

Beating BDD Episode 39

Sam Milburn, mum to Jack, is a passionate advocate for more awareness and better access to treatment for BDD. In this episode, she shares her hard-won advice for other parents, including how to navigate the system on behalf of your child while also looking after yourself.

“It can feel quite lonely, and scary. I just hope that by sharing my story, it will help someone else.”

How Jack’s BDD first appeared

[02:38] Sam’s son Jack was diagnosed with BDD at 12, around the same time he received his autism diagnosis. Fortunately, Sam already had some knowledge of BDD through another family member.

[03:50] The first signs were the excessive time Jack spent getting ready, and the compulsive rituals he needed to go through to leave the house. If anything in the routine went wrong, he’d have to start from the very beginning.

[05:45] The BDD crept up slowly, making it hard to pinpoint when things really changed. Sam reflects that the laughter stopped, the socialising stopped, and eventually Jack became housebound.

[08:10] At first, Sam would do whatever Jack needed to get out of the house. But over time she learnt how to phase out some of those compulsions – even when some of them initially worked. Finding other people who had been through it really helped.

Getting a diagnosis

[10:18] Jack was already under CAMHS for his autism diagnosis, which gave Sam a direct route to assessment. She flagged that he was struggling to leave the house and having meltdowns, and he was seen by a psychiatrist who confirmed the BDD diagnosis.

[11:30] Sam had to push back against initial suggestions it might be OCD or agoraphobia, repeatedly explaining that the avoidance was rooted in appearance concerns. The first therapist assigned to Jack had worked with only one other person with BDD before. Good CBT with a therapist who understands autism is key.

Treatment – what worked and what didn’t

[14:27] The recommended therapy for BDD is CBT alongside ERP (exposure and response prevention), usually combined with medication. But the CBT approach requires careful adaptation for autistic young people – standard techniques like thought reframing can be very hard to grasp.

[14:53] A senior CAMHS psychologist eventually made real progress with Jack over 18 months. She tailored the ERP to his interests – taking him out to do Pokémon hunting while he worked through exposure tasks.

[17:04] Things were really looking up for Jack, and the family hoped things would continue to go well. But his progress flagged, and when they returned to CAMHS, Jack’s therapist had gone on maternity leave. Two replacement therapists didn’t

work out, prompting Sam to push for a referral to the Maudsley – the specialist BDD CAMHS clinic in the UK. He was referred in late 2024.

[20:10] In the meantime, the Maudsley did an at-home assessment and prescribed an SSRI. But because of the long waiting list, Jack isn't due to start therapy until July 2026, about a year and a half after the initial referral. Fortunately, the medication has been transformational: Jack now leaves the house every day, goes to the gym, and has got a job.

Advice for parents: the practical stuff

[23:11] Sam's top starting points for parents:

- Learn as much as you can about BDD. The more you know, the more empowered you'll feel to push back when needed. Sam recommends *The Parents' Guide to Body Dysmorphic Disorder* (see Resources, below)
- Start the referral process – via your GP or the school SENCO – to get your child assessed by CAMHS. Online appointments are available for children who can't leave the house.
- Use the BDD Foundation's parent resources page – you can print it off and bring it to appointments to help keep clinicians focused on BDD rather than other conditions.

[26:26] On talking to your child about BDD: some will be relieved to have a name for what they're experiencing; others will resist. Sam's advice is not to push the diagnosis but to focus instead on the things BDD is stopping them from doing – and frame treatment as how to get those things back.

[29:29] On navigating school: ask for a meeting with the SENCO – without your child present – as early as possible. Useful accommodations can include a later start time, a reduced timetable, and a discreet card that lets your child come in late without having to explain themselves.

[34:36] On advocating within CAMHS: it's fine to ask what BDD experience a therapist has, and how they plan to adapt therapy for a neurodivergent child. Try to be present in sessions so you can help translate and so you understand the homework. (Parents often become the co-therapist at home.) And if the child isn't connecting with their therapist, speak to CAMHS.

Advice for parents: looking after yourself

[39:40] Sam's first message to parents: this is not your fault. BDD is never caused by one thing, and going back over what you could have done differently doesn't help.

[40:31] Take the pressure off yourself and your child. If the most they can do today is watch a film, that's enough. Anything that brings laughter and connection counts. Sam worked her way through Lego video games and stand-up comedy with Jack.

[42:25] Make time to regulate yourself too. Get out of the house, meet a friend, find a way to let off steam. A small group of trusted friends who know what's going on makes a huge difference. Online parent communities – such as Facebook groups for parents of children with OCD or BDD – can also help reduce the isolation.

Resources

1. The BDD Foundation: bddfoundation.org

2. [BDD Foundation – help and support for parents](#)
3. [*The Parents' Guide to Body Dysmorphic Disorder: How to Support Your Child, Teen or Young Adult*](#) by Nicole Schnackenberg, Amita Jassi and Benedetta Monzani
4. [Challenging OCD in Young People with ASD: A CBT Manual for Therapists](#) and [Challenge Your OCD!: A CBT Workbook for Young People with ASD](#), both by Amita Jassi
5. [Body Dysmorphic Disorder Support for Parents and Carers](#) – Facebook support group set up by Sam

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