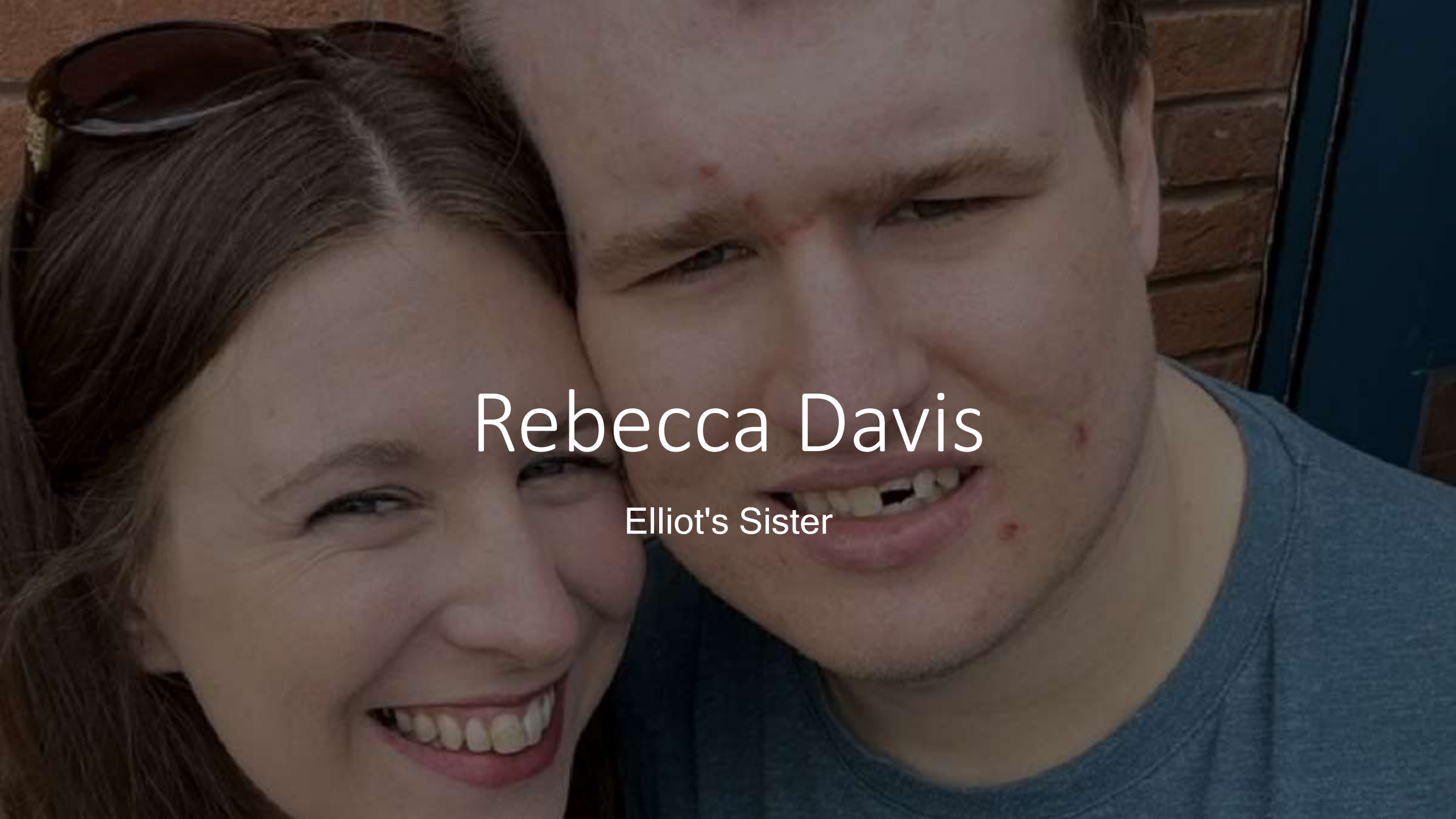




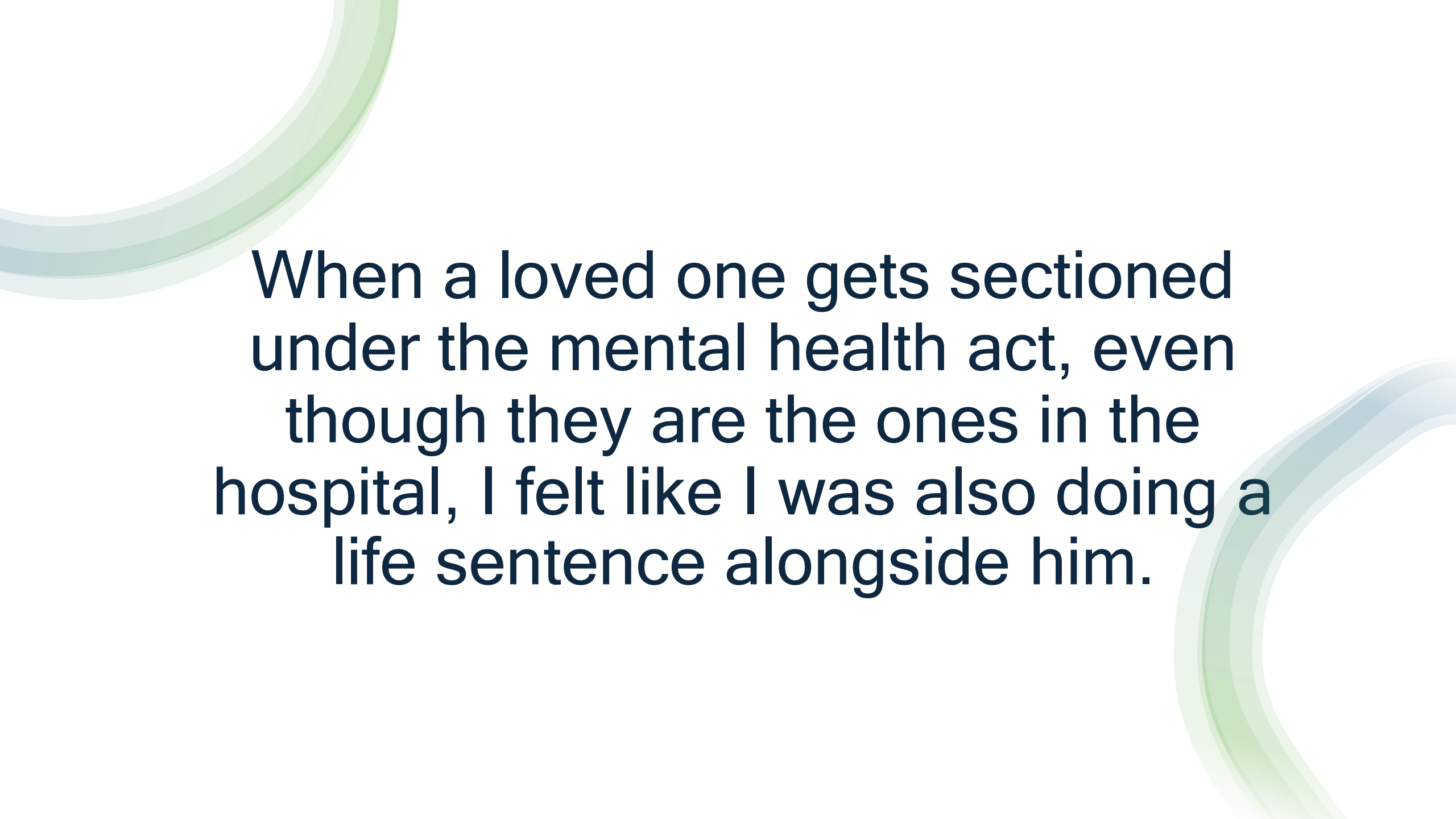
Rebecca Davis

Elliot's Sister

About Elliot

- ❖ This is Elliot, He turned 30 last month.
- ❖ Elliot likes buildings which are unusual shapes, such as football stadiums or the Gherkin in London.
- ❖ He loves his star wars figures, and he carries them around in a huge backpack wherever he goes. He loves being outside, being with his family and loves a toby carvery.
- ❖ He has Moderate Learning Disability and Autism Spectrum Disorder.
- ❖ Up until now, he was very misunderstood, and he suffered the consequences.





When a loved one gets sectioned under the mental health act, even though they are the ones in the hospital, I felt like I was also doing a life sentence alongside him.

Our experience of a loved one being in hospital

- ❖ Having a loved one in hospital is always heartbreaking at first.
- ❖ They are in an unfamiliar setting, different noises, different staff, away from family, and most importantly for you to understand is different cultures.
- ❖ While some hospitals are caring and supportive, others aren't and use abusive practices.
 - parents and siblings are isolated away from their sons/daughters,
 - excuses made time after time on visits
 - Families are excluded from important meetings, usually regarding their best interests and discharge planning.
- ❖ Perhaps this isn't always intentional but it feels that way for families who are tired of fighting the system.
- ❖ Those ward staff need strong, rights-based leadership and strong positive cultures.
- ❖ My heart was broken for 4.5 years.

The impact on the whole family

- ❖ The impact on us as a family has been huge and this isn't recognised.
- ❖ We are seen as a nuisance or, in my case, "The Difficult Sister."
- ❖ For example:
- ❖ My daughter was 18 months old when Elliot was sectioned.
- ❖ I missed out on so much of her young life, fighting to get Elliot home.
- ❖ Although I was present, my mind wasn't—I was constantly:
 - On teams calls.
 - Writing emails.
 - Sending complaints.
 - Taking phone calls.
 - Submitting safeguards.

The impact on the whole family

- ❖ At one point, when Elliot was harmed by a staff member, I stopped sleeping/
- ❖ Although the fight came to an end, this still causes me sleepless nights now.
- ❖ We would get some hope, feel like we were getting towards a discharge, but the RC would change their mind due to Elliot's up-and-down behaviour.
- ❖ Despite having reports from autism specialists, the hospital team continued to ignore the advice given.
- ❖ They created so much stress and anxiety for Elliot and myself that he couldn't cope.

The impact on the whole family

- ❖ One thing I hope you learn from today is that, as commissioners, you can challenge the mental health team for evidence of keeping someone detained unnecessarily.
- ❖ I got frustrated time and time again hearing from the commissioner, “What the mental health team says, I have to agree with as they are the professionals.”
- ❖ I don’t think you do—if you believe a person can live independently in the community, you should be standing up for that person.
- ❖ I’m sure North Yorkshire will now be looking at Elliot and his team and thinking:
- ❖ This is exactly where he needs to be, and he’s thriving.
- ❖ Hospital was unnecessary, cost NHS England thousands, and gained him nothing other than:
 - Lasting trauma.
 - A concoction of drugs that he probably doesn’t need.
 - It felt as though the trust saw Elliot as a financial asset, delaying his discharge time and time again for this reason.

After discharge when you have the right team in place, how does it feel

- ❖ We didn't get the right provider the first time round.
- ❖ We had to work really hard to get them to see Elliot as a person and show others they were getting it wrong.
- ❖ This made Elliot anxious and caused disruptive behaviour.
- ❖ His world got smaller and smaller, and we were back in a culture that felt like long-term segregation but in the community.
- ❖ The constant worry that he might end up back in hospital was terrifying.
- ❖ Communication broke down.
- ❖ They eventually gave notice, and that's when I contacted Ashleigh for help.

After discharge when you have the right team in place, how does it feel

- ❖ Ashleigh's teams - Unique Community Services - came on board in September 2024, and Elliot is like a different person now.
- ❖ We still have ups and downs, but they're few and far between, and he's very settled.
- ❖ PRN medication has reduced, as well as his self-injurious behaviour.
- ❖ Having the right team in place:
- ❖ Improves Elliot's quality of life.
- ❖ Improves my quality of life.
- ❖ I used to jump when the phone rang or when his name came up on FaceTime, as I didn't know what I was going to see when I answered.

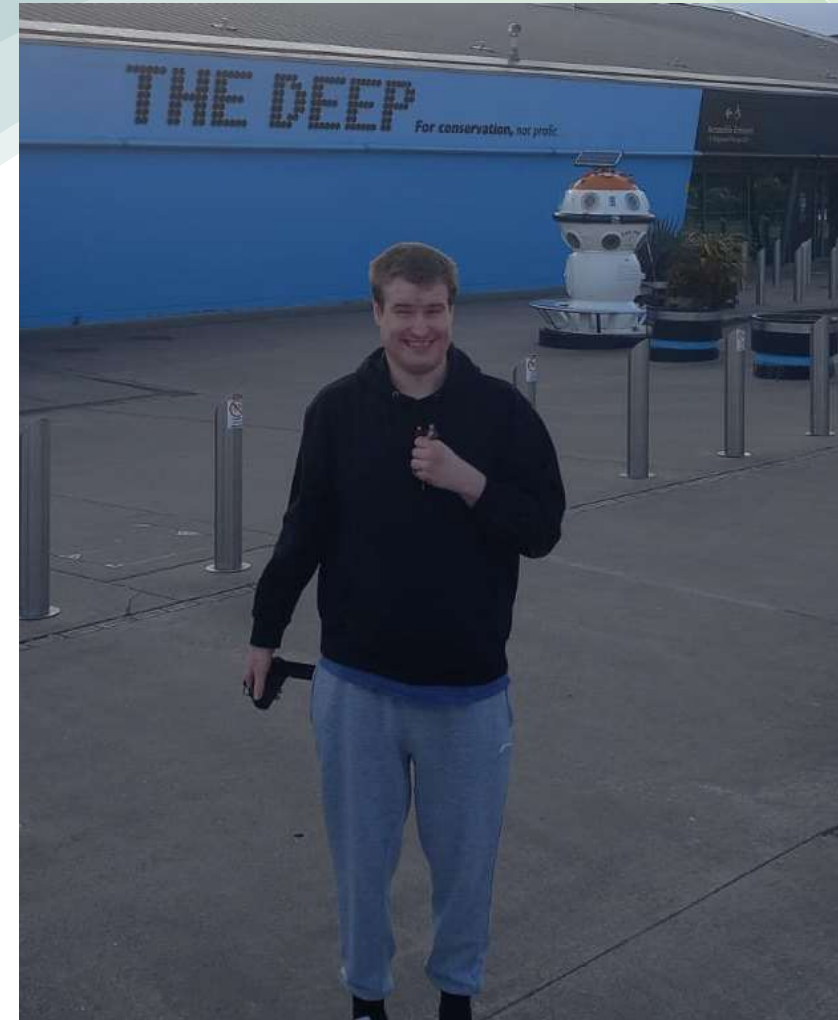
What staff said about Elliot

- ❖ He's dangerous and not fit for the community
- ❖ He's an aggressive man
- ❖ He's not safe around your children
- ❖ He will never learn.



What staff say now

- Bright, passionate, and deeply creative
- Strong love for trains, photography, and painting
- Enjoys simple pleasures like good food and long outdoor walks
- Confident, articulate, and self-advocating
- Honest and enthusiastic, inspiring those around him
- Adventurous spirit with a growing sense of freedom and independence
- Articulate, intelligent, and funny
- Has clear ideas about his support and preferences
- Feels safe and secure with his support team
- Proactively participates in planning his activities
- Experiences reduced behaviours that challenge due to person-led support
- Continuously pushing boundaries and exploring new interests
- Communication and active listening are key to his success
- Thriving in an environment that nurtures his potential and well-being



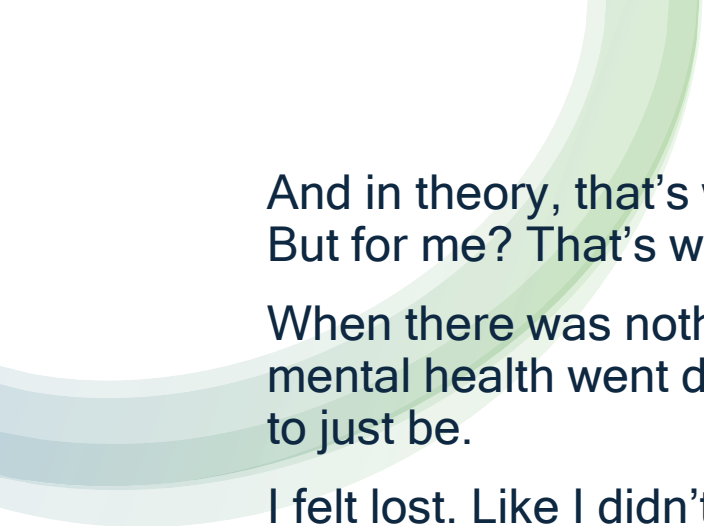
Before we finish, I want to share something personal with you

Something that often goes unsaid when we talk about recovery, healing, and the people around the person at the centre of it all.

As a sister, when my loved one was finally discharged and I knew the right team was in place it felt like I could finally let go a little.

The constant worry, the sleepless nights, the pressure of trying to hold everything together, it started to ease. There was relief, yes. But there was also this deep, almost overwhelming gratitude. Gratitude that Elliot wasn't navigating it alone anymore. And truthfully, that I wasn't either.

For the first time in what felt like forever, I was allowed to shift from being in crisis mode to just being a sister again.



And in theory, that's when I was supposed to take a moment.
But for me? That's when I crashed.

When there was nothing urgent to do anymore, when I wasn't constantly on high alert, my mental health went downhill. I had been running on adrenaline for so long that I didn't know how to just be.

I felt lost. Like I didn't know who I was without the crisis.
The scaffolding I'd built around myself to stay strong, it suddenly vanished. And everything I'd been holding in came crumbling down.

That's the part people don't talk about.

How, as a sister, or as any caregiver or close support person, you carry so much through it all.
And then in the quiet, after the storm, you're left alone, trying to pick up your own pieces.

There's still fear, of course. Setbacks never fully leave the back of your mind.

But now, there's also hope.
Hope that healing is possible.
That your loved one has the support they need.
And that maybe, just maybe, you can start healing too.



Questions?

Thanks so much for listening.

I'd love to open it up now in case anyone has questions, thoughts, or reflections. Whether it's something from my experience that stood out to you, or something that connects to the work you do with families. I'm happy to talk more about it.

