

0:04

Say maybe understand my disability, let me understand different.

0:19

I don't know so much because I don't know how many people actually out there know about FASD.

0:31

I think we understand of course more but people around us know it, but people on the outskirts they, because it doesn't affect their lives.

0:44

So sometimes I want to do the research on it.

0:49

So, I feel like we do have to be patient with them.

0:53

And so, we have to stand but they're coming.

0:57

because it's, you know, if I, even though it's quite a big thing, especially in the UK, people don't really with the, the drinking culture that we have, you know, people don't want to listen and be told not to have a few drinks while pregnant or that's what I was thinking.

1:21

Right.

1:22

Yes, I was gonna say I, I, I'm thinking, I'm quite grateful that my, of course, my mum and dad know, but it took them a while, to, you know, change what they thought was the proper way to raise a child.

1:42

, because, you know, people have different ways of raising and talking to a child. So I think, you know, just have a level of understanding even if you don't completely understand what it's like having a child with the brain damage or as such.

2:06

But just take, ask them just to maybe just do the research is the biggest thing or just take their time because, you know, it may take us time to understand a few things.

2:24

And, you know, and if they need help, we can help them to understand.

2:32

And how like talk to us is, is a big thing because sometimes some of us are a little bit like got emotional side to us.

2:43

Either some of us get angry or, but the thing is I think, take their time talking with us because it will just so then they can understand and then we can understand at the same time if it's coming across.

3:07

It is quite a difficult one for me personally to say how I want my parents to talk to me because they, that's how they, it's I was very fortunate when I was a child that my friend did that.

3:24

Well, she didn't have FASD but I can't remember what she had, but she took her time and well, she knew what she needed to do and not, certain things not to say because sometimes like I said, with the emotional part.

3:43

So, people with FASD do have an emotional like roller coaster because talking to parents or doctors or teachers, it's an thing.

3:59

It's a bit to someone that we have brain damage because with some, some people just, it, it's, it is the time that you take into talking with us and us with them.

4:17

It's a whole new concept to some people.

4:21

So, it was like, when my brother, Ed got a big family, he had, a black out, when he went the ball, it was like the German thing, isn't it?

4:35

The Hops Festival?

4:37

Mhm Yeah.

4:39

And my mom was talking to the doctor about FASD and the doctor was like, what's FASD? and like what you did years of research on to everything else that you're, you're meant to be learning, but you can't take that one extra step to learn about FASD, because I think it was a brain doctor.

5:01

You know, when they did the scans and everything because he, he, he was having seizures and he was blacked out and everything.

5:09

And my mom was just like you, this is your job, your people in desperate need and she took her time with the doctor to explain it and then the doctor was just shocked like that.

5:25

So it is just taking time to help the people.

5:33

Yeah, like, because I, I found that I'm certainly like, I'm more sensitive to like touch and like my emotions.

5:39

No, not my emotions.

5:40

My senses are definitely more heightened than I would say some other people.

5:46

So, when, like, I go to the dentist or if I go to the doctors, like, I would like them to sort of understand that I feel everything more than everyone else might do.

6:00

So, they just need to be as, as Rachel said, I, I, I kind of just agree with everything Rachel said, like they need to be a little more patient.

6:07

They kind of just need to make a little bit more time and sort of just like, try and understand that I, I, I might not be able to, like, do some of the things that a normal patient might do.

6:20

Like, when I was younger, I had needle phobia.

6:22

Like I, I was terrified of needles.

6:26

So, like, they need to take a, like a little bit of time to just like, sort of help us and sort of like, like, reassure, I don't know, like, reassure us or like, come up with something to sort of help us get through whatever we're doing or like, whatever is going on and, oh boy, this is where things get a little bit complicated for me because I don't know if this is because of my FASD or whether it's just me being me, but it's probably just me.

7:08

and probably anyone else that knows me, know this.

7:13

But when I was little and up to now I have been terrified of any medical procedure.

7:22

Anything, I was terrified.

7:25

I would, if I had to have an operation, I would run down the corridor.

7:31

Ringin.

7:33

I mean, screaming, I would scream, I run and it did not go well.

7:40

And you had a lot of operations, didn't you?

7:42

Yes.

7:43

Yeah.

7:44

And now I've realized that all those operations that I've had have got me to where I am now, if that makes any sense.

7:53

But, yeah, I mean, it's hard really because, like, you want them to know that we've got FASD.

8:06

But then oddly enough, every doctor's appointment that I've been to, they've never, well, they've never asked me if I have FASD because they probably got it on their records.

8:22

But I don't know.

8:26

but they haven't talked to you about it.

8:28

We've heard that from, like Rossi who's another person who is part of this committee.

8:33

He said before that they in, in all of his doctor's appointments, none of this feel like, well, people, like, obviously I'm sure they know about it.

8:43

But if they don't then, and if they wanna ask, then I won't be afraid to ask.

8:51

But sometimes it might not be on the document you because they've got a lot of documents to go, especially with us that we do have quite a, especially me have a long medical rap sheet of like problems.

9:08

Sometimes it gets pushed because it's not their priority to make sure then now that point that you're ok.

9:18

So I had my operation, they didn't ask.

9:22

But I said I told them that I had FASD or should I say mom told them because I was, I was not gonna talk to him, but sometimes you have to lead the conversation because of everything, everything else too, they have a load of other patients.

9:38

They're not gonna remember about FASD or like that.

9:42

But as long as they did their research, you know, that's something we can help them with that research, we can give them like a leaflet or something.

9:52

Just to say like this is the brain damage that I have.

9:56

This is what I go through and stuff.

10:00

Yeah.

10:04

What's FASD?

10:05

They've got, like I said, so many other things on their mind, they should, maybe their family life, whatever.

10:13

Yeah.

10:13

Sometimes just as long as they understand what it is and then they tell the next person or someone they know like, oh, like this information and then the best way I think to go about is just to help, help them understand it because I only try to treat that medical problem at that time.

10:38

If I may interject here, I, I wanna say, I think FASD is definitely pushed back as something that's not as important as other medical conditions.

10:49

And I'd like to say that is completely inaccurate, like from what I've been told and from what I understand FASD leads to a lot of different things.

10:58

Like, for example, a lot of problems.

11:01

Well, I don't wanna say problems because that's, oh, I don't know about anyone else.

11:05

But do you guys hate the word problem?

11:08

It's a, it's a different, like if, if someone says you have a problem, like, and then they mean it as in, like if someone says, oh, yeah, you have a problem because of FASD.

11:21

They call FASD a problem.

11:23

It's not a problem.



11:24

It's something I've been born with.

11:25

It's not like I can help it.

11:26

That's something that really bugs me.

11:29

Sorry, getting off track there.

11:31

no.

11:32

I feel like they push it back as if it's not a medical condition that's as important as some other things.

11:37

And I, like, I would like to say that it is because FASD can lead to other medical conditions.

11:43

Like, if you, that maybe someone has FASD, they could probably see, oh, maybe they have that and that's why this happened or that's why they have this or that's why they have that.

11:54

And like, I feel like FASD is actually quite an important thing to know about and I guess, yeah, go on, go on.

12:01

But with, like I said, at that moment in time, unless you do bring it up, I have FASD.

12:08

Could it be that then they won't go down that road because, like, I have so many more things to worry about.

12:16

Sorry.

12:17

FASD of course, is a big problem to deal with but they've only got one job and make sure that whatever you have is not life threatening.

12:29

Yeah, teachers are a huge, huge impact on all of, like, all of our lives.

12:35

Not just people who have FASD but like, everyone and the problem with that is like, I, I definitely think because I have FASD, I get tired so much more easily because my brain's just working overtime to just like, try and concentrate in class or like, try and focus on what someone's telling me.

12:57

But even right now, as you all were talking to me, I've actually got music on in my ear because that's helping me to concentrate because otherwise if I'm just focusing on something, my attention is just gonna go elsewhere.

13:09

So I feel like teachers need to understand that.

13:12

If we're not paying attention in class, it's not because we're not like, we don't give a shit.

13:16

Sorry.

13:17

Excuse me?

13:17

No, we, we don't care.

13:20

It's mainly because like, we can't concentrate because like our, our focus may be tethered elsewhere.

13:28

Like it's not because we don't care.

13:29

It's just because our brains are wired a little differently.

13:33

It's like, here at the moment I have my support dog, Sonny and, and she's just wandered off at the moment because she smells food, but she helps me relax and focus.

13:47

you know, of course, I didn't have her when I was in school, but I remember just running on one hour sleep or 1 to 2 hours, let's say, of sleep.

13:57

And then I would be woken up at that time when, you know, when you get into that nice deep sleep because I, I like, I never ever got to sleep and then I would get to midday like lunch.

14:09

So you go out for lunch and you go around running around for a little while, but then you bring back in after I'm really exhausted and tired and that's when the problems would happen.

14:21

, like I would cry or I would hide underneath the table.

14:33

So it would be nice if they just gave us like just time to just, like wind or relax.

14:42

Hm.

14:43

Because especially like I said, when you come from that, that lunch break, you're on that high, you're on that side.

14:52

and trying to tell kids with our, with our brain damage.

14:55

Now you need to sit down and pay attention.

14:58

That's not gonna happen.

15:00

Yeah, though, if we don't get our own way because we're tired or we're overstimulated, we're gonna act out.

15:09

So I feel like maybe after lunch we should be able to at least have that time to just to relax and say, ok, this is your Zen place, this is for you to calm down and when you're ready to rejoin the class, because that was my big problem because I would just be too tired to continue.

15:29

And so literally my mom and dad will run every week to go, come and get your child.

15:35

Like, please just come and get her, we can't deal with her.

15:40

and, that I need to, I have behavioral problems and that was their big thing.

15:48

Oh, she has behavioral problems.

15:49

She just needs to learn to cope with it and everything and that will just wind you up even more because you're like, no, I'm trying, this is my way to tell you, please.

16:00

I need your help.

16:03

I don't know with anyone else but when you don't get that help, you start because I'm, I like, you know, go and ask for help.

16:11

Sometimes I will sit there and I won't do anything but I fidget and usually I used to have a TA that was paid, you know, to come and help me.

16:21

She never did, by the way, she was a terrible TA she, you know, she didn't care as long as she got her money.

16:29

You know what I mean?

16:31

But yeah, I would always fidget and just not want to ask for help because sometimes when you've been shut down so many times from asking for help in the end, you just give up and that was, you just give up in the end and you you, you know, becoming that problem child.

16:52

Yeah.

16:52

Again, you know that it's gonna get you home because you don't want that place anymore because I, it, it caused me big mental health problems being in that school that everyone, all of this and everything.

17:11

I'm not gonna go into it, but I almost did and do something.

17:17

But thankfully I didn't and I get to help the next generation and out there with their FASD but it was just that situation where you think you're there, you're paid to help people, even people without FASD, you're there to help, you're not there just to sit around and just twiddle your thumbs and look pretty, you know.

17:42

So for me, mental health was a massive thing throughout school.

17:46

Like I, I can't tell you how bad it was for me.

17:51

Like, but ever since being out of school and like not being in education, not having that stress, not having that, like that pressure, that's a huge thing about school.

18:04

School always tells you you need to do your best.

18:06

You always got to do your best, do, do, do, do, do.

18:10

And it puts a lot of stress on our shoulders because like we've got to, we're expected to like, like, basically just balance all of this work, right?

18:21

Balance, sleep and balance friendship when we get so tired that we can barely function at the end of the day.

18:31

Like, I don't, I don't see how that's supposed to help us.

18:35

Now, if you give us homework here, you're sending us home where we're supposed to be relaxing to do more work and then come in the next day and do more work.

18:45

But where do I get to relax?

18:47

Yeah.

18:48

My, my.

18:49

Yeah.

18:50

Yeah.

18:50

With my, sorry, with my homework.

18:52

My mom just went, don't worry about it.

18:54

Like she could tell that I was stressed.

18:56

She went screw the homework.

18:58

You are tired.

19:00

You're gonna act out even more the next day.

19:04

So she'd literally just always write in the book.

19:07

She's not gonna do it.

19:09

And just she, she tried with me once and then it never, never worked out.

19:16

I was terrible with her work.



19:18

Oh my God.

19:20

Her work for me was absolutely.

19:23

Oh my God.

19:24

Oh my God.

19:26

Yeah.

19:26

I, I, I, I, I completely agree, man.

19:30

I just, just not, no, no, no, no, any homework that I, I tried to do but I didn't because it was too hard for my brain to process and yes, me and maths does not match.

19:50

I'm terrible with maths.

19:51

I mean, I'm all right now, but back when I was like, what 15, 14, like back in my, at my first school, whenever we did maths, I would really, really, really struggle with the work and all my tutor could say was, oh, come on, you can do this, you know this and I'll be like, I don't, I don't know it.

20:16

Like I, you may have just taught it to me, but I've forgotten.

20:20

Or can you?

20:22

And I, I would just sit there and cry and I'd go home in tears to my mom saying I don't want to do this anymore.

20:29

And memory is a huge thing for me and like, I don't know if you guys as well, but for me, memory is a huge thing.

20:38

I, my short-term memory is abysmal.

20:41

It's so bad.

20:43

And then people I go into school one day I learn things, go into school the next day.

20:48

I was like, oh, we're gonna go over what?

20:50

We went in lesson that yesterday and then what did you learn yesterday?

20:57

Was that that lesson or that lesson or?

21:00

We just don't know.

21:01

I, I don't, I don't know.

21:03

We are trying our very best.

21:06

Yeah.

21:06

No, we always try our best.

21:08

But then like people are like, oh well, it's not good enough.

21:10

You need to try harder.

21:12

Like what teachers literally go oh, so long as you try your best, it's ok.

21:18

And then when we try our best it's like, oh no, that's not good enough.

21:21

But bro, you're contradicting yourself.

21:25

wake up.

21:31

Oh, if you don't understand something, feel free to ask.

21:36

I'm not afraid to share my experiences.

21:38

Like I don't care, man.

21:41

Just, just like if, if someone wants to like, be like, oh, what's your experience with FASD?

21:46

Just talk to me, like, the best way to get to understand FASD is to talk to someone with FASD.

21:53

Don't, don't think.

21:55

Oh, yes, I've read a book and now I know everything about FASD.

21:59

No, you don't, don't, don't expect to do a course on FASD and be like, oh, yes, I know this.

22:05

Now you don't, there are millions and I, I, I, well, I don't actually know, but I'm assuming there's millions of different ways FASD can affect you.

22:17

Right.

22:17

So, just, just, just because you've read one book or you've met one person with FASD does not mean, you know, everything on FASD because you don't.

22:26

Exactly.

22:28

I mean, it just, it annoys me because people are like, oh, yes, I know what I'm doing now because I've met someone with FASD.

22:35

You, you've met me, I, I, if I, if I grabbed someone with FASD and put me next to me, I guarantee we will not be the same.

22:46

It's like grabbing two human beings and saying, oh, yes, you're a human being and you're a human being.

22:51

That means I know everything about human beings.

22:53

No, every human being is different.

22:57

Exactly.

22:58

And every person with FASD I like to assume is different.

23:02

Don't assume, you know everything.

23:04

No, you don't.

23:06

That's my two things.

23:07

Don't assume, you know everything and, and talk to us because some of us are more than welcome to help you and help you understand what we're going through.

23:17

What we're doing now is OK because it's quite simple when like we, we're, we're just talking over our feelings.

23:22

But if it's like a massive long list with like tick, tick, if it's yes or no questions, like I especially find yes or no questions incredibly hard because I don't know like what the, what they might mean.

23:36

So like for example, they might say like, do you struggle with sleeping?

23:41

And I, I i it might be yes or no.

23:43

But like what if I struggle with sleeping?

23:46

But now I don't like I used to but now that I've taken precautionary measures to help with my sleeping, do I say no, I don't struggle with sleeping or do I say yes, I struggle with sleeping.

23:57

Just, just like an interview would be fine.

24:00

Like if someone just wants to hop on a call with me and just ask me a few questions, like, how's your day-to-day life?

24:07

How do you think it impacts you?

24:10

I'd love to, I'd love to have a chat with someone and, and explain to it because I feel like it's a massive thing.

24:16

It has to be discussed.

24:17

It has to be like expanded upon.

24:20

Like if they just listen to me, like if someone, if I'm having a conversation with someone like you guys are doing, now you're just listening to me, you're trying to understand what I'm talking about.

24:31

You're like, taking my opinions on board.

24:35

That's, that's the kind of thing that, like, I love and I respect if someone, like, listens to me and takes my opinions on board, then you have my respect.

24:44

Like that's it really just listen and be patient.

24:49

That's all when people, like, give you time to say what you want to say.

24:57

Like if it hasn't or say if they've told you something and, or they've asked you something and you don't quite answer straight away.

25:07

That's, and they give you time to process.

25:10

I think that's one thing.

25:12

Mhm.

25:13

, yeah, like, yeah.

25:23

not judging me.

25:26

is, you don't respect someone that you, you're judging, do you, you don't go up to someone and judge them and then respect them at the same time.

25:38

yeah, listening.



25:39

Like everyone does the same listening, but most importantly, just how do I put this into two words?

25:50

it's gone out my brain now.

25:53

Respect.

25:55

We have, well, we have respect but I think it's just like everyone else and yet again taking your time with us because you want us to respect you.

26:09

It, the thing is, it needs to be mutual, you need to be able to respect them on their opinions and they need to respect us on our opinions and everything because it's not just one way personal way because you are asking for respect, but then you're not giving it back because it's, it's all about me.

26:34

I'm the only one that really matters where in actuality, everyone matters.

26:39

Even if you have the brain damage or not, you just go, I respect that you don't understand or what will not understand but whatever, you know, I think it's just, just mutual.

26:54

Just all, just listening, taking time.

26:59

I was gonna say following on what said I'd say three.

27:06

Treat us the way, the way that you would want to be treated.

27:12

There.

27:12

It is the, is that what you were trying to say, Rachel?

27:16

Pretty much my break down play.

27:18

I said it for you.

27:20

So yeah, treat, treat us how you would want to be treated.

27:26

So if you want to be treated in that way, you treat us in that way.

27:29

If you don't, don't.

27:31

So that's my see in, in that show.

27:34

Yeah, that's what I feel like in the big bad world.

27:39

I do feel a bit alien sometimes, especially before I knew I knew my siblings had FASD as well, but you feel alienated because you feel like you're the only one with the whole brain damage.

27:53

It's like like with depression, you know, you feel like you're the only one going through that, that pain and but in naturalness, everyone's going through it, people that are just like us are going through exactly the same emotions.

28:10

We're all in this together really