

Rett Syndrome with Beth Johnsson

Speaker Key:

CB Chantal Boyle

PS Paul Shriever

BJ Beth Johnsson

00:00:20

CB

Welcome to The Sunflower Conversations. Your hosts today are Chantal, which is me, and I'm joined by Paul Shriever. How are you doing, Paul?

PS

Very well, thanks, Chantal. It's a pleasure to be here again with you guys.

CB

And our guest is Beth Johnsson. Beth joins us to talk about Rett Syndrome, which is a rare genetic disorder that affects brain development, resulting in severe physical and mental disability. It's estimated that around one-in-10,000 girls are born each year, and it is very rarely seen in boys.

Beth, it's her daughter who has this condition, so we're going to find out a lot more about this in today's conversation. But, first of all, Paul, just wanted to have a little chat with you. We've been working hard, haven't we, on the Jersey launch?

PS

Going to be very exciting. It's about bringing the island, making it with Hidden Disability awareness and making it a Sunflower-friendly island. I'm going to leave that to you because you're a little bit more informed about it than I am, but it's been a busy few weeks putting it together.

00:01:37

CB

Yes. No, it's been really exciting. It's been in the planning for months, led by the Government of Jersey, to create a Sunflower-friendly island, so that is to the

benefit of people who live there and work there and visitors. And if you haven't been to Jersey, it is a stunning place. Have you been to Jersey?

PS

Personally, I haven't, no. I'd like to go.

CB

Have you been, Beth? Have you been to Jersey?

BJ

I have actually been to Jersey, yes. Yes, just once a long time ago. It was beautiful.

CB

Stunning.

BJ

Yes.

CB

Really stunning. This is really exciting for people with non-visible disabilities and Sunflower wearers because it's really getting the conversation out into the open about non-visible disabilities. And the great thing is that it's being led by the Government of Jersey, and they're bringing along all the businesses on the island to take our training. All those employees will know it, and they'll be able to start the Disability Inclusion conversation at work, but now they're ready to also talk about that within the community, so supporting their friends, their customers and visitors. We're really excited.

00:02:48

Our colleague, Ruth, is on her way to Jersey. And she's going to be on hand to talk to the community tomorrow, over the weekend, so we're praying that it's going to be nice weather for her and everybody else who's participating. They're doing a nice, it's a Sunflower Shop Window Competition in their main street in Saint Helier, so that will be fun. And they've got scavenger hunts and talks happening. There's lots of things going on. Art competitions. It should be a really nice celebration and the beginning of the whole island understanding and knowing about hidden disabilities and the Sunflower.

PS

Boosting awareness. It's great, isn't it? It's a good thing.

BJ

Yes.

CB

Definitely. I was hoping to go with her on this visit to support her, but she assured me she was able to cope on her own.

PS

Disappointing.

CB

I'll go for the one-year anniversary. Maybe we can bring it slightly more into the summer months.

00:03:55

PS

Yes.

CB

Welcome, Beth. We don't want to delay any more talking to you. We met at your employer's launch, which is Comic Relief. Your employer's also become Sunflower-friendly, created a Sunflower-friendly space for employees. And you shared with me at that launch about your daughter's rare condition, which is Rett Syndrome.

Although she is now in a wheelchair, you did say to me at the time that you wish that the Sunflower was around when she had been younger because it would have made such a difference for you to have that in spaces when you were out with her, for the understanding.

BJ

Yes.

CB

And you mentioned that you think that other parents of children with additional needs, special needs would be able to make use of this. Can I ask how old is your daughter now, and what's her name?

BJ

Her name is Hannah, and she is now 16, which seems crazy. 16.

CB

Yes, a teenager.

BJ

Yes, very much so.

CB

Tell us, what is Rett Syndrome, and can you explain Hannah's symptoms, please?

BJ

I can. And it sounds like a simple question, but I'm going to preface this with, it's not that simple an answer. It's quite a long answer. I think there are a few ways to answer the question, what is Rett Syndrome?

00:05:15

You've touched already on what it is scientifically. From scientific perspective, Rett is caused by mutations on a gene called MeCP2, which is on the X chromosome. And the gene makes a protein which everyone needs for their brains to function properly, and in people with Rett, they don't have enough of that protein, meaning that the brain doesn't function properly.

As you mentioned, it affects around one-in-10,000 girls born every year. It does predominantly affect girls. In really basic terms, because girls have two X-chromosomes, where the one X is damaged, the other X is strong enough to counteract the damaged one, so you get symptoms, but you survive. In boys, the X-chromosome is damaged, the Y-chromosome is not strong enough to counteract, generally.

Where the mutation happens in boys during gestation, generally, they don't survive either pregnancy or early infancy. Having said that, there are boys who do survive. I know boys who have Rett Syndrome. But they tend to be even more severely affected than girls, and it's much, much rarer in boys.

00:06:35

It's not hereditary. It's just a random mutation that occurs during gestation. And I guess one of the crueller things about Rett is that you don't really know that a Rett Syndrome until they're about 12 to 18 months old. It can differ. Sometimes it can be more obvious more early. But because it's a developmental thing, so children are often born, typically born quite normal, quite healthy and develop normally for about 12 months, and then because at that age, certain skills would normally start to develop, that's when you see that they don't. Before that point, it's often not really spotted.

From a scientific perspective and a global perspective, those are how it looks. From a parent's perspective and in human terms, if you ask me in the street, what is Rett Syndrome, my answer is more along the lines that it is a devastating

neurological disorder which, effectively, steals your daughter from you at around 12 to 18 months and thereafter in small pieces.

Around 12 to 18 months, develop starts to slow down, skills that have been acquired to that point have been lost. There's a period of regression where things like, if the child has started talking, if they started to walk, those skills might deteriorate, go backwards. And that's when the first symptoms start to develop, often things like handwringing, screaming, frustration, sometimes self-harm, things like pulling out hair and things like this, often from frustration.

And then over time the symptoms worsen and deteriorate further. You might get periods of plateau and slight improvement, but then you can get further periods of regression, often in teenage years.

In terms of, you asked about Hannah's symptoms specifically, so she followed a relatively typical trajectory, I suppose, for Rett. She was born totally healthy, completely fine pregnancy, textbook pregnancy. She arrived on her due date. She was very easy. And then she developed normally for about 12 months.

00:09:03

And then there were just small things that started to creep in. She started to be less content. She had screaming episodes for reasons that we couldn't explain. And then from those screaming episodes, she started to actually pull out her own hair, so in clumps, huge clumps of hair.

CB

Making me wince. That's really making me wince.

BJ

Awful, yes. To the point where we shaved her head. She had gorgeous, thick brown hair, which she does still now have, it came back. And, yes, we ended up just shaving it, really, because that was the only thing to stop her grabbing it.

CB

Causing herself physical pain.

BJ

Yes. It's funny, really, when I look back. I think we were so devastated at having to cut her hair, it was just so awful. And now I think that was nothing, really. It was just aesthetic. It didn't matter. We knew it would grow back. But at the time, it was horrendous.

And, yes, now we know that that was a frustration thing, because she'd hit the age where she should have been learning to communicate, learning to make her personality shown, make her little independent steps, as children do at that age,

and she couldn't. It was a frustration reaction, which now we know is actually quite common.

00:10:29

CB

Yes. So you started to see these developmental differences for where she should've been at at that stage. What was your next step? What did you do? You obviously got a diagnosis, but as it's quite a rare thing, how did you go about that?

BJ

Yes. It took a while, and it took a while, really, to... It was about 18 months that these frustration things started coming through, and that was obviously a big, what's going on here? But before that, I think, retrospectively, the benefit of hindsight is to go, oh, that was a sign, that was a sign. She was quite hard to wean, for example. She had a lot of reflux. She gagged a lot. And know I know that was Rett Syndrome. But, also, lots of small children have reflux and they gag.

She was our first child. We had no point of reference. And developmentally, she was hitting her milestones. She did learn to walk. She did. She had about 15 to 20 words at one point. She could climb up onto a table. She didn't ever get to climbing-a-tree stage, but she [overtalking].

CB

But climbing a table, that's good motor skills to do that, and balance.

BJ

Absolutely. I've got photos of her standing on a low coffee table and almost dancing a little bit. She had imaginary play skills. She would talk to her dollies. She had fine motor skills. She could turn the pages of a book. And these are all things that disappeared. They're things that some girls don't develop at all. But because she was, they were there, those skills. They were a little bit late.

00:12:22

But everyone that we spoke to was just, oh, they all catch up, they all develop at different stages, she'll get there, she'll get there. And it wasn't really until the hair-pulling and an almost imperceptible tremor in her hands that we thought something's really up here, and at that point, started to go to the doctor, started to ask for referrals.

But because she was meeting those milestones, they were very reluctant to test, because she was little, and it's testing, it's blood tests, they didn't really want to do it. And there was a universal thing that she was globally delayed, which is just the label they put on if they don't really know.

And that went on for a few months, with us going, no, no, she's not quite right, we need to test. Because we were keen to have another child, and wanted to know if there was anything potentially hereditary going on. And, actually, it wasn't until we were pregnant with the second child that they agreed to do the tests, because then it was, well, okay, let's check that there's nothing hereditary so that we can be prepared for what's coming. We got the tests done. And it was then six months until we got the final results.

CB

May I ask about that test? How do they know what they're testing for? Is it a blanket blood sample? How do you even go about discovering it?

00:13:52

BJ

We had a couple of appointments with a geneticist. And you go through everything. You have to go through the whole history, all the symptoms. They do a few non-invasive tests, can she do this, can she do that? And then they create a list of things that they think it possibly could be. And the blood gets sent off for testing on all of those things.

And our geneticist, and this is only our experience, I don't know what happened to other people, but our geneticist was very clear that she was not going to tell us what was being tested for. Because she said, if I tell you what we're testing for, you will go home, you will look all of them up, and it will be awful. And she said the chances are they're all going to come back negative. She really didn't think that any of them would come back positive.

And, actually, we would get a phone call every time... Because all the results don't come back at once, so the result for one particular condition will come back. And then three weeks, the result for another condition will come back.

CB

That must've been so stressful for you and your partner. Oh, my gosh.

BJ

What agonising wait. We would get a phone call every time the next result had come in, and they would say, we've got the results back for Fragile X. It's not Fragile X. Oh, okay, great. And, actually, Rett Syndrome, we got the result... Before Rett, they called and said, there's only one result left to come. We didn't know what they were testing for. They said, there's only one more left now. And when they called for that, they didn't say. They just said, please can you come to the hospital? It's like, okay, [overtalking].

00:15:37

CB

The word you used earlier on was devastating. And I guess it's that word, the devastation started with that call.

BJ

Absolutely. I can remember it vividly. 3rd of February 2010. I don't know any Rett parents who don't remember the D-Day, we call it, Diagnosis Day. It's a drip-feed of knowledge, and I think it has to be. Because if you found out everything on Day 1 that was coming, if someone had told me on that day, when Hannah was still, to all intents and purposes... She was mobile, she had some words, she was pretty much on track milestone-wise, a little bit delayed. Yes, she had these episodes, but she was pretty fine.

CB

The thing is, it was only you and your husband that were able to pick up on these things, wasn't it? All the medical profession hadn't, weren't concerned.

BJ

Yes, and you couldn't deny that she was pulling her hair out, and these things. These were also phases, and children do go through phases and do strange things. If someone had told me on that day all the things that were coming and all the symptoms she has now, I think I'd just not have got out of bed again.

CB

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00:17:10

PS

Is there any support for families such as yourself and for Hannah? What sort of support is given to you?

CB

Do you mean by the healthcare system?

PS

Yes, I mean in any form. I'm just interested to know. Do you get by the healthcare, by the NHS?

BJ

That also is a really hard question. I think it does vary much. Postcode Lottery, for

a start, is one of the reasons we still live where we live. I do think it varies where you live. We got amazing support from an organisation called Portage, and that was pre-diagnosis, but they intervened with children before the age of five, so only up to five. And that's where there's been a referral done that there's some kind of delay or there's some kind of special needs regardless of the diagnosis.

They were amazing for us. Helped us fill in the arduous, horrendous forms you have to fill in and did a lot of signposting, picked up a lot of the horrible admin that comes with it all. Mencap have been really good. We get support from Mencap. Hannah gets a bit of time there.

Yes, it's not forthcoming, I would say. It doesn't get handed to you. You have to find it. You have to look for it. I would say other parents are 100% the best source of support, both other Rett parents, as I said before, being within the Rett community and there being people who really do know what you're talking about.

It's a bit of a double-edged sword because, because it's a condition which, it's not terms progressive, but symptoms get worse, Hannah is in a much worse place now than she was ten years ago, when you talk to parents who are much further down the line, it's not always helpful to know that this is coming. And I think that's particularly true pre-teenage years when your daughter's really doing quite well. And then you talk to someone whose daughter's maybe 17, 18, plus, and it's not so good. And that can be hard.

00:19:29

But the plus side is that you talk to people who really get it, and they've been there, and they've got so many... There's a wealth of advice and information that parents have that you don't get from medical professionals.

CB

Do you think she knows what's happened to her?

BJ

That's a really difficult question that I think is a bit of a no-win answer. My answer is, yes, I think she does. Her relationship with my dad was something that tells me that she does understand because he had a pretty catastrophic stroke in his early 50s, so when I was ten, and he went from being someone who played football and cricket and went skiing and played golf, was really active, to being someone who had very limited use of his left side. And he adapted brilliantly, and he did learn to do a lot of things, but he couldn't go back to those things.

And he and Hannah, they just got each other. He was the one person who never was able to get on the floor and play with her and really interact with her when she was little, but he just didn't need to. He looked at her, and she would laugh, and vice versa. They absolutely worshipped each other. And I do think they just had a shared understanding of having lost something that wasn't coming back

but being all right with that and having that kind of camaraderie and bond.

00:21:01

Yes, he passed away almost six years ago, and it was my worst fear of having to tell her. It's really well-documented now that girls with Rett are really cognitively able. She has a multitude of symptoms. She has lost most of her mobility, she can wait there, but she can't walk. She can walk, with full support, a few steps. She has lost all her speech except for two words, which are no and Mummy, and they are not said in an excited manner, they said in a help-me manner, which is heartbreaking.

She's got very limited hand function. She's developed all kinds of medical complications, so she's got epilepsy, she has scoliosis, she has apnoea, she has respiratory problems, she has digestive problems. She's waiting for a gastrostomy. She might need spinal surgery. There are over 50 symptoms of Rett Syndrome, all of them are awful, and some of them are life-threatening, and she has a lot of them. I haven't counted, but there's a lot.

CB

And painful, by the sound of it.

PS

Yes.

BJ

They are, yes. And she's incredible. I don't know how she copes. I think we spend a lot of time talking about how do parents cope and how do families cope, but, actually, she's the one who has to deal with it 24/7. And she does. I think it's an amazing lesson to have in front of you all day, every day, of someone who puts such an amazingly brave face on such a difficult situation.

00:22:50

PS

Can you communicate, or has that disappeared now? Is has it never been there?

BJ

She doesn't communicate in conventional terms, but she is really good at getting herself understood, with people who know her, at least. And I think this is also quite typical of girls with Rett, certainly the girls that I know, they're really, really sociable, love people, love being centre of attention.

Hannah is outrageously flirtatious, embarrassingly so sometimes. She's got an amazing sense of humour. Everyone who meets her will talk about her sense of

humour and her incredibly infectious giggle. She just makes people fall in love with her.

Sometimes it's talked about as being similar to autism. And actually, socially, she's just so engaged. Her eye contact is her main source of communication, so she will look you in the eye, she will give you sideways glances, she will roll her eyes, she will do all the other things that other teenagers might do. And her communication, a lot comes through her eyes.

She uses her face and her laugh and her vocalisation. She can make noises, so we get a lot of moaning, just low-level in a teenage, moany way. We get a lot of giggles. We get a lot of screaming, angry screaming. I always say it's quite easy to know broadly what she's feeling, but pinning down the why is much harder. When she's moaning, you can go, well, are you bored, do you want me to change the channel, do you want to listen to music, are you hungry, do you want this...? But she hasn't really got a way of communicating why she is feeling how she's feeling and pinning down the specifics, which is hard. It's just guesswork.

00:25:10

She very rarely cries, but when she does, it's real. It's really real. And I just don't know, when she's crying, does she have toothache or is she upset because she's locked in a body that doesn't work?

PS

And with time, is that something that you've learnt because she's your daughter? Do you understand more of how she's trying to communicate simply because she's your daughter and you've had years with her, so you can read the signs and say, well, I think that's that, or that's this, because she's your little girl?

BJ

Yes, I think so, I guess in the same way that parents know their kids best. Yes, I think we probably can read better and know more what's going on, but that obviously is also an anxiety thing. We won't always be here. She's not always with us. We increasingly... As a 16-year-old, she doesn't want to be with us all the time. She has to hang out with her parents and her three annoying little brothers all the time. And that's not what she wants to do. She makes that very clear.

CB

Oh, does she?

BJ

Oh, yes. Oh, yes.

CB

I'm thinking about the frustration that you were saying about you know her better, the family know her better, than anybody, obviously, but it's difficult to know what the causes for certain emotions are. And I was just relating that to when my babies were babies, and just the crying, and I never knew why they were crying. And somebody else might say, that baby needs to be fed, and I'm thinking, well, how on earth do you know that? To have that continually...

00:27:08

And I know how it made me feel. It made me feel terrible to not be able to just do this magic wand and release the pain that the baby, both of them, were feeling. And so, I can definitely empathise of that feeling that you were trying to explain of not being able to know is it a toothache or what-have-you.

BJ

Yes, I think the worst feeling as a parent is helplessness. To feel helpful to your child's suffering is just the worst. I can remember, when she was quite small, sitting with her and watching an episode of Mr Tumble where there are...

CB

I remember that well.

BJ

Kids with special needs and additional needs. And I can remember him being with a child in a wheelchair, and the parents being there, and just thinking to myself, I don't know how they do that, I couldn't do that, I just couldn't do it. And then, gosh, it turned out to be so much catastrophically worse than I could ever have imagined.

00:28:22

But that's it, one thing is it is a drip-feed. And so, it's not that I knew then what was coming, and that is a way of coping, of almost, we'll cope with what we need to cope with today and won't look too far ahead, I think one way of coping was to have three more children.

I don't know if we would have had four had Hannah not had Rett. As I said earlier, I was five months' pregnant with the second when we got diagnosis, and that year is quite a blur for both my husband and I. We don't really remember the months following diagnosis. They're quite blurry and quite dark.

But then we had a baby, and you can't be in darkness when you have a brand-new baby. I don't know if this is just me, but all our kids have songs attached to them. And his is Here Comes the Sun, by the Beatles.

CB

Oh, that's lovely. That's really nice. Mine's Here Comes the Thunder and the Storm and the Rain.

BJ

Wow.

CB

No, sorry, carry on.

BJ

No, the lyrics are, it's been a long, cold, lonely winter, and here comes the sun. And he brought the sunshine back. And we had to get on with it. And, actually, almost as he was born, I said to my husband, we have to have another. Literally within 24 hours, said, we need another. Because just...

PS

Wow.

CB

He needs a playmate.

00:30:01

BJ

I wanted him to have the typical sibling experience. I wanted him to have a comrade. I also wanted Hannah to have a support network that wasn't just us. And I wanted to know that when we're older and they're older, it wouldn't just be my eldest son, Matthew, just feeling responsible. We didn't have them so that we could cope, but...

CB

It has helped.

BJ

We have a houseful of energy and life and laughter. And they're amazing with Hannah. They've not ever known anything different. They're amazing. They take care of her. They know there's whole new sets of rules. They're effectively young carers, but they're an amazing team as well. They're best buddies with each other.

PS

Amazing.

BJ

They bring a whole different experience into our home, which is a more typical parenting experience.

CB

Yes, and it brings balance, doesn't it?

BJ

Yes, absolutely, and, as I say, just life and energy and laughter. And it's not...

00:31:10

CB

It's nice for Hannah to see them just messing about, being brothers, being boys.

BJ

Oh, yes. No, she likes nothing more than them either falling over or getting in trouble.

CB

Oh, right, that's when she giggles?

BJ

Those are her two favourite things. If she's really grumpy, they know what to do. They know how to make her laugh.

CB

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BJ

I think, also, in terms of coping, we very quickly got into fundraising, so we threw ourselves into fundraising for a charity that I then ended up working for for ten years, eight years. Reverse Rett is a charity that funds research into treatments and a cure for Rett Syndrome, and it was founded the same year that Hannah was diagnosed.

There's a Rett charity called Rett UK who offer family support. And we reached out to them, to start with. And we had some support from them in the early days. But quite quickly, I felt like this is supporting me, but it's not really making any difference to Hannah's future. And then we found Reverse Rett, and we found that Rett Syndrome had been reversed in mice in the labs in 2007.

CB

That's interesting.

BJ

Which is a huge scientific breakthrough. And Reverse Rett were funding research. It was founded by a group of parents of girls with Rett. And they were funding research into speeding up treatments, so trying to replicate that reversal in humans.

00:32:50

And, also, a big part of that work was supporting newly-diagnosed families. We wrote a manual for newly-diagnosed families, which we called Never Give Social Workers Tea, which is a whole other story. We ran parent mentoring programmes, so like matching newly-diagnosed parents with parents who were slightly further down the road, slightly less raw and in shock, who could just listen and offer advice. And I did a lot of mentoring.

And although it is harrowing to go back, because it takes you back to your beginning as well, it's good to know that, actually, when you can say to somebody, with your hand on your heart, I get it, I've stood there, I've stood where you're standing, you will come through it, the sun will come out again, and it's not all darkness from here on in...

CB

I mentioned when I introduced you, about the Sunflower, that's how we started talking, and you said that it would have been helpful. Can we start off by asking you what do you think about the Sunflower?

BJ

I think it's brilliant. It's just such a simple idea that has so many benefits. I think I did first come across it at Gatwick, actually, many years ago. It feels like many years ago.

CB

That would have been right.

00:34:18

BJ

And, yes, just I think at the time, I thought it was Gatwick's initiative themselves and thought, God, what a brilliant idea, because these are such big challenges to people who are facing these kinds of issues that the smallest thing makes such a big difference.

And I think when I said it would've made a difference when Hannah was small... Before she was diagnosed, it was really when she hit the point where she was having these screaming episodes. She would particularly have them when we were out and about in public. She's the opposite now, where she's much more likely to have a screaming fit at home. If we're out, she's sweetness and light and smiling at everyone. People don't believe that she's ever anything except angelic. Like, oh, you should come home with us.

But, yes, she used to really, really scream the place down. And what she particularly couldn't cope with was waiting, anything that involved waiting, waiting in a queue in a café, waiting at a bus stop, anything where she just had to wait. And she had particular dislike to certain places. She hated Boots, for example. Absolutely hated Boots. She would start screaming the minute we went through the doors. And when you have small children, you spend a lot of time in Boots. Yes, she hated it.

And at that point, she was only 18 months, and it's an awful thing to say, but she looked normal. She didn't have any kind of physical disability. She was in a totally standard pushchair. You wouldn't know that there was anything neurodivergent about her at all. But she would be screaming. And we would get so many stares and comments. I can vividly remember I had one elderly man walk past me and go, shut that thing up.

00:36:19

CB

Oh, gosh.

BJ

Yes. I was just broken. And when you are not armed, that can just ruin you. I overthink everything, and I would spend the next day, two days thinking about what I should have said, if only I had done this, what if I had said this? All of the things. And you just replay it and replay it, and then that consumes you, and you're anxious, and then she's anxious.

And something as simple as... What I actually did, once she was diagnosed, I actually made cards, little, tiny credit-card-sized cards with a tiny bit of typed information, saying that she had Rett Syndrome, this is what it is, this is why she's shouting. And if you'd like more information, please go here. Thank you very much. And I printed off maybe 20, and I would just have them in my pocket every time we [overtalking].

CB

You took the power back, didn't you?

BJ

Yes, exactly. And I didn't have to use them that often. Somehow, having them, I think I must've been emanating some kind of, don't mess with me...

CB

Yes. Back off.

00:37:31

BJ

Because I felt stronger when I had those [overtalking].

CB

Yes. That's interesting you say that, isn't it? Because that's what we hear, isn't it, Paul?

PS

Yes.

CB

That Sunflower wearers feel so much more confident. They feel so much more emboldened because they have had horrible, negative experiences where people have totally judged them, been cruel and mean. We see this all the time, don't we, Paul?

PS

Yes, absolutely. It's a way of just feeling a little bit more empowered, isn't it? And people question... They still say to me, why on earth didn't anyone ever come up with this before or sooner, something for a hidden disability? How many hidden disabilities are there where you don't see it? You see someone in a wheelchair, and immediately your reaction is, or you think, goodness me. But there is so much that isn't seen, and it's just a sign just to say, please be patient and just give this person a bit of time.

BJ

Yes. I think it is really empowering. And, yes, when I had those cards, the few times that I did, someone would stare, and I would just be able to really calmly go over, I didn't even have to interact with them, I'd just hand them one and walk away.

And a couple of times, because I was still in the vicinity, that person would come and actually give it back to me and say, thank you very much, I'm sorry. And that happened two or three times. And even if that didn't happen, I was able to walk

away feeling calm, and I could leave it there. I didn't want to carry that with me for the rest of the day and feel like, ugh, why didn't I say this?

00:39:10

I think there is something really empowering about just... It's like your armour. I can do this. And when I had them in my pocket, I didn't worry about going out any more. I was like, I can go out, and if she screams, I don't care. [Overtalking].

PS

How good is that, to feel that way?

BJ

Yes, empowered [overtalking].

CB

We do have Sunflower cards, so, developing on from what you created with your laminating machine at home. We do offer, and it is in response to what you've said, Sunflower wearers the opportunity, if they wish, to create their own bespoke Sunflower card, which has a bit of an explanation on the back about what they are experiencing and the type of support that they may need. And it's, exactly to your point, to do with what you have just explained, for those people that find that useful, or for parents or individuals themselves. Yes, it's really good. This brings us on to our final question, and I don't know how we've got here so quickly, Beth.

BJ

It sped by.

00:40:23

CB

What advice do you have for parents who are at the beginning of their child's health journey with Rett Syndrome?

BJ

I would be really clear that I've been speaking about our experience and about Hannah, and all children are different, and all children with Rett Syndrome are different, really different. The main things would be, and I think this rings true, it's probably true for everybody regardless of whether you have a child with Rett Syndrome, but I think accept help when it's offered.

I don't take this advice very well, I should say. But I think we have a sense of pride of, got to do it on your own, you've got to get through this, and I don't need anybody, and I've just got to get on with it. If help is offered, especially in the

early days, just take it. Don't be afraid to. I think let yourself off the hook.

Again, I'm not very good at this. But I do think it's so overwhelming, there's so much, and you almost overnight go from being a mum or a dad to being, also, a physio and an SRT and an OT and a social worker and a nurse and a consultant and an epilepsy expert, everything.

You have to be everything, and, on top of that, an advocate because your daughter can't fight for her own rights, she can't fight for herself, and you have to become willing to have those arguments. You have to fight for everything. It's a horrible situation. But, yes, my feeling is, when you get that diagnosis, as with many diagnoses, you should get handed everything your child needs on a plate. And you don't. You really don't. You have to fight for every little thing.

You just have to know that you can't be everything all the time. And it's okay to have bad days. It's okay to have a really good cry. Actually, it's really important to have a really good cry now and then. And I think that is one thing, if there are any silver linings, I think things like this do teach you to really celebrate the small things.

00:42:36

When you don't know what your daughter's voice sounds like, you don't take anything for granted. And when you don't know if she might have... She might aspirate, and she might not wake up tomorrow morning, and she might have a seizure today that hospitalises her, you just can't look too far ahead, and you can't worry about things that don't matter. You have to have a sense of, never mind. My six-year-old hasn't learnt his spellings this week, oh...

PS

Yes, it's not the end of the world.

BJ

I'm not going to stress about it.

PS

Yes.

CB

It's all about perspective.

PS

Yes, absolutely right. That's the word I was going to say, perspective. It just puts things into perspective.

CB

If you're interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. Thank you for joining The Sunflower Conversations podcast. Remember to hit subscribe.

00:43:49