a sort of transition period between school and home where they wash themselves or they neutralise whatever's happened and then they can do the compulsions and things at home so it sort of wipes out whatever would have happened during the day that OCD wouldn't have been happy about.

For some and luckily as we get older, there's a kind of social aspect to that too where you can't be you know flicking light switches on 20 times in a classroom when you're 14 years of age necessarily, and then some are just very specific to people and places, so it would be that it would happen at home because their sister's there. Or something like that. Yeah okay. Yeah and so with that though it's really important to know that if it is happening at school, school we're very much a part of this team of breaking up with OCD. Because often we have to actually talk to, especially teachers I mean again it's almost an attachment system there if they're good teachers, they're trying to help reduce the child's distress so that they can learn, and we need to sometimes get in there and work with teachers and be like we need this child to actually know that they can handle that.

Okay. Yeah.

3. Introducing SPACE

So we've just been talking about accommodations that families make which can keep the OCD, I guess, cycle going. There's a programme called SPACE that I did for our family to help with stopping these accommodations. Can you talk a bit about this programme? Absolutely. And what it stands for? Yeah, sure. So SPACE is a treatment that has been developed by a man called Eli Lebowitz and he comes out of Yale. And it is a programme that only parents need to do and it is about parents' behaviour and them changing their behaviour over the child or their whanau member with OCD. They're not trying to change what that person's doing.

SPACE itself is Supportive Parenting for Anxious Childhood Emotions. That's what SPACE stands for. And is very much focused on the adult's behaviour or the caregiver's behaviour over what the child or the person with OCD is doing. Yeah. Okay, okay. So what would the programme format look like? Like if I was thinking about doing the programme, how would you explain that format? Yeah, I suppose just going back a little bit, what SPACE is about is it's kind of got two components to it. One being how to be supportive. So how you can be accepting, sort of validate what the child's going through or the person's going through and also put in sort of the confidence you've got in them to be able to handle it.

So there's that component to SPACE. And that's sort of the supportive component, we call it. The other one is reducing the accommodations component. So it's sort of broken into those two things and both as important as each other. However, the supportive part has to come first. And if OCD's been in a whanau for a while, then that supportive part is actually quite tricky because being validating to a child can tip to being very over-empathising or very much giving in to OCD and being very, very concerned about the child's emotions that are happening because of that. So almost unable to tolerate those emotions while trying to validate them with the child.

And then the other one is the confidence in a child can also tip to it being like, this is not a big deal, so just get on with it. You know? It's not just about going, I can see that you can do this or you can tolerate this hard feeling. Sometimes if OCD's been around for a while, we can be quite dismissing and also just get on with it because this is, you know, our whanau are having to go through a lot because of it. Yeah. Yeah, so I think for me going through the SPACE programme, rather than just trying to always work out at home if what you're doing is right or wrong and then you're waking up overnight thinking about it, you know, should I be doing this or not?

It gave me the confidence, which I took back to the family, to know that what you were doing was supportive care for your child. And it does also give you that sort of framework to do that as well as reassure your child that, well, what changes you're making is for their benefit and that they have the ability to do it. And it's tailored so you can do it in, like, the small increments or whatever you need to do for your individual child. Yeah, absolutely. Which was good. Yeah. Yeah, and that's exactly what we see. So we're giving the parents that sort of language and helping them to be able to be supportive, so not tipping either which way, and then giving them the...

almost giving the parents the reassurance that it is OK to drop these accommodations and why it is, you know, the sort of science behind that and things. Then, as you know, we go through and we again map out all those accommodations and you pick specific targeted accommodations that are going to... ..that are definitely a parent behaviour or a caregiver behaviour and that happen regularly enough that you're able to keep consistent at not putting them in. And then following that, as you know, we make a bit of a plan as to how that's going to roll. So you're going to now do this instead, which will have a kind of supportive statement in there.

And you'll put in whatever you're going to do instead, how and when that's going to begin. And then we have a whole session on how you're actually going to tell the child about this, because none of this is against the child or all of a sudden just dumped on the child. It's very much... ..None of it's a surprise to the child that it's going to happen. And then you go away and you sort of implement that plan and then you come back again to the therapist or the group, if you were doing it in the group, and you tell everyone how it went and what went down. I don't think when you did it we needed any extra sort of additional parts to it.

However, if you have a child that can become very aggressive if you were going to pull down on an accommodation or reduce an accommodation or you were going to, or they might threaten self-harm, that type of thing, then we do work with parents on some additional things. Because what can happen if a child is like that is that you then... ..stop with your plan, obviously. And actually, that's kind of a false equation in a sense. Like, yes, if there is a safety aspect, you increase some safety and you act in a way that you can provide some more safety, but you also keep reducing the accommodations.

And another thing that we didn't need to use when you came and did SPACE, is around parental conflict or parental...coordinating both parents or members of a Whanau, because, of course, we all parent differently and we've all got different... Each person will have been doing things a bit differently. And so sometimes you need to work with parents on just getting that sort of supportive equation as a universal kind of message to the child. So, in regard to that, if you had a child that was going between two families, both parents or caregivers would need to implement the SPACE technique, really, to make it effective.

You couldn't just have one household. Yeah, no, you can have one. You just need one person that's doing accommodations to come down on them. And that's actually even the same with school, to be honest. Whoever's in the system, if somebody reduces an accommodation, it's giving the child a message that actually, they can handle and they can tolerate something. However, in an ideal world, yes, you would have anybody doing accommodations for the person with OCD to be in the same room and having these conversations, because, of course, life's busy. So even if you are in the same household, parenting with somebody else, it can be very difficult to find the time to sit and work through what you're going to say and how that's going to run and also then sort of...

brainstorm any kind of difficulties that you've got around that. Yeah. So I did it in a group format, as you have mentioned. So you can do it one-on-one. Is that available in New Zealand? Yeah, so actually it was set up. It is set up as a one-on-one therapy. And again, it was set up because some children, even adults, don't want to engage in any kind of therapy. Or they may not develop mentally, be ready

necessarily for some kind of therapy. So it gives an alternative treatment for OCD, essentially. And because of that, it was set up and Eli started out just having them as individual sessions with individual caregivers.

Okay. Yeah. The same process. Yeah. But you'd just come in once a week, almost like you would if you were just having therapy. Okay. Yeah. Whereas, as you know from the group setting, we tend to do five to six sessions for two hours. Yeah. And that is because, one, that group aspect is so incredibly useful because it can be so isolating as a parent. Yeah. Even within a whānau, you know, grandparents, aunties, uncles who are like, what are you doing? Like, what is going on in this family? And it's hard for people to understand if they're not actually going through it. Yeah. So that's the sort of, aside from SPACE strategies itself, that's very useful, as I think you found with being there with other parents.

Yes. Yeah, the group aspect was incredible. And just hearing other people's challenges and not feeling alone. Yeah. Because it doesn't feel like there's many people in your own sort of circle that will understand what is actually happening for your child. Yeah. And how hard it is. It sort of hijacks your whole family. Exactly. Yeah, yeah, yeah. And it's amazing. Each group you do, like there's so much laughter, you know, and then there's so many tears. Yeah. And we often have quite a lot of dads, which is, and that's, you know, we'll quite often have one parent, even though it'd be nice to have both just because of caregiving for other kids and things like that.

And it is particularly good for dads because often they're not talking to anybody about anything. And then they have these other people there that are going through. And if they themselves have OCD, we talked about there is, you know, sort of a genetic link there. Often they can be very self-blaming. Yeah. So to be able to sit with other parents and discuss that. And so how many would you have, like, what would your maximum be in a group for SPACE, because they are small groups? Yeah. It's sort of different wherever it's run. We here in Christchurch do about six parents. It's really important to say that it isn't offered very often and by very many people.

There's 11 of us on the SPACE website. That are trained in SPACE in New Zealand. And everyone runs them privately apart from one DHB, the Waikato DHB, who runs it through them and they're awesome. And that's a shout out to Jacob and Arden because they have just kept pushing this programme. And ideally, this is also part of Open Closed Doors is that actually SPACE would become part of every DHB. This is just a programme that everyone should be able to access. Okay. Yeah. So how do you access SPACE? So at the moment to access SPACE, you can go on the SPACE website, which is spacetreatment.net and you go under there and you can click on New Zealand and the 11 of us come up.

There are people that understand SPACE that may not have necessarily been trained there. Yeah. And part of that is because Eli has got a lot of resources there. He has put out a book which is Breaking Free from Childhood OCD. And that's an excellent book and it's almost a manual. So any therapist that's trained in OCD and has understanding of accommodations, which most should. Yeah. Can actually also support parents to go through that manual. Okay. Parents can do that themselves. Yeah. And in fact, some people trained in SPACE and SPACE groups, you go through the book as you're doing it. So does your child need to be under a psychologist to access SPACE?

No. And in fact, they don't even need to have a diagnosis of OCD. Okay. It can be that you as a parent think that they do. You can talk to who is running the SPACE. Yeah. And we have people that we would say the child has more OCD tendencies. And before it becomes full blown OCD, the parents come in and that's been incredibly useful. Okay. Yeah. Yeah. How does, you mentioned Open Closed Doors? So that's your exposure response prevention. Is that what that is? Yeah. So do you wanna, how they complement each other, SPACE and. Oh, and. Yeah. So SPACE and ERP complement each other beautifully in the sense that while a child is learning how to manage and that they can tolerate and that they can break up with OCD, the parent is also doing the same thing and learning that their child can tolerate and that this is all gonna be okay.

And by reducing accommodations, they are actually supporting their child to recover. And it can be that you just have SPACE. Like I said before, you don't actually have to have the child going through ERP. And sometimes a therapist will do both. So they might see the child and do ERP and they might see the parent and do work on the accommodations. And some people that might be that the therapist is separate with the child and, but the parents might be going to a SPACE program with somebody else. And that can all work as long as there's sort of communication. Okay. Yeah. So with the SPACE program, do parents usually tell their child?

Seeing as the children aren't in the program? or do they usually tell the children that they're doing this? I mean, I know for myself, I can't actually remember whether we told our child or not. If we did, we're doing SPACE, but obviously during the process, you are working in partnership with them to explain how things might change a little bit. But what do most parents do? Yeah. And most parents just say something like, I'm going off to learn how to help you or how to help our household because I'm sort of letting the team down in some way. So I need to get some skills as to what's to happen.

We're very wary that we're discussing children who haven't necessarily given consent for them to be, I mean, they've given consent for their parents to, but the parent's going to come anyway. And so we get parents to ask, are they okay that they share their name and their age and what's going on for them? So there is a conversation that's had before coming into the SPACE group. And some kids don't want their name shared and their age shared, and that's absolutely fine because it's about the parents' experience. And so they can discuss things that they're accommodating, but they just wouldn't use their child's name and things like that.

Yeah. And it's just confidentiality is one thing that we make sure that children know before coming in that, where possible, that they're not going to be identified. Yeah. Yeah. And as someone like myself, we did the SPACE programme, and that is the tools that you get, you'd be using, I guess, lifelong. But is there like a timeframe on when a family might expect to see, I guess, improvements for their child? Yes and no. If you can go away and not do any accommodations, then it's going to be a lot quicker. It's like ripping off a Band-Aid. It's like breaking up with OCD. You can go and do ERP week on, week off in a very small increment.

Yeah. And that can take, you know, two years. That can take a long time. But if you decide, you know, within a few sessions that you're just going to break up with everything that it's wanting you to do and stop following its rules completely, then it's going to be a lot quicker. Same with the accommodations. Okay. Yeah. Because I know, like, one of our accommodations is we couldn't discuss a certain topic. Mm-hmm. At our dinner table. Mm-hmm. Because it would upset my child. Mm-hmm. And then I'd want to discuss it, but then you'd, because you, or you'd avoid discussing it because you don't want to upset them.

Mm-hmm. But through the SPACE programme, I learned that it's actually okay. We shouldn't be stopping these conversations to have. Mm-hmm. And so it gave me permission, I guess, to be like, well, we're having this conversation and you're safe. Yeah. And you can just, you know, you don't have to be involved in it, but you can listen and you're safe and nothing bad's going to happen. Yeah. So I think, you know, things like that make a huge difference. Absolutely. For families, you don't have to, shh, everyone don't talk about it. Mm-hmm. Yeah, because essentially, you're giving the message to the child, right, that it is unsafe to use those words or talk about this topic.

Yeah. And so by you not doing the accommodation, just off to the side of them, even like that, it's going, well, they can see and look and reference their parent and be like, well, they seem to think this is safe, you know. Yeah. They are safe and they are, they are essentially giving me the message that I am safe. Yeah. Whereas if you put in the accommodations, you're saying, yeah, you're right, I say he's right. Like, this is not safe. Yeah, can't talk about it. This is not a good, yeah. Yeah. Yeah. Okay, so then as a parent, do we just stop, just stop accommodating everything and then we'll get a quick result and be done.

We'll move on. Yeah, I do advise against doing that. Okay. Like, don't be walking away from listening to this video or this conversation. Okay. And stop all accommodating. It does need to be a planned process. The child does need to be informed and you also need to really think about how you are going to consistently not put in that accommodation. Because I know for myself as a parent, I can have great ideas and I can hear these things that I need to do as a parent, read about them, listen to a podcast. But I might not have thought through if I can actually consistently then keep that up. And that's a very important part to reducing accommodations is once you have informed the child that you're going to stop doing that, whatever accommodation it is, you actually then need to follow through with that every single time.

So there's thought that needs to go into that. And reading something like Eli's book is a really good idea and take your time to think through that. He also has excellent podcasts that he's on and things like that that you can listen to. Ideally, you'd do it alongside a therapist. But I mean, that is just a very difficult thing to access at the best of times. And you, so if you can't, you would get on board, try and get on board with the other parent or caregiver and really nut this out before you pull back on accommodations. I know there was discussion during my SPACE group that like what accommodation to tackle first and the feeling of course is that you just want to, the one that is the most annoying or takes up the most time for the family that you want to tackle first.

But how does, how do you work out what one? Because I seem to recall there was some, I don't know, sort of system or some that would be preference, preferential over others to do. Yeah, yeah, yeah. Absolutely. So that's a whole part of it is, and the first one is to actually nail down that it is a parent behaviour. It does take a wee while to get your head around that sometimes because you're like, oh, well, if I just do this, then that would stop their behaviour. But it's like, no, no, no. So it needs to be an actual your behaviour. And then it needs to be regular enough that it's making some kind of impact.

So you'd want it to be happening at least, you know, once or twice a day. Okay. And something you could be consistent then doing and you'd know what you were going to be doing instead. Yeah. So you work all of that out before going and you can list them off. Oh, this is probably my most important ones and then sort of run through that and work out how you're going to do that. Okay.

4. Open Closed Doors and Bergen 4 Day Treatment

Now you mentioned Open Closed Doors earlier, can you talk a bit more about that, about what that is? Yeah, so it's a charity that was set up by a few of us in 2025 because we were incredibly concerned about the lack of intensive treatment for OCD. So you can get ERP therapy in New Zealand and that's usually like a weekly type situation. And what we find is you can have a client knowing what to do, they go off to do their exposures and then by the time they get back the week later OCD's got back in their ear and they're back to doing whatever it was. And we know from research all around the world that intensive treatments can be very useful for that.

So we set out to try and find how we could bring some kind of intensive treatment into New Zealand. We talked to lots of different ones and often they were inpatient treatments for around three weeks in different countries and that was often to do with insurance. They just got money for those who, it wasn't necessarily that people had to be there for three weeks to work on the OCD. And we had heard of the Bergen four day treatment, it's something that those of us in the OCD world knew well. Research coming out of it was quite unbelievable. So it was kind of like what is going on there. And once we met with Bjarne and Throsta and spent a few different times talking to them, we actually realised that the treatment was not only useful in the sense that it was just four days rather than the three weeks.

There was a lot of parts of it that really fit with New Zealand. So for example, you eat kai together at lunchtimes on the four days. As therapists and clients, there's a Norwegian word called being human. I can't remember, I can't actually pronounce it very well. And so that time is just about sitting and being human together, not expert and client and things like that. It's just sitting and having kai and talking about the world and things like that. And the other thing that really resonated with us was it was about empowering the person with OCD to become their own therapist.

So instead of having to have us and pay, you know, all this money or spend years with a therapist helping you, it was about getting a client from coming in with reasonably severe, I mean, we've had extremely severe that we've been treating, to being able to by end of day three, actually know what they were doing and know how to do it and not need us around. And then by day four, they come up with a plan of how they're going to continue that on. So we liked all those aspects and we decided to go with them. They were incredibly supportive of us and a Norwegian cheese company who helps sort of sponsor a lot of their work, flew five of us over to Singapore.

And I was very lucky that I got to put together this clinical team, all people that have already worked in OCD for a long time. And all who are very passionate about supporting people with OCD in New Zealand. So we flew over to Singapore and we did two weeks of observations over there, two treatment rounds. We knew the research and we were kind of sceptical about the research, to be honest. Research, you know, that is what research is. Sometimes can look a little bit better than it possibly is of what is actually happening. And the people walked in on the first day. They were severe. They had severe OCD.

So things like unable to sleep, not feeding themselves, not being able to wash themselves or toilet themselves, that type of thing. They walked in and we were like, whoa, this is just... There is no way in four days that these people are walking out the door being able to do any of those things. And slowly but surely watching the Singapore team, we were like, OK, well, you know, this is a bit different. And instead of focusing on stopping doing compulsions, it was focusing on what the person wanted to do. So, for example, they wanted to be able to, Well, most people want to be able to toilet themselves by themselves.

They wanted to walk around a mall and look at makeup without whatever. They really worked on what they would do if they didn't have OCD, what their world would look like if they weren't ruled by OCD. And by the end of those four days, those people were doing those things that they wanted to be doing. We actually, even on the taxi ride home, had a conversation about did we think they were actors? Because it went so well and I was like, oh. And then luckily we got to observe the next treatment. And they weren't actors. Yeah. Great. Overseas, Bergen four day treatment has been used for six year olds and up.

And at the moment, we have treated just over 40 people and they've been 15 years to 25 years. And that's just because that was the way that we've been having to sort of roll it out. Our next treatment is actually in Christchurch in September and it's 11 years to 15 years. And then we start in Auckland in January doing 18 and all the way up so that we've got adults all the way through. Yeah. The idea behind us doing these treatments, though, is not so that we, as Open Closed Doors, keep running it. The idea behind it is that we make enough noise and we train up enough people in Te Whata Ora, essentially, so that these programs can be run by all DHBs around the country.

So that if you are diagnosed with OCD, then you are put into one of these groups. And that's the way it is run in places like Norway. If you're diagnosed with OCD, then you just go and do a Bergen. It's a four-day treatment and break up with OCD. Yeah. That's excellent. Thank you. Thank you.

5. Help-seeking pathway

Hey, I'm Evan. I'm a consultant child and adolescent psychiatrist. I'm in an open-clinic in Christchurch called Mind Horizons Psychiatry. And nice to meet you. Nice to chat, Evan. I was just wanting to ask a few more questions about the health-seeking pathway, the children with OCD. For ourselves, we first had an autism diagnosis a couple of years before we got the OCD diagnosis. But in hindsight, I realised that it was probably a couple of years that the OCD traits were prevalent. But we were treating it probably more like autism. And we were able to seek help privately because we'd already gone through some psychologists for the autism diagnosis.

But I was just wondering what the usual pathway is to get a diagnosis and help for children. So the usual pathway, if parents are worried. Is to go to your GP. And a lot of parents kind of, I think, wonder, should I be worried or not? And my normal thing to say is that

if you are wondering that question, it's better to go to help professionals ask and get reassurance. Rather than let things kind of go on too long the other way. Some of the things that I would kind of start worrying about now in people, or if you're kind of thinking about things like OCD, is this person spending more than an hour a day on kind of rituals or with really distressing thoughts?

Or are they particularly distressed by the sessions or the intrusive thoughts and things like that? Or is it significantly impacting their life? Like, is it making school hard? Is it making family life hard? Is it making life hard? All of those are things that make me a little bit worried as a clinician. And I think it's reasonable to worry about that as a parent. And any GP would be interested in that. Okay. And so once you've seen the GP and if they wanted to take it further, what would that look like for a family? There's different pathways. So it kind of depends on how severe the symptoms are.

On the kind of moderate to severe end, then there's normally a referral to the public mental health system. But there can often be a quite substantial wait for it. And on the milder end, and often while you're waiting for the public system, if you're even on the moderate or severe end, sometimes GPs can let people in with organisations like Mana Ake or Manuka Rere or various community organisations that can start doing some kind of work with you and that other person before next steps need to be taken. Yeah. And when you talk about a significant wait, but I mean, how long is [unclear]? Yeah. I mean, it's different.

Is it months to sort of years, and it'll all change depending on the severity of the case and the age of the child too. Absolutely. It's different in different parts of the country as well. I can only speak on Christchurch because that's the only region I've really worked in. For someone that wasn't on the kind of, real upper end of severe, the wait time has got over the vicinity of 10 to 14 months. Once you've got the referral of the [unclear], and that can be a bit of a hurdle as well. Yeah. What I suggested to parents is go early, so if you're worried, go early, and don't be afraid to ask again if your initial referral was declined.

And that sometimes they, because of the huge number of people on the wait list, there has to be a threshold where, yeah, a child has a certain level of unwellness before they get accepted. And so if things are getting worse, even if they're declined and sent on another pathway, go back to the GP and say, look, things are getting worse. Can we try again? Yeah. Yeah, that's a good point, because otherwise you might have parents that are like, well, before we do a referral, we just have to wait. But again, my things can change and they need to be served. Yeah. And then certainly if young people are severely unwell, normally, I'm not going to say why, because the system is run by people and there's always problems, but normally the system should pick up, and if you're communicating to the GP at Nats, there's really severe, and the youngest is at risk, that often does expedite things.

But when I say it expedites things, there's often still months before people get seen, even when things are really severe. Okay. Yeah. So you were talking about what the GP, how you might do Mana Ake or something. Yeah. Is that sort of a way a family can support a child while they're waiting? Is there anything a family can do at home? Yeah. So... Yeah. So obviously using kind of any resources in the community is a good idea. Yeah. And then when it comes to kind of supporting the young person at home, a lot of kind of helping young people with OCD is validating the experience. It's a very real distressing experience for young people, but they're not enabling some of the rituals and behaviors.

And so kind of trying to support young people to distract them from the behaviors kind of... Even if you don't have a diagnosis, you can call out the behaviors and go, you know, is that the worry talking? Yeah. And maybe let's do something else that's just really fun to try and distract you and break that cycle of needing to do this again and again and again, or really getting stuck in your thoughts. That's one of the most useful things you can do. Okay. Yeah. Because it is trippy. Because I think we found the track probably of thinking kind of how if we're reassuring, that we're enabling it. Yeah.

And as I said... That's what's so hard is because you don't want to see your child in distress, so you're... And it's so natural as a parent. You go, right, this short-term thing that this person does relieves their distress temporarily, even though we kind of know, or your clinicians probably know, that actually that's reinforcing that behavioral pattern and making things harder. So, and that's what, you know, even if you can get in with something like an Akiwana Kari, so there's someone else to support you to kind of go, hey, it's hard to sit with that distress. Yeah. And I doing the right thing by kind of distracting and redirecting and rather than just kind of leading some of those behaviors.

Yeah. Cool. Thank you. Okay. So with once you have been all seen, for once you get an appointment with the mental health service, that's, I guess, if we're going public or private, if you can... Who is most likely to be involved? Like, who will you see or the child see? Whether you go public or private, does that change or...? It can change a little bit. In the, again, I'll talk for Christchurch, because I'm not certain about how I go about placing the capture on things, but in Christchurch, normally you'd have an initial assessment with, like, a case manager. So normally that's like a therapist or psychologist, and that will work with you to get an understanding of what's going on for your young person in the same unit.

Then they normally bring those cases back to their wider multidisciplinary. And they discuss it with their team, and the psychiatrists are better than their team. Okay. And then there'll normally be kind of a plan that's agreed on with you, with the young person, with the MDT, and then kind of work through that with the team. And sometimes that plan might involve medications, and normally if the case is

complex or if medications are needed, then you'll have an appointment with the psychiatrist. But sometimes if the case is not as complex, then you might keep working with the therapist, and then kind of see a psychiatrist if things get more complex.

Right. So when you can work with a therapist, or therapist and psychiatrist, as you already chatted about, what other, like you said, if it's a complex case, what are the more intensive or specialist treatments available for OCD in New Zealand, and what kind of children would get prioritised for those more young adults? So I guess the gold standard treatment for OCD is something called exposure and response prevention, and it's normally done as part of CBT, cognitive behavioural therapy, and a lot of the kind of, child and family therapists and have experience in that sort of work with young people, and they kind of work on that with the young person and the family.

That's probably the most important thing for OCD if we can access it for younger people. Remind me, what was the other part of that question? What children, if there's a, like, what children are prioritised for that treatment, or is that, as you said, the gold standard treatment, is that what we try and get all children? If we can. Therapists if we're lucky enough. And if we can get, at least in the public system, and then if we can get that person through the door by the level of kind of moderate to severe mental illness, then that's almost always the kind of, the first line treatment that we'll be using for OCD.

Sometimes obviously people can't get through the door, and so then it's kind of, if you are looking at therapists or psychologists in the community, it's really worth checking whether they've got experience with that sort of work, because some therapists don't, and really that's what you want to be doing is exposure and response prevention. Okay. Yeah. Yeah. Well, that's a good point to make, that when you're a family selecting, a therapist. Yeah. To check that they, yeah, that provide that therapy and treat children with OCD. And it's very reasonable to ask this stuff. You know, almost every therapist would want to have a good, be able to have a good out and around with you.

And if they know that this is something that's outside of their skill set, because obviously there's sometimes something that's outside of some therapist's skill sets. Yeah. Then, then actually being upfront at the start before you have an appointment with them is really helpful for them because they can say, Hey, look, I don't have the expertise, and i dont want to kind of lead you astray. That can be spending a lot of time waiting to get in with any therapist. Then at least you can find someone that might be able to help you off the bat. Yep. Thanks, Evan. You mentioned before like with the OCD and being referred to like a mental health unit.

Is, is OCD classed as a mental health disorder? Or is it more seen as a neurodivergence or? It's a good question. Cause there's a big overlap between OCD and people with neurodivergence and it is considered a mental health condition. But I mean, I think of it as a little bit academic. Yes, we have to say, so this is neurodivergence, this is OCD. And therefore it's a mental health condition realistically, it's a young person that's struggling. Yeah. And through the line of the sand is a little bit complicated, particularly when huge numbers of people with OCD also have ADHD and also have autism and have all sorts of other conditions.

Many people with OCD have other mental health conditions. And I think the stacks are something like one in four people with OCD has two other conditions. So it's really common to have kind of co-orbidity. And so technically speaking, not neurodivergence, but very commonly neurodivergence associated.

6. OCD and co-occurring conditions

You were talking about how OCD is quite common to occur alongside things like autism and ADHD. I know for us with my child, it is the case, having the autism diagnosis and ADHD diagnosis. Why do they commonly occur? Do we know? I was going to caveat this with saying I get nervous talking about neuroscience because our knowledge is still in the dark ages. And a lot of what we say is just good guesses. The theory is that actually there's very similar pathways in the brain. And that's what we think. But if you ask me again in 20 years time, I might have a completely different answer for you. But that's kind of what we think at the moment is that similar pathways in the brain.

And then also people with neurodiverges have huge levels of stress navigating a neurotypical world normally. We know that stress is a massive risk. And that's a big factor for all sorts of other mental health conditions, including things like OCD. So that's probably a contributing factor as well. So that could be then why with OCD symptoms, I guess I've been kind of [unclear]. I've noticed that sometimes we can go through periods where there's no symptoms. And then other times my child's quite distressed with OCD symptoms. And it's sort of knowing that stress or understanding that can be a problem.

Yeah. Sort of. And then this. There's so many factors that can influence everything going on in an [unclear]. Some people have complicated lives. And yes, things like stress, things like demands on them from school, things like family dynamics, and probably dozens of other things that we just don't know how to point the finger at. Yeah. And so it's really important to remember that if the OCD is getting worse, it's not that treatment's failing. Or it's not some failure on the young person. It's just OCD's getting worse. And if OCD's gotten better, great, let's celebrate. But it doesn't necessarily mean it's been cured.

And we kind of always have to kind of remain vigilant so that if things kind of start creeping in again, we can support our young people with kind of all of the techniques that they probably learned to get things better. Yeah. So that if there's dips, we can help them with those dips. Yeah. Thank you. Are you able to talk to me about how OCD and tics might be related? Yeah. Again, they're very similar pathways in the brain, is the kind of thinking. And lots of people with OCD also have tic disorders or tics. Yeah. And I think I read something saying something about 30% of people with OCD have tics as well.

And there are obviously differences between OCD-related behaviors and tics. So tics are normally kind of short, sharp, purposeless movements. Whereas OCD-related kind of compulsions tend to have more purposefulness to them, they're often more kind of deliberately repeated. And you can... Then there are variable levels of resisting both of them. Obviously, having tics and OCD does make things a little bit more complicated for supporting young people. And the other kind of relevant piece of that is that young people with the tics tend to develop tics a little bit younger than OCD tends to creep in.

That's very generalized... Okay. But the tic could be a sign. Yeah. That's showing that this is a brain that kind of follows the pathways a little bit. And that if you notice, in fact, some young people obviously get help from a health professional and all, but then kind of, I would be keeping an extra eye on, you know, as they get a little bit older, are they still tics or are they becoming more compulsions? Yeah. Okay. And then in regards to that, talking about sort of knocking out for [unclear], for me with my child, it was quite tricky because there was a lot of very complicated questions being asked.

And so I just thought it was to do with autism and the giftedness. And so I guess it was, everything was answered for a long time, which enabled the patterns to continue. So... And I know thats just my one example, but, you know, what can parents look for to know it's not, you know, anxiety or it's not tics or it's... Yeah. It is hard. I think that the particular, the really challenging thing to figure out is that autism versus OCD related kind of compulsions. Yeah. And the kind of thing I go back to is, is this a behavior that is kind of repetitive and self-soothing? Or is this a behavior that's a result of distressed kind of obsessions?

And even drawing that line can be really difficult. But, you know, a lot of people with autism do have repetitive behaviors, that they're doing it as a way to calm themselves and kind of stem or soothe themselves. Yeah. Whereas people with OCD have these really distressing thoughts. And if they aren't acting on those thoughts, then they get even more distressed. And... That's... That's how I would look at things as a parent. But then equally, even teasing that out, unless you've got a very articulate young person, they may not be able to tell you that. And so sometimes it's time, and sometimes it's kind of working with health professionals to see what their perspective of it is.

Yeah. In terms of teasing things out like tics, whether this is a tic or a kind of an OCD-related compulsion, a lot of the time, like, the complexity of things is a useful tell. So if someone is needing to turn the light switch on and off and off again, it's a pretty purposeful movement. And it's not kind of more involuntary muscle movement. So, yeah, it is normally a short, sharp, non-purposeful, yeah. Thank you. We're talking about having additional diagnoses, does that make treatment any different for OCD? Does it affect it in any way? It definitely can. It can make things a little bit more complicated.

And it depends on what the additional diagnosis is. Obviously, additional diagnoses can make diagnosis with OCD more challenging or vice versa. So it can kind of go hidden almost, for longer? And then management can become more complicated. So one of the most common ones I kind of deal with a fair bit is ADHD and OCD. And that is something that's got kind of quite severe. They're ADHD and they're inattentive and they're impulsive and working on them on the kind of challenging these behaviors in therapy through exposure and response, which can definitely be hard. Yeah. And because actually sitting down with a therapist and kind of developing hierarchies of things that are distressing them, it's not something that sometimes young people can do when their ADHD is not being well managed.

So we need to kind of manage all conditions this young person has. And so it might be that you look at treating the ADHD, and then we support them with the OCD side of things. That can be a whole different kill. Especially in terms of worsening OCD symptoms with ADHD communication sometimes. But it's a we need to kind of sort everything at once, rather than me doing one thing in isolation. Yeah. I think that's how we got to the point of diagnosis was the trial of ADHD medication and it worsened. Yeah, OCD, some treating IDEX for it was at the time, but that is something that happened. So yeah, there is a balancing act to get a good treatment plan.

Yeah. What can parents do when neurodivergent traits make the ERP therapy harder to do? I mean, obviously advocate for your child and often when they're pressed con health systems. Things can get messed, and you know your kid better than anyone else. So if you're seeing, Hey, I'm taking my young person to therapy the way, and they're doing nothing because they're too distracted in therapy and they're not, they're not able to stay on task and, and maybe they've been diagnosed with ADHD and we've not had a meeting with the doctor about medications for that. Talk to the parents and say, look, I'm worried that actually we're wasting your time here.

And, and we're wasting my young person's time because they're not in a space where they're able to do that. Let's try and can we, can we look at optimizing to make things a bit easier for them in the room? If there's anything you can do. And I think that that applies whether or not the young person's got neurodivergence or other comorbidities and that if things aren't working, it's really important for

families to say that because a lot of the time you kind of, there's this big power dynamic between you and a, and a therapist or a psychiatrist, but and, and it feels like, oh, I don't want to say anything wrong because I might upset them.

Any decent therapist or psychiatrist wants you to say if things aren't going right for your young person, because you, you're spending hundreds of hours with them. They're spending an hour a week. And so everything you can do to say this is working very well, or I'm not sure this is working is, is, is massively helpful for your young person. And I guess you also don't want your child to then be possessive of say a therapist because it's probably something [unclear] actually for a very long time. Totally. Yeah. So you need to find the right fit, don't you? You need to find the right fit and you need to, at least you need to come and make it work.

We do everything we can to make it work. But the other thing obviously that parents can do is kind of talk through, normally there'll be hard work and things that will come with, you know, yeah. And so if the therapist hadn't told you what that is, check in with your young person, talk it out, have these conversations, support them around keeping them honest, doing their homework is all massively helpful for parents. Why sometimes do new diagnoses emerge? Like as kids go through the system, is it that I guess they've always been there, and it's just here as things progress and one thing sort of solve the next thing pops up or how does that all interact?

Okay. That can be and sometimes it's, it feels like you're just collecting the alphabet when you go to the health professional. It's eh. Some of it is that things have already been, have always been there and the clinicians getting to know the young person and, and identifying those things. Sometimes it might be actually like we said earlier, we start treatment for one thing and it worsens something else that was hiding under the surface. And then also young people grow, and develop, and as their brain develops, their propensity and risk for other mental health conditions goes up as well. So it might be that this, this wasn't here, and It's just that the passage of time has meant that this young person has now developed something else.

Okay. I know some families that are resistant to getting assistance for children cause they don't want to collect an alphabet. Yeah. What do you say to people that have that that worry, I guess, about, about that? It's a difficult, it's a difficult situation because no one likes giving a label to a young person. And I mean, in an ideal world, we wouldn't have to give anyone a label. We could have a perfect way to communicate this is... this young person and these specific difficulties that this young person is having because our labels are, they're okay, but they're not great in that, you know, this person with OCD will often look very different to that person with OCD and that, that thing might be the same condition.

They might not, who knows. And that kind of knowledge of the brain type isn't there. Yeah. What a label is useful for is communicating efficiently though, in that, in that perfect world where you had a psychiatrist that could tell a GP, give them a perfect summary of this young person, you'd need many, many hours to kind of communicate that information from both of them. And it's just not viable. Whereas actually if we've got the letters, OCD or ADHD or autism or whatever, it's a way to kind of efficiently communicate. Okay, this is a start as to how this young person's brain is. It's not the young person.

This is not the OCD patient, the ADHD patient. This is a patient that has a brain that works a little bit like this so that the next person that picks up their care and goes to support them has a bit of a foot in the door to go, okay, I understand that this person's brain works like this a little bit. Let's get to know you a little bit better. And so we can target our treatment and support you as well as possible. Yeah. That is, that's good. There's also a link I understand between OCD and eating disorders or, or when, when do they like the OCD become an eating disorder? Yeah, there, there is a big overlap again with OCD and eating disorders.

And the differentiating factor tends to be, is this behavior because I'm really distressed. And and, and that eating related behavior is a kind of a compulsion in the way to self-soothe or have I got weight or body image concerns and I'm, the eating related behavior is kind of more tied into that. Yeah. Are you able to just explain a bit more about what ARFID is and how it might be related to OCD or the differences? Yeah, it's a good question. And, and certainly in the kind of space between eating, eating disorders and OCD, and then ARFID sort of sits in a bit more of a kind of complicated space in between, ARFID tends to be not driven by, I want to lose weight or I want to have a certain body image.

It tends to be more sensory related stuff or, so textures of food or certain kind of types of food or things like that, that young people particularly struggle with. So again, it, you, you might have OCD, eating disorder and ARFID, or there might be one or kind of combinations of the above, but it's kind of, yeah, there's, is this behavior driven by a desire to lose weight, broadly speaking, is it driven by kind of these intrusive thoughts and compulsions or is it food tastes weird and has odd textures and, and that's kind of how we would differentiate broadly speaking. And that would fall in the autistic category too, with the sensory.

Yeah, big overlap with people with ASD and ARFID. Yeah. And food then too. Yeah. Yeah.

7. Medication

You've spoken about the use of medication in children with OCD, can you talk a bit more about that? We used medication for our child, and it made a huge difference. It definitely wasn't the first step in the process, but it allowed my child to, I guess, get their brain space to do the therapy work. But if you can just talk a bit more about that, it would be wonderful. And I think medications are one of the things people always have to talk about, because no parent wants to have to give their children medications, but they work really well in OCD. Again, we'd normally try and encourage our best effort at doing something like exposure and response prevention first, because psychiatrists are also not thrilled about throwing medications at young people if we can avoid it.

So making sure that, at least for the mild to moderate cases, that we've done as much as we can in terms of the therapy space. But then, as you say, some young people are just so stuck that they need something to kind of get their foot in the door so that they can do that therapy work. And that's the role where medications can play a big part to play, is they can make that therapy side of things a lot easier for young people to engage in. The medications that we normally use as a first line are SSRIs, something like sertraline or fluoxetine are probably one of the two most common ones for young people.

And they do help massively with the OCD symptoms, but they can take time to work. So often it might be that, if things are really severe, we might look at starting the medication and then try and get them in with a therapist as quickly as we can so that by the time we've found a therapist for your young person, the medication's hopefully doing its job and can... make that a little bit easier. Obviously on the milder end of things, it's normally when that therapy's not been successful that we might think about trying medication to help increase the likelihood that therapy is going to be successful.

Yeah, we were doing some therapy and then we did a pause [unclear] animation process happened and they started to work. And in that time, my child was able to return to school and do those things. And then we went back to therapy. It was... Then beneficial. Yeah. Yeah, because we would do the home way after we got sent something like this. So we noticed a huge difference. Yeah. And a lot of parents do. Yeah. Yeah. And how long would children stay on medication for? Or... Depends. And, I mean, really, the medication, I like to see it kind of a little bit like a cast on a broken leg in that meditation's there, just to hold things together while we do all the healing ourselves.

And so the therapy is kind of what's helping the bones and everything like that. And that's really the important thing. But the cast is there holding things together. So my normal suggestion for young people and probably every psychiatrist is a little bit different than this, is that we use the medications, if we use the medications, we use it to get you well. And we use it to enable the therapy. And then we want to give you a period of wellness so that your brain can get used to those skills and implementing those skills. And we don't kind of knock things over straight away by taking a risk.

But obviously we don't want you on these medications long term if we can avoid it. So I would normally say after about six to 12 months of wellness is when I'd normally, with my young people, would look to carefully come down on the medication and see, are they still doing what we need them to? Do we still need that cast? Or, can we live without the medication now that that therapy's been in place and now that, that support is there. Sometimes we take medications away and the OCD comes back with a vengeance and it might be that we have to carry on for a bit longer and then look to try again. But a lot of the time it is just that cast.

We cut that cast off after six to 12 months and it's not that big of a deal anymore. So yeah, they then have the skills to manage anything that comes up. Yes. With the medication, if you have some of the co-occurring conditions like ADHD and [unclear], or some of the more that we've talked about, do you know how that can affect medication? Yeah, definitely. ADHD, I find, can go one of two ways. So generally, if someone's got ADHD, the most common medication we use is stimulant medication. And I would say, it's hard to know the exact numbers of kids I see, but a decent proportion of them, actually, when we start the stimulant medication, the OCD does get substantially worse.

And so it's a really difficult balance between optimising ADHD, so that they can do well at school and they can engage in the treatment, and not making the OCD significantly worse. And that's a, yeah, it's never easy to solve. Sometimes we get lucky, and some people, they go the other way, is that we start stimulant medication, and the OCD kind of patterns get better with the stimulant medication. And that's obviously a lot for someone to manage, because it's, you know, kind of the two conditions are not fighting each other. Yeah. Yeah. Autism can be a common trend as well. We see something called paradoxical reactions in autism sometimes, where the way the medications are supposed to work don't necessarily always work the same way in people with autism.

And a lot of it is from how we study our medications, and that these big drug companies, when they're introducing new medications, doing these big studies on medications, kind of the typical patient is this kind of neurotypical European man in his mid-forties. And so for a young, neurodiverse, particularly autistic person, there's not a huge number of studies on them with these medications. And so clinically, often we see that if we start a medication in someone with something like autism, sometimes the response isn't what anyone expected. Yeah. It doesn't mean that we should do anything different for those people when we're deciding whether or not to start

medication, but it does mean that it's really important that if a doctor has told you, hey, this is what the medication should do, and it's not, tell the doctor.

And advocate for your young person so that, because the whole idea of medications is to make their life easier, and if the medication seems to have made everything worse, it's important that the doctor hears that so that we can figure out, figure out how we can help the young person. Can you talk about the side effects with medications, I mean I know there's a lot. Yeah. Or could be, but there's also some that are more common. I'll limit this to just talking about SSRIs because that's the kind of first-line treatment, and I'm going to carry out this with saying, always ask your doctor because it's really important because things might change.

It's really scary when you look up or search a medication, because the list of theoretical side effects is horrifically long. And then there's also this kind of selection bias that if you Google SSRIs, people that had a great experience tend to go and post on forums and stuff like that saying I had a great experience. It's normally people that have had a horrible experience that post on forums. So be cautious, obviously be informed, but be cautious about what you read. But there are definitely side effects that are worth kind of being aware of. The reasons that I tend to kind of warn people about are the more common and then obviously more severe stuff, if I went through the whole list of things, we would spend hours and hours.

But the kind of common stuff is gut upset, anything that affects your brain, is going to upset your gut at least a little bit, because there's huge numbers of nerves in your gut just as well as if they're in your brain. So young people often find that they might be a little bit constipated, they might have a bit of diarrhea or nausea, or just kind of bloating. In the first few weeks of starting an SSRI, I find that tends to settle down once their bodies kind of get used to that medication. But it can flare up again if we needed to try other doses, if we needed to increase it or swap them for different SSRIs or other medications.

The other side effect that I see a few of it, is kind of we're seeing the agitation or anxiety in the first few weeks. Again, as your body's kind of getting used to this medication, it can sometimes make people feel a little bit on edge. Most of the time that settles down as well. But it might be that same thing as the gut upset and that it kind of flares up again if we increase the dose. The thing we worry about with that kind of sense of agitation is that in a really small number of young people, I think it's about 1 in 115, that can lead to worse things than suicidal thoughts. So any young person, when we start them on an antidepressant, it's really important that we're aware of where those thoughts are to begin with.

And then as parents kind of having an open conversation, having an open dialogue with your young person about are these thoughts that have creeped in since we started the medication. It doesn't necessarily mean we have to stop the medication. In fact, most of the time we persevere because the thoughts do tend to get better. But if your young person is getting those thoughts and they do seem to be worsening with the medication, it's really important that you know as a parent, and it's important that their medical team knows as well so that we can make sure we've got a really good plan in place to support that young person in their life.

Other side effects that we see a fair bit sometimes people get a bit of a dry mouth, some people get a bit of a headache, and then sometimes people get sort of sexual problems and sexual dysfunction. Obviously that can be a bit of an awkward conversation with your young person, and almost any care service in the country will offer young people a chance to talk to their psychiatrist without parents in the room. So if they are getting some of those problems, that can be a good opportunity for them to talk to their doctor without the awkwardness of talking about it with mum and dad. Yep. The other thing that's really important to kind of be conscious of with SSRI and with side effects, is that if, the best way to kind of minimize them is to take them regularly.

Which is hard for young people because young people have busy lives and remembering to take a pill a day can be really tough. Yeah. And so the problem is if you're starting the medication and then you miss a couple of days and then you remember to take it and miss a couple of days, you're going up and down, up and down in your system. And that can mean you get all these kind of side effects from starting it and side effects from coming off it, and it's just this horrible cycle. So I really encourage the best way we can manage side effects is, one is obviously talking to your doctor, but two, supporting young people to take it every day.

Whether that be mum and dad help with reminding them, whether it be simple things like setting an alarm on your phone or having the medication sitting next to the toothbrush in the morning to tie it into something that you do, so that young people are more likely to take the medication, then they are less likely to get all these side effects from going up and down and hopefully have an easier time with the medication. Yeah.

8. Supporting your child

I've always found it quite difficult to explain OCD to other family members or friends. How would you explain that to someone that's not living it? I like to take things, I think of things from a reasonably evolutionary lens, and I find that's often easier for people to kind of understand. So I tend to explain to kind of lay people that I see it as a, probably what used to be a helpful thing for us to a degree. That's become somewhat unhelpful over time and in this person, and that back when we were all cavemen, checking behaviours were

really helpful. Because, you know, checking that your food wasn't covered in mold, or checking that, you know, you're kind of prepared for everything you need and you weren't going to run out of water when you were chasing antelope or anything like that was probably really helpful.

The difference with OCD tends to be we've got that good check, but the off switch isn't so good. And that a lot of people with OCD, that checking behaviour is still useful for us. You know, as someone without OCD, it's important you checked you lock the car or you locked the front door once. But most of people without OCD, their brains go, OK, I've checked that, I remember I've checked that, I don't need to check it again. And that's where that kind of off switch can get a little bit broken in OCD, in that they check it, but then they need to check it again and again and again and again. I think that's a useful starting point for kind of explaining to other people about the OCD.

And I think it's really important that we have a tap for young people and that this is not a young person that's attention seeking or it's not a young person that's just a naughty child. It's a young person that's going through lots of stress and that this is their way of... Managing that stress. Yeah. When treatment feels too hard for a child, what is available or what can be done to help them? Like if you've got a child that is not wanting to attend, to see a therapist or psychiatrist or... Yeah. It's hard. It depends on the age of the child as well because obviously a resistant eight-year-old's...

A very different to a resistant 17-year-old. I guess the first thing as a parent I would do if your child's able to kind of reflect is kind of talk to them about the distress that things are causing them and the family and kind of have a really open conversation with them and try and work out why. Why they don't want to do that. Because sometimes there's really valid reasons why. They might hate their therapist because they... They hate working with men and they've had really horrible experiences with men and they've got a grumpy male therapist and that's a relatively easy thing to solve. But sometimes there might not be a good why.

And so that kind of reflecting and supporting young people to understand the benefits of it is really important. Sometimes we don't get there and sometimes it's time and that the young person has to go realise that parents and family aren't... going to enable or kind of feed the OCD and it might be that things get worse for a little bit before they recognise, hey, I do need help. You know, we all have different levels of challenges in our life before we kind of realise, hey, I need help. And young people have that too. I would say that if you've got the foot in the door with a therapist, or with kind of the public system or anyone, ask them as well and say, look, I'm really worried about my young person, but I can't get my young person to come to therapy and they're not telling me why, or these are the reasons why.

And try and come up with a plan with them to kind of problem solve them. Okay. Should family talk to the child's school about them going through the OCD process, or what's going on for them? Yeah. I mean, that's a complicated thing for families because obviously it feels really private and personal kind of mental health challenges. My normal suggestion is yes, kind of with a caveat, and that if your kid's got a sensible, good teacher, then actually having them involved can be really valuable because there may be a whole bunch of obsessive and compulsive behaviors that are happening six or seven hours a day, that you don't know about.

And so, having the teacher being aware of it, obviously teachers are never going to be experts on exposure and response prevention, but at least being aware of it and aware of the strategies that you guys are implementing can be really helpful so that they can see are things getting better in the environment as well. But then, clearly this is a lot of sensitive information for a young person. And so, depending on their age, involving them in that conversation is obviously really important. And that, if you've got a 17-year-old and you just go and tell their teacher, this person's got OCD, they might feel really betrayed.

And so, kind of seeing are they comfortable with bringing in all of that support as much as possible. Yeah. For me, I did speak to school for my child, but it was not because of having the traits at school. It was just more the sheer exhaustion and sort of, because they weren't sleeping or, so that the teachers understood that there was other stuff going on. Yeah. And, you know, particularly when schools have metrics to sort around attendance and stuff like that, which obviously puts a lot of extra stress on the young person. Actually, them understanding the whole picture can, not always, but in an ideal world, mean that they might take a little bit of that pressure off in terms of, right, let's take a collaborative, supportive approach rather than, this is a young person that's just missed five days of school this month because they, bunking off because they don't want to be there.

It's obviously a very different approach to this is a young person that's really struggling and going through some really tough treatment and some tough time.