

Autism and ADHD with Clare and Matilda Kemp

Speaker Key:

CB Chantal Boyle

CK Clare Kemp

MK Matilda Kemp

VO

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

00:00:20

CB

Welcome to the Sunflower Conversations. I'm Chantal, and today I am joined by Clare and her daughter Matilda. Matilda is going to talk to us about her experiences at school. Matilda is nine, and she has ADHD, and she is autistic. Welcome, Clare, and welcome, Matilda, how are you both?

CK

Thank you. Thanks for having us on.

MK

Hello.

CB

We met each other at Strictly Come Dancing Live Tour. Matilda was with her mum, and in an amazing shiny outfit. She'd got a shiny top to match her shiny trousers, and she really looked like she was, maybe, going to get up on the stage and do some dancing, herself. And so, yes, that's where we first met.

00:01:08

Matilda spoke so eloquently. We did a little mini interview. I invited you both to join us on the Sunflower Conversations, to just have a little bit of a deeper conversation. Did you enjoy the Strictly Come Dancing Live Tour, Matilda?

MK

Yes, it was really good, especially Ellie.

CB

Who was it, sorry, Ellie?

MK

Yes, Ellie was the best.

CB

Ellie is the winner, the overall winner, from the show, is that correct?

CK

She didn't win on the night, did she, we were a bit... Because they vote on the night, she didn't...

CB

Who won?

CK

It was Layton, wasn't it?

MK

Yes.

CK

Which is fine. Which is fine. We like Layton.

CB

It was a stunning show.

CK

It was, I think.

CB

What I really enjoyed about that, was that they had a BSL interpreter on the massive screens the whole way through.

00:02:00

CK

You know the sign-language lady?

MK Oh.

CK

Yes, it was really inclusive. It was lovely.

CB

Yes, and apparently, it was audio-descriptive, as well, for the actual show, the TV series, for people who were watching it at home, throughout the series. It was audio-descriptive, and it wasn't last year, so it's great that they're making steps for inclusivity.

CK

Yes, really good.

CB

Matilda, can we start off? What do you enjoy about school?

MK

I like art, play and lunch, and I don't mind maths.

CB Are you quite creative? Do you like drawing?

MK

Yes, I like drawing and painting.

CK You like PE, too, don't you?

MK Yes.

00:02:46

CB

What are favourite activity in PE? You're nine, so you're in primary school, aren't you?

MK

Yes.

CK

Yes, Year 5, aren't you.

MK

I like do football. I like football.

CB

What kind of position do you play, are you up front, or are you in the goal, or defence?

MK

We didn't really do that. We just did matches.

CB

What activities do you like doing when you're not at school?

MK

I like acro-gymnastics. I like girls' football. I like going on my swing.

CK

Yes, you can't see, but next to us, we've got a doorframe with a pullup bar and a swing attached, so Matilda spends a lot of time on her swing. That was your Christmas present, wasn't it?

MK

Yes.

CB

I didn't know you could indoor swings. I've seen the baby ones that bounce about in.

CK

Yes, it's brilliant, actually. It's your favourite thing, isn't it?

00:03:43

MK

Yes.

CB

Does that help you regulate, being on the swing?

MK

Yes.

CB

What a great idea.

CK

Yes, we've got a little mini trampoline, as well, haven't we?

MK

Yes.

CB

You like to be on the move.

CK

Always.

MK

Yes.

CB

What things at school do you find tricky?

MK

Sometimes friendships, and writing a lot, or theme, or RE.

CK

What about when things change? When things are different at school?

MK

Oh, and if there's really big crowds, and stuff.

00:04:24

CK

You don't like the playground, sometimes, so you?

MK

No. Sort of.

CK

What about if your teacher wasn't in, would that be all right, or would you find that tricky?

MK

I have to know when he leaves, if in the morning, and then there's another teacher, and I'm going what, you didn't tell me?

CB

Okay, so the teacher is aware of your needs in that sense, so he tries to make sure that you know what's going to be happening for the day, so that you've got that calming influence.

CK

Yes. You've got a visual timetable, haven't you?

MK

Yes.

CB

That's good. It's nice to know that you're supported by him. You mentioned friendships, what is it that you find difficult about those?

MK

Sometimes there's arguments. Sometimes I want to do something, and they might not want to, and then it'll get into a squabble because oh, I want to do this, you want to do that, and then we don't know what to do.

CK

I think you misunderstand things, sometimes, too, don't you?

MK

Yes.

CB

That must be very difficult when you're not sure what the problem is, or why your friends might have an issue about something, and your completely not aware of it. How do you resolve those problems, or do you come home to mum, and say they're not speaking to me, and I don't know why?

00:05:51

MK

Well, usually, I would either tell my teacher, or sometimes I'd leave it, and then in the morning, we're fine again. It's usually in the morning, we might have an argument, but then we'll sort it out by ourselves. But sometimes, we'd have to get our teacher involved.

CB

Do your friends know that you're autistic, and that you have ADHD?

MK

Not all of my friends, but some of them.

CB

Does it help the friends that do know? Do you think it helps them to be a bit more gentle with their approach to you?

MK

Yes. I saw one of my friends yesterday. Because she knows that I have disabilities, she gets me more, and if I get upset about something, she'd cheer me up, and then she'd get why, and she'd understand.

CB

She sounds like a keeper. It's the friends you want to keep.

CK

Yes, she's really, really good. She's got a brother, hasn't she, with hidden disabilities, as well, so that helps, definitely.

CB

Friendships are very difficult anyway. A bit complex, a bit of a minefield.

00:07:11

CK

I think when you're a girl, and things have ramped up a bit in Year 5, haven't they, things...

MK

School drama.

CK

School drama. Yes, we've definitely noticed a difference.

CB

I have a friend, and her daughter, you remind me a lot of her, actually, exactly the same things. When she was your age, she would say oh, it's just drama all the time. It's a lot of drama. She tries to stay out of it as much as she can, but it's quite draining.

CK

Yes, and I think when you don't really know what it's all about, that's really tricky. Sometimes it takes a while to work it out, doesn't it, so we do lots of talking at home, and lots of trying to work it out, but it's not always clear.

MK

Yes.

CB

When did it become apparent that Matilda neurodivergent, Clare?

CK

I think when Matilda was in Year 3, we noticed. In Year 1 was lockdown, our first lockdown, and I'm actually a primary school teacher...

MK

Used to be.

CK

I used to be. I thought that homeschool would be a breeze. It would be like Blue Peter. It really wasn't. It was really difficult to get Matilda to do any of the tasks. But also, it's Year 1, so everything was quite active, and play-based, we tried to make it fun.

00:08:43

Year 2, it ramped up a little bit, but again, we had another lockdown period. And then in Year 3, you really started to say that you didn't like school, didn't you? She wouldn't want to go to school, but then she'd be all right when she was there.

MK

I loved the teacher, though.

CK

Yes, you've always liked your teacher. But then, when she came home, it was very explosive, and meltdowns, and we couldn't really understand why. We went on holiday, actually, we went to a holiday in Egypt, and Matilda really struggled with sleep, going to sleep in a different bed. At that time, you found it quite hard to manage when you were angry, didn't you?

Yes, just really started saying she hated school. We found it really difficult. Now I think back, when we reflected, it was Year 3 becomes a bit more serious, they have to sit down more, it's more formal.

CB

That's right. Because up until that point, they spend a lot of time sitting on the carpet, and that's very grounding, isn't it, if you're neurodivergent.

CK

And lots of free-play, so in the afternoon, it's quite active. But also, because there'd been lockdown, I think Year 2 for Matilda, they had to...

MK

I missed some of the learning, and other stuff. It was straight after Year 2, and I'm like, oh, okay, we're doing...

00:10:06

CK

[Overtalking].

MK

Yes.

CK

But also, that Year 2 wasn't as formal as it may have been without lockdown because there was that massive amount of time where there was a lag. We really felt in Year 3. Year 3 was when we really noticed it. I remember emailing the SENCO, and saying we really need some help, can we have a meeting because it was becoming very explosive at home.

CB

What I wanted to just say, to interject there, is for parents who are going through similar experience, is it difficult unless you've got a knowledge of neurodivergence, to separate is this child just being difficult, and naughty, as

opposed to there's something here that they're actually struggling with, and that's why?

CK

I often think about that because, obviously, I've got a background in education, and actually, my husband recognises that he's neurodivergent.

MK

He is, definitely.

CK

He is, definitely. But I guess as the years have gone on, we're two, two-and-a-half years in, I've got a lot more of an understanding. But initially, we did, we thought Matilda was just being naughty, and we were questioning ourselves.

00:11:31

The first thing you're told is go on a parenting course, have you tried this parenting course, so you look into yourself and think what am I doing wrong. Then I was like, no, just something niggled, and you have to follow your gut, I think.

And then I started to look up about ADHD because, obviously, I realised that Matilda was very active, and she needed to move constantly, in quite unique... Like climbing. Without being stereotypical, she wasn't your typical girlie-girl. I said I think she might have ADHD, and the school were like, what? They thought I was absolutely mad. And then I started to keep a diary.

MK

What school?

CK

Your school. When I came back and had a meeting, and showed them the diary, luckily, our SENCo is very knowledgeable, she was like, oh okay, yes, maybe. But it wasn't until Matilda was assessed that they actually came back to us and said she's definitely got ADHD, but actually, she's autistic. I had no idea. But the profile for a girl that's autistic, compared to a boy that autistic is completely different. Matilda is a spectacularly good masker. She's really good at masking.

CB

That's the issue, isn't it, for girls, is the masking.

CK

Yes. It's a massive issue, and we're trying really hard to work on her being authentic, and saying I find this really difficult. I think you're better this year with your new teacher, aren't you?

00:13:13

MK

Yes.

CK

He really gets you. And he's spotting stuff that we see, and that's really helpful.

CB

Because it means he's in tune with her, and you want that, don't you.

CK

I think he's understood. The year before, that wasn't the case at all, so therefore, Matilda's anxiety was really high, and she just didn't like school at all. Therefore, the impact outside of school was much, much harder, which isn't her fault because she was like... You were having to keep it all inside, weren't you, all day. But now she gets more movement breaks, would you say?

MK

Yes. I used to feel like I just couldn't ask for one because I was too nervous if they were going to say no.

CK

Matilda's got a massive fear around getting in trouble.

CB

That makes sense, nobody wants to stand out for the wrong reasons, do they, at school, you want to fit in. Of course, nobody, generally, wants to get into trouble, so that completely makes sense.

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What types of support, you just mentioned movement breaks, has the school put in for Matilda?

00:14:40

CK

What would you say is different this year? What do you get that's different?

MK

I get a wobble cushion. Mine broke. I had this thing you can move your feet on your chair.

CK

A band.

MK

I got ear defenders.

CB Pardon, what was that, ear defenders?

MK

Yes. I got fidgets from the school.

CB

That's great, and they provided that for you.

CK

And actually, you can see our cat in the picture. They also have animals at the school, and Matilda really has a real affinity with animals. They're really calming, and you love animals, don't you? They, part of her movement breaks, incorporate that.

MK

I'm allowed to see the ducks and chickens, and stuff like that.

CK

And also, just things like assembly times are quite difficult for you.

MK

Yes, you used to just have to sit on the floor, but I'd have to move. Now I get to sit on a chair behind everyone.

00:15:40

CK

But also, if it's like an assembly which Matilda's struggling with, or sensory stuff, maybe it's too loud, or it's too busy, or she feels hemmed in, you're allowed to ask...

MK

Yes, I am allowed to ask because there's always, at least, two, or one, assistant. An assistant in the assembly, so they can take people out.

CB

That's really good. Because I'm just thinking back to when I was at school, or even when my children, who are older than you... Not the younger ones so much because there was a few children in his class who are autistic, and the school did seem to support them within the classroom environment. They had ear defenders on, and things like that. But the older one, it was very much you had to sit still. When I was at school, you had to sit still, and stop fidgeting, and stop moving. That's just torture, isn't it?

CK

Actually, that's really interesting you say the word torture, because not this Christmas but the Christmas before, for the first time, the school saw Matilda have an autistic meltdown. Do you remember, it was during the Christmas show, and everybody was there, there was parents there, teachers there. In a way, it was a positive thing, in the end, because it meant that they saw what she'd gone through.

There were two performances in the same day, one in the daytime, and one in the evening, and the difference... I could only go to the evening one, and my friends were saying but she loved the daytime one, but she was grey in the evening. Everybody else was singing and dancing, she was stood at the back frozen still, which is like a fight or flight [overtalking].

00:17:21

CB

Yes.

CK

She had to come off the stage. She was so distressed. It was late in the evening for her. We actually got some support from a charity called Mencap, and they came and said what adjustments were made there, we talked it through with the SENCo, who was brilliant, and took it all on board.

Children didn't know that they could leave to have a movement break, or that they could go to the toilet. But Matilda said there was bright lights, big crowd. She was stuck in, she couldn't move, and she described it as a physical pain, and she couldn't take it anymore.

Whereas this year, it was much different. She was involved in the whole process. She was able to say how she felt. She sat on a bench on the end. She actually did

a duet with somebody. The whole experience was completely different because adjustments had been made, which was amazing.

CB

It's so simple to do, isn't it?

CK

Yes, and that's the thing. I've got a little WhatsApp group with other special needs parents that I've met along the way, because I always say the people that really get it are people in the same kind of boat as you. I said to them what would you like me to share? What would you like people to know?

00:18:46

The fact is that adjustments that you make for neurodivergent children actually benefit all children. That's the key. If we learn in a multisensory way, and if all children are given movement breaks, and if all children are allowed to move their body while they're learning, if they're all allowed to lead their learning, all those kinds of things actually benefit everybody, and make the children happier. It's a quick fix, really.

CB

Yes, you've got to come out of this really old-fashioned way of education. I just don't understand it. It gets even worse, particularly for boys, who really have to move. Getting into trouble for just gazing out of the window. For doodling. Getting into trouble for doodling.

CK

I work for a charity, so I'm still in the education system, but a bit more in an indirect way, and I go into secondary schools, I work with bereaved children, and often they're neurodivergent, too. And actually, my boss doodles the whole time when we're having a meeting, but she's focused, she's involved, it's just an expression, it's a way of her keeping on task.

When you think that the education was set up in Victorian times to control the masses, but we're teaching children to question everything, and lead their own thought, then telling them you've got to sit still, you've got to give me eye focus, you've got to not move, it doesn't make any sense.

I reflected on being a teacher, myself, and think I would go back and do things completely differently. I hope that we see a change in the system, really.

00:20:35

CB

I was going to ask, do you think that there is room for improvement?

CK

Massively. Massively, don't we, we talk about it all the time. And I think that, actually, in a primary school setting, generally, although it's hard for neurodivergent children, they fare better because the schools are smaller, generally, the teachers know them well, they don't have to move from person to person. But as soon as you get to secondary school, that's when the wheels fall off, often. And obviously, Matilda's in Year 5, and we have to look at schools, and that's one of our biggest concerns is secondary school.

CB

What elements of it, particularly, are you concerned about?

CK

What are you worried about with secondary school? We're just worried about the size, I think, of the school, that there's 15-hundred children in a secondary school, and that's overwhelming. Moving from one place to another, that's where Matilda finds it hard to organise herself and navigate those things.

And when there's hustle and bustle, and sensory triggers, that's quite hard. I worry about the formality of it, and the fact that in a day she might have seven different teachers who might not understand all of her needs. That's not just to say Matilda, that's any child, really.

CB

Yes, a friend of mine, her son has got ADHD, I think it's ADHD, and he's only just been diagnosed, and he's at secondary school, and he, very often, is getting up and leaving classrooms.

00:22:24

We're a bit ahead of the game, that's what people tell us, because we've got an early diagnosis, which we've had to fight for, and pay for privately. We had to do that privately, in the end. I'm in a world where I have got lots of people, now, I know who are in that position, and the wait times are horrendous. We're talking two years, maybe.

CB

That's a significant amount of time in a young person's life.

CK

It really is. Yes. I get angry quite a lot because I see the impact of that, and we experience it, and we're actually ahead. I always say to people we're protecting

Matilda's future mental health, that's what we're doing. Because when we got her diagnosis letter it said Matilda's at a massive risk of burnout, of all these scary things. and of course, we want that to not happen. I probably should take myself off of some of the forums I'm on, but I hear about it a lot, and actually, we could do so much better.

CB

It's all unnecessary, in a sense, isn't it. As you said, it should be taught as part of teachers' training, I don't know whether it is or not.

CK

The other thing that all of us parents said is that you might get a day... I don't remember in my teacher training any training on neurodivergence, but that was some years ago. But actually, there should be part of the general training is... Because actually, we know that there's more children being identified now, and some people say oh, autism wasn't there, I'm like, yes, it was there, and ADHD was there, but we reacted differently.

00:24:19

We know now, and so, we should understand, and we should know. And girls and boys present differently, there's such a range of different kind of symptoms and behaviours that go with it.

No teacher goes into education with bad intentions, everybody wants to be doing the right thing, and working with children and making their lives better, but they need the training to do that, and there needs to be more awareness. Matilda's had teaching assistants say things like well, everybody wants to sit at the back.

CB

Oh, gosh, it's so insensitive.

CK

Or you don't need to go to a special school, you can go to a normal school. What did you say to that?

CB

Oh, gosh, Matilda? What did you say, do you remember?

MK

No.

CK

You said to me well, what's normal, mummy?

CB

You should have asked the teacher what do you mean by that? You should not be put in that position in the first place, it's incredibly insensitive.

00:25:24

CK

We've got more awareness, haven't we, we know now that, actually, neurodivergence is just a neurotype, and we've got lots of different neurotypes, and that's what makes the world a brilliant place.

CB

What do you think about the Hidden Disability Sunflower, Matilda, because I know you were wearing it at The O2 when we met the other weekend?

MK

It's really helpful because if you're in a queue and it's hours long, or you can't get in somewhere, and there's a big crowd, you can ask someone, and you don't have to be shy to do it, and they can, maybe, say some suggestions like you can go to the front, or you can go to the middle. They can tell you how long it'll be, or they can say we can put you near the front, so then you're still in the queue, but you don't have to go all the way in. That's happened at the park, Alton Towers.

CK

Do you know what, it happens. I was trying to think of places where we've worn it, and where it's helped us, and one of the places was at the Tower of London, where one of their beefeaters was just like, oh, of course, come straight through. They were amazing.

MK

And Legoland.

CK

Legoland. Alton Towers, we went to recently, and they were just incredible. Matilda finds queues really difficult, and they're were brilliant, weren't they?

MK

And The O2.

00:26:51

CK

And at the O2, yes, we were able to use the disabled toilets. And also, when we've been on holiday, we book the assistance check-in.

MK

Oh, restaurants.

CK

And restaurants. Oh, yes, we often might say... Where we're queueing, for, I don't know, I think it was Wagamama's, wasn't it, and Matilda couldn't sit on a table where you're sharing with other people [overtalking].

CB

Yes.

CK

They managed to get us a booth. It's just a little sign, a little way in.

CB

It really sounds like people have been very kind to you whilst you've been wearing it.

CK

They have, yes.

CB

And that's what it is, it's just an ask for kindness. Right, you go and jump on your swing, we'll take the laptop upstairs. Thanks, Matilda.

MK

Thank you.

CK

You want to say goodbye?

MK

Bye.

00:27:38

CB

Enjoy the climbing later.

CK

Let's hope that we don't get any broken bones.

CB

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CK

Yes, I think you wanted to know about the process, didn't you, the diagnosis process.

CB

Yes. Do tell me.

CK

I actually think we were quite fortunate. Once we had this holiday, and I didn't perhaps say, it was very challenging at home. Matilda was like a volcano. It's not really who she is, either. It was clear that she was telling us that something wrong.

And so, we spoke to the SENCo, but the difficulty we had was they weren't seeing it at school, which is very typical with girls who are neurodivergent, and she said, well, you can apply for an EHCP, which is an Education Healthcare Plan, but we don't have a lot of evidence. We will support you in it, but we don't have the evidence, really, that we need to go for it.

At the same time, then we knew that we wanted to explore a diagnosis and see what the issues were. We went through that, we saw the doctor, did the NHS process, and then we also went through the private route, as well.

At that time, it would have been about November time, and we finally got seen in the May the following year.

00:29:35

CB

That's a long time.

CK

But that's a lot better than it is now. I know that, through my work and also just through meeting other neurodivergent families, the wait time now is about two years, on the NHS. Maybe even longer.

CB

And there's no support, is there, throughout that whole time.

CK

No. I think I mentioned, I've got a WhatsApp group of local parents, and sometimes they say, oh, I've got another friend who's really struggling. The reality is, you collapse as a family because bedtimes are so hard, because what goes with neurodivergence is often sleep difficulties. We just never get any time. Children can be aggressive, and violent, and lash out, and say things like they don't want to be here anymore. It's really scary, and you assume you're doing something wrong.

Yes, it's really hard, but we were very fortunate to be seen fairly quickly, now I realise. We went, and we were there for hours, and filled in lots of forms, and Matilda had to lots of activities, and conversations, and that's when they said, actually, Matilda's autistic. It blew my brain. I was like, what?

CB

You were not expecting that, at all.

00:31:01

CK

No, I thought they would say she had ADHD, but actually, she had both. That's quite a conflicting diagnosis because you've got the ADHD part of the brain is right, let's go, let's move, and it's constantly I want to do this, I'm spontaneous, I've got no impulse control. And then autistic side of the brain is much more like I need routine, I need structure, I can only sleep here, I don't want change. It's constantly battling.

And so, then, we had the diagnosis in the May, and then we saw the NHS paediatrician in the August, and they confirmed, basically, everything that the private person said.

But in order to get her support at school, that process has been much, much harder. We got the diagnosis in the May of Year 3, and the main reason we pushed for a diagnosis was because we wanted to have support in place so that we would then be able to choose where she went for secondary school, and also make sure that she had provision at school. We are midway through Year 5, and we still haven't got that finalised.

CB

Oh, my goodness. The things that the school have done has, really, just been down to the class teacher being open [overtalking].

CK

And the SENCo, they're not getting the funding for that. They're doing that because they're lovely and because they can see that Matilda is struggling. And also, because, as a parent, you have to be, I always say this, a thorn in someone's side, which is not who I want to be, at all.

00:32:35

But the people that seem to get their biggest change and impact are the people that are persistent and just constantly call, and nag, and say I'll take the cancellation, I'll do this, I'll do that. But it's a real mental load. It's really exhausting.

CB

That's what I was going to say. The scenarios that you've described, particularly with the child really finding evening times difficult, I guess they've had the long day, they've masked all day, the evening is when it's all going to come out. That seemingly negative behaviour is quite crushing for the parent.

But also, it's isolating because it's one of those things that they probably don't want to share with their friends, whose children are going to bed at a certain time and being judged.

CK

All the time. Yes, and you compare, and when you see you see... Social media is a killer, isn't it, you see all these perfect things happening, and you think, oh, my gosh, I have to wrestle my child to do anything.

And of course, you love your child. I love her so much, we all do, and it's not through any fault of her own, it's because she's trying to fit into a system that isn't designed for her, and for many other children.

They always say do a parenting course. I can't tell you how many parenting courses I've done. I've done the ADHD one. I've done the autism one. I've done the managing violent behaviour one, so now I'm a ninja.

00:34:19

CB

Are these offered through the local authority?

CK

Yes, they are. I actually like them because you meet other people in the same boat as you, and I always go, let's set up a WhatsApp group. The one that I did for

autistic children, there were mums there who were getting three hours sleep. How do you function? How do you function on that?

We're really fortunate, we met the paediatrician in the August, and I said sleep is a massive issue for Matilda, she can't turn her brain off. We would have to stay with her until half-nine sometimes, at night. This was when she was in Year 3, into Year 4, so seven, eight.

CB

it's late.

CK

Yes, it's really late. It means you have no evening. My husband and I would just never see each other. We pushed for melatonin, and we got the prescription.

CB

Melatonin is a sleep aid, isn't it?

CK

Yes, well, it's a naturally occurring hormone that we all produce, but when you have ADHD, and often autism, you don't produce enough of it. And also, with ADHD, you've got a dopamine rush, just everything is a bit imbalanced. She would say I'm so tired, but I can't turn my... That's also when she would be like, mummy, [inaudible] hold it inside. And all the worries of her day that she's kept inside.

We've got melatonin, but I know other families that are, like I say, three hours sleep, and they can't get a prescription because it has to be a paediatrician that prescribes it.

00:36:01

CB

And it's difficult to get [overtalking].

CK

Whereas you go to other countries, and you can buy it over the counter.

CB

What would you say... If you could get in front of the Minister for Education, what would be the top three things, this is what you need to do now?

CK

I think it's adjustments. I think, first of all, we've got change the education system entirely. I think there needs to be more flexibility, more understanding that not all children are able to sit and copy from a board and do that for eight hours a day.

I think there are a lot of children that need forest school, they need to be outside, they need to be learning in a way that ticks all their sensory needs, all their kinesthetic needs. We just need to look at it. All the Scandinavian countries are sending their kids at a later age, and they're all fine.

When does anyone ever ask you what your SATS levels were, or really, what your GCSE levels were. I just think we focus too much on academics and not enough on... We say that we worry about mental health, but then we make these children have to do things that don't fit with that. We need to look at the education system.

00:37:15

Homework, I question whether there's a need for homework because, actually, they've been at school all day. We don't really do much homework, to be honest, which the primary school teacher in me really struggles with, but that's my conditioning. But that's the last thing she wants to do. She wants to be outside on a swing, just decompressing, and regulating herself.

But also, I think we need to look at how we celebrate success. Is it all about achievement and how many medals, and stickers, and things we've got? Or is it what you've done that's been kind today. Sometimes I have a problem, and I think quite logically, and both my husband and Matilda will come at it from a different way, and they come up with a really amazing answer, and I think yes, there's not just one answer to things.

But I think, also, we need to train our teachers to be more aware of what neurodivergence looks like, and what adjustments we can make to make everybody happier. Because like I said before, the adjustments you're making for a neurodivergent child are actually going to benefit all children, really. Movement, short chunks of information, not having to copy from the board, processing time, different ways of looking at things.

CB

I think that those are excellent. And absolutely, I agree with every single thing you've said there. One of the things that is very enlightening is this way that we judge, and how we hold people in esteem because of what they've achieved in their grades. Well, actually, everybody is different, and we all bring something different to the table, don't we?

00:39:13

CK

Absolutely.

CB

It really shouldn't be judged solely on an exam grade.

CK

I have to say I'm a bit worried about Year 6 because Year 6 is when they do past papers. I used to teach Year 6, and I would always try to make it fun, but I imagine Matilda sitting through hours of test-based stuff. Tests make her anxious anyway. The government introduced a Year 4 times-table test, where I think it was six seconds thinking time, and then they had to come up with an answer for times tables.

Now, in Matilda's assessment, she needs 20 to 30 seconds processing time, so I can say to Matilda, Matilda, have you done your teeth, and she won't hear it. It's not that she's being rude. And I used to go Matilda, have you done your teeth, sometimes, I'll be honest, but I have to say, Matilda, have you done your teeth, I have to come in front of her, make sure that she's focusing on what I'm saying.

And so, that kind of test condition is just you're never going to get the best out of her, but does she know what times means, if she's given equipment or she's given the time to write things down, and work it out, yes, she knows the answer. Do I, as an adult, in my daily life, have to test myself on times tables, no, I don't. If there's something that I need to work out, I'll whip out my calculator and work it out.

00:40:44

CB

Exactly. I have never been able to learn my timetable.

CK

And that's all right.

CB

And my mum had a mind where she could just... If it's six times six, she can just say it, I can't. I just can't do it. I used to feel like, I'm a bit stupid.

CK

But you're not stupid. It's just that your brain works differently. It's like spellings, my husband finds spelling really difficult. Well, that's great because we've got predictive text. Matilda will dictate her messages to her friends into the iPad. There's ways. We've got technology, now, on our side, and why aren't we using that more in class, and why are we stills sending spellings home to learn?

I just think that, actually, I want my child to have a financial awareness, and a money understanding, and can she make her own bed, and can she... Matilda makes her own bed every morning, she makes her own pancakes. She's a kind person, she's creative, she's funny. Actually, we're doing all right.

CB

The key thing that you mentioned is mental health, and it's not being considered, at all, is it?

CK

Well, but then we do so much on it at school, and we're always talking about it, but it doesn't get backed up, and that's a real contradiction that I think is really difficult.

If your kid is struggling, then you are struggling because you're intrinsically linked to your child's mental health. I always say we'll get the EHCP fight out of the way, and then we've got to fight for where she's got to go for secondary school. You just do, just keep fighting, but I wish it wasn't like that.

00:42:22

CB

No, because some people don't have the tools in their toolbox to fight that fight.

CK

Yes, you're right.

CB

It's so unfair.

CK

And also, we know that there is a genetic link with neurodivergence, and actually, the person that is helping me, that is amazing, is an advocate, a special needs advocate, and she, herself, is autistic, and she's got three autistic children. The reason she's working in SEN situations is because she's had to do it herself, and now she's training to do it with law, and she's brilliant.

But I often think about there's so much paperwork you have to fill in, and forms. For example, we went to tribunal about Matilda's EHCP plan, because it was rubbish, and we were told accept it, go to tribunal. We accepted it in Easter last year, and our tribunal date was January this year, so that's how long it's taken.

We had an email three days later from the team, to say that it had been adjourned. I was really confused. The borough didn't submit all the paperwork, so then it was delayed until March.

Now, we are supposed to be looking at Matilda's secondary school, apparently, we have to decide by the summer term, but I don't consult with secondary schools because I don't have a... I can, but not properly because I don't have the right plan of what she needs, and what funding she gets. I was so angry.

00:43:55

But I was thinking I'm a primary school teacher, I kind of know the system a little bit. I'm not neurodivergent, as far as I'm aware, but when there are people who are neurodivergent, and things like dyslexia goes hand-in-hand, finding it hard to organise yourself, finding it hard to fill in forms, finding social situations difficult, how do these people deal with that? I think what happens is they likely give up because it's too hard.

CB

Yes.

CK

Then you've got all these families that their needs aren't being met, and that is a travesty, really.

CB

Well, it is, because the other thing is, of course, not only does it impact that family, it has a wider repercussion for society.

CK

Of course, it does. Of course, it does.

CB

It's so shortsighted. Inclusion really is essential.

CK

It really is. Even having this conversation is part of it, isn't it?

CB

Yes.

CK

It's just raising awareness, which is why we were so excited to see you at The O2, we were just like, amazing because it matters. It really matters.

00:45:06

CB

If you listen to this, please, give it a share because it is very important. There are so many young people. The statistics of neurodivergence is like one in six, or something like that. It's very high.

CK

Yes. And also, for us, parents, when we got our diagnosis letter for Matilda, it was 48 pages long. It's huge, which is when the NHS paediatrician just said yes, I agree with that, with amazing resources, and suggestions. I think the statistics that worried my husband, and I were about with girls that have this, it's a complex diagnosis that Matilda has, they are far more at risk of eating disorders. Far more at risk of mental health issues. Matilda has been diagnosed with generalised anxiety at eight years old.

CB

Yes, that's young.

CK

That's hard to swallow. And also, that they are more at risk of suicidal ideation. That is what drives me, drive me every day, that whatever we do, we want her to feel comfortable in her skin, to advocate for herself. To protect her future mental health because it's hard enough being in this world, let alone when everything is confusing.

CB

Yes. Those things, that's stacked against her, and it doesn't need to be that way. We can make a change. I could talk to you all day, Clare, but we are running out of time.

00:46:38

CK

That's all right.

CB

Can I just ask you, as we close, how important is the Sunflower to you as a family, and do you think it's needed in schools?

CK

I actually asked Matilda that question, and she said no, I don't want it at school, which I think reflects herself, that she's becoming aware of being different, and that she doesn't, sometimes, want to be different. She wants to fit in, like we all do.

But I think it's so important. I'm not embarrassed, or I don't have any shame, or fear, I'm always going with my family, look, should we just tell them that we've got neurodivergence in the family, and let's see what can happen.

But you feel a little bit protective, and what's lovely is when you see other families, and I often see other girls that are wearing it, and they go like you're in a club. You might not want to be in the club, but you're in the club together. There's just a kindness that comes with it, and it means that's it's all right.

Usually, when Matilda makes... I wear it more now than her, you just get that look of compassion, and then you think, okay. Because it's stressful. It's really stressful. Matilda's scared of going on the train, she finds London overwhelming, but when I say, look, let's put this on, and let's see what happens, yes, it really helps.

CB

That's brilliant. Thank you. Thank you so much for your time.

00:48:10

CK

No worries.

CB

Thank Matilda when you see her.

CK

I will.

CB

When you go back downstairs, and she's on her swing.

CK

Yes.

CB

Have a lovely time at the climbing place.

CK

Thanks ever so much for your time.

CB

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00:48:37

VO

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