



Hospital to Home: Beth's story

Hospital to Home:

Beth's story

Foreword

For people with learning disabilities and autistic people living in hospitals, irrespective of whether these are assessment and treatment units or secure services, the two main issues that typically hit the headlines are either abuse scandals, which happen all too often - for example, Buddock Hospital, 2006; Orchard Hill, 2007; Winterbourne View, 2011 and Whorlton Hall, 2019 - or the numbers of people still living in these units, which remain inordinately high - in June 2021, for instance, there were 2,075 children, young people and adults with a learning disability and/or autism living in hospital in the UK and the average length of stay is over 5.5 years.

As the Transforming Care agenda, the national plan to move people out of hospitals into homes, has pushed for more people to live independently, and rightly so, there is a great deal of activity and process around counting numbers, writing reports and recommendations. When a scandal hits, the occasional MP or minister is outraged and the story remains topical for a while. This media energy soon fades and fizzles out though, and the people in hospital are forgotten once more. Ever constant in the background, however, are the desperate families - some vocal, others struggling to navigate the system, all trying as best as they are able to speak up for their loved one's rights and to shine a light on this dehumanising practice.

What we rarely hear, amidst all of this outrage and paper work, is the story of the people themselves, and equally, the good practice that exists around the country when clinicians and professionals in hospitals adopt approaches which enable the individual to move into their own homes. As an organisation, we have felt the frustration and, at times, the outrage when we are planning or advocating for an individual who is trapped in the system. However, we know that the blame game does not provide solutions that are sustainable for the individual, and that one way to gain traction in the system is to share people's stories in order to show real examples of what is possible. We are still coming across professionals who just don't believe or can't see how the individual they are working with could live their life in their own home, and this is a further reason these stories need to be told.

Although we have chosen to call this book series 'Hospital to Home', these stories will record the experiences of both individuals who have left the hospital and are settled in their own home, as well as individuals who are still within hospital settings, but whose transition needs to be slower in order for the eventual move to be sustained. Each story will be told from the individual and/or the family's perspective.

Beth's story is the first in the Hospital to Home series. The story has been written by Beth and Beth's dad, Jeremy. Beth is a vibrant young woman who has been failed by the system and has, as a consequence, ended up in 16 different settings in 7 years, many far from home, and spent just under 3 years in locked seclusion, because specialist services could not meet her needs and did not understand how to work with her to get the best out of her. Beth now lives in a new setting, provided by Mersey Care, NHS Foundation Trust, where she is given a great deal of control over her daily life choices and where staff understand Beth's autism and adapt to her, rather than expecting Beth to adapt to them. Although Beth is still on the journey to independence in her own home, her progress in such a short space of time is testament to her own resilience, her father's national campaigning, continuous support from her family, and the work of the staff team around her who take their lead from Beth in their support of her.

Thanks to Beth and her dad, Jeremy "Jez" Harris, for sharing Beth's story, and the staff at Mersey Care for their support.

Jayne Leeson MBE

Changing Our Lives CEO

Hi, I'm Beth.

I love drama and I love animals and nature. I'm at my happiest walking in the beautiful hills near Clitheroe where I currently live, fishing with my dad or relaxing with my pet guinea pigs. I'm into getting my hair dyed, playing the keyboard and singing.

I'm also autistic. I find everyday life really tough because so many things make me anxious. I also have lots of sensory issues relating to loud noises or unpredictable events.





When I was growing up, I found being told or expected to do things like going to school, getting dressed, or going to bed really upsetting because I didn't feel in control. It made me confused and sometimes I got really angry and lashed out.

At first people said I was being difficult on purpose. They said my mum and dad weren't strict enough. No one understood how even my own desire to be good was in itself a demand that I couldn't cope with.

**Nobody
understood me.**

School was really hard, 'cos it's full of people telling you to do things at specific times. I didn't want to go or when I was made to go, I experienced really bad meltdowns and became challenging to staff and other children.

So, professionals that work in social care sent me to a different type of school. I liked some of the things there. They had chickens – I loved them, like I love all animals (animals never tell you what to do!) but there were too many children in the school who were really naughty and noisy and I found it too upsetting.





I got moved again. This time to a school that was miles from home. Because of this I had to stay there during the week, and I could only go home to my parents at the weekend.

I hated it because it looked like a prison and I still had loads of teachers and staff telling me to do things. It didn't matter if it was things that I wanted to do – it was the *being TOLD* to do them that triggered my anxiety. Eventually this school gave up on me too and I was moved again.

This became the pattern year after year...

I would go to a 'service' that promised that it could meet my needs... But it couldn't because they never asked me what my needs were.

They just assumed my autism could be handled by using strategies like boundaries, rules and timetables – the very things that triggered my anxieties and resulted in meltdowns.

And for this, they blamed me.

They never thought it was *their actions* causing the problem.

I went to 16 different settings in 7 years.

16 times they did the *same thing* expecting *different results*.

16 times I found it *too difficult*, and 16 times they *blamed me*.

Eventually, the professionals making the decisions decided I needed to go into a secure hospital, where I was told I would get specialist care to **'treat'** my autism.

I was promised that experts would find medication that would help me manage my anxiety and the aggression I was displaying.

I was promised I would be in an environment that would be calming and relaxing.



I was just 15 years old when they locked me in hospital.

It was hell. It was further away than the schools were, so I saw my mum and dad even less.

It wasn't calming or relaxing. It was noisy – **really, REALLY** noisy.

There were 9 other distressed young people in the ward. They shouted and screamed and cried all day. They called out for their parents. They played horrible music at full volume. They hurt themselves too – and they showed me how to cut myself or tie ligatures to stop the pain.

The noise wasn't just made by the other patients. The building wasn't the calming place I'd been promised. Every few steps you had to go through doors which banged shut behind you, a constant reminder you couldn't leave. Staff had huge bunches of keys which jangled noisily, grating on my ears. Every time another person had an incident alarms would go off – loud piercing, screeching alarms which hurt me.

So, I had more meltdowns than ever.



When I get distressed, I want to run away. To escape the thing or person causing the anxiety.

In hospital I couldn't do this 'cos I **was locked in**. So instead, I became *challenging*. I know now this is my 'flight or fight' response kicking in when my brain becomes overloaded by too much stimuli.

Because there were so many different staff, I didn't get time to build the trust I needed to tell people I was getting distressed. They were just faceless strangers. So, I overloaded and became really anxious. They restrained me then put me in a seclusion room.

Seclusion rooms are designed for **short term usage to manage distressed behaviour**. They are empty rooms with no bed or chair. There are no toys or games. You get a mat on the floor to sleep on – no duvet. This is so you can't hurt yourself or the staff when they come in the room.

Every time the staff tried to put me back in the ward it wasn't long before I got overwhelmed again and the resultant behaviours put me back in seclusion. Sometimes I deliberately did things to get me put in seclusion because **I felt safer in there**. In seclusion I couldn't hurt others, I was away from the loud music, I was away from the distressed young people.



It wasn't long before the hospital stopped trying to integrate me back onto the ward.

I lived in the seclusion room.

My parents would drive hundreds of miles to hold my hand through the hatch in the door because **they weren't allowed in the room to hug me**. Because of blanket restrictions the unit had in place **I wasn't allowed anything in the room with me**. The iPad I used to distract myself when I felt I was getting overloaded was **forbidden**. I couldn't watch the videos I love of guinea pigs squeaking, or the clips of circus acrobats (I wanted to join the circus and be either a clown or an acrobat). I couldn't watch films or listen to soothing music to calm me down.



So, I had even more meltdowns and ended up being restrained more and more often.

I was regularly forcibly injected with sedatives and had my clothes taken away so I didn't use them as ligatures.

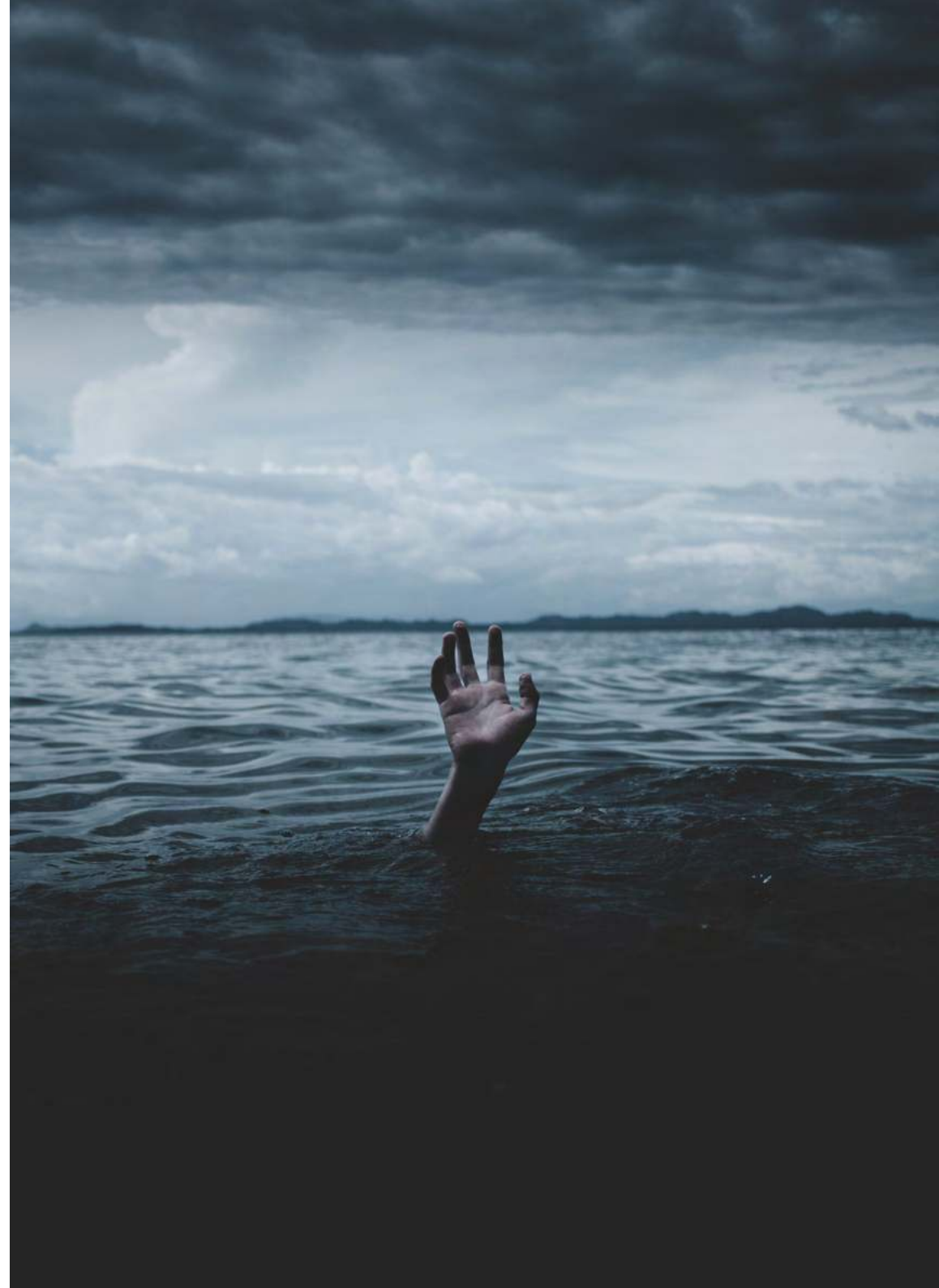
Some staff would talk to me through the hatch and were nice to me. Some got to know how to relax me by massaging my hands through the hatch.

Most were agency staff who were only there for a day though. They didn't know what I liked or how to help me calm down. They wouldn't even talk to me. Because they didn't know a thing about me, I would ask them for things I wasn't allowed. If they gave me pens, I would hurt myself with them because **I didn't want to live any longer**. Because so few people even spoke to me, I invented imaginary friends and talked to them instead.

I became really poorly both mentally and physically. I didn't get out of the seclusion room and staff fed me to keep me quiet, so I put on loads of weight and became diabetic. My muscles wasted away and I had skin problems through a lack of daylight.

Because I was so distressed in seclusion I wasn't in a state of mind where I could benefit from therapies or talk to psychologists. So I just stayed in seclusion.

Alone, scared and anxious.





Three years later on my 18th birthday I was allowed out!

I went to the pub for a meal with my parents, I had a limo ride and loads of great presents.

Even though I was really well behaved, the hospital still locked me up when I got back and I wasn't allowed out again.

Because I turned 18, I had to move to an adult hospital. I hoped it would be better, but it was even worse. The hospital wasn't for autistic people so the staff didn't understand me, or why I did the things I did. Being with adults was terrifying as some were aggressive to me.



So, I was placed back in seclusion...

This time *without* a hatch to talk through.

I was alone.



My behaviour didn't get worse, but the understanding of those around me did.

They just saw me as a **threat**. They didn't understand my autism, my sensory needs, or my demand avoidance. They just saw me as a **risk**.

I was restrained **more and more**. The longest episode lasted nearly **4.5 hours**.

On one occasion they didn't restrain me properly and in my panic to escape the pain of being held by loads of people I kicked out – *wouldn't you if you were being attacked?* – so the police were called on me.

It's always my fault, *isn't it.....?*

This failure to understand me led to the hospital deciding I needed to be sent to a High Secure Hospital.

They said only somewhere like Rampton could '*manage*' me.

It wasn't about meeting my needs –
it was about '*managing*' my behaviours.

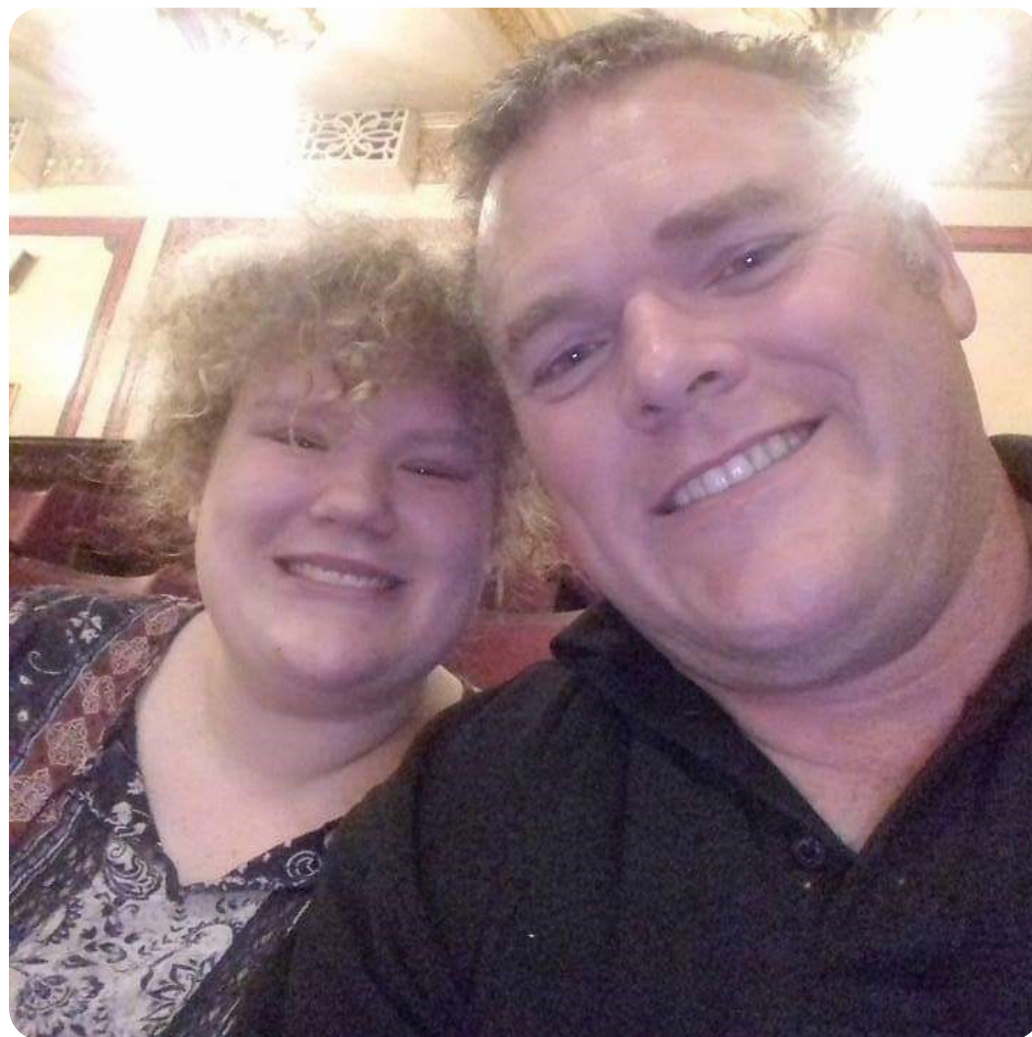
For years my dad had been fighting for my needs and my Human Rights to be met.

He managed to get experts on autism involved in a review of my care and a specialist team were brought in the help staff meet my needs. They were amazing! **They treated me like a person instead of a problem.** They saw past the behaviours and looked at how they could remove the triggers for my distressed actions.

It worked! I was calmer and happier than I had been for a very long time. They talked to me about what I liked and began to do things in ways I wanted instead of what the hospital thought was best. If I wanted to go for a walk, they took me out and let me enjoy fresh air and bird song. I could decide to have music on, they got me an iPad. They let my mum and dad come in the room and hug me. **It was so different.**



One day my dad told me that I had been offered a place at a specialist setting called Merseycare in Lancashire. It was where the specialist team were from. They said I would have my own flat and be cared for by people who knew about my autism. I cried when I found this out because I was so happy.



On the 14th December 2019, **after almost 3 years locked in a seclusion room**, I moved to Merseycare. The staff there had even thought about the journey to my new home. They let me follow the journey on a sat nav, they put jelly Christmas decorations on the minibus windows. They had my iPad filled with animal and guinea pig videos. They gave me headphones to quieten the noise and they sat me on pillows to absorb the bumps and vibrations. Best of all – my mum came with me in the minibus and my dad was at my new flat waiting for me. I was so unbelievably happy and couldn't stop smiling.



I have been in my new home for over a year now.

I'm a totally changed person.

First off, I have been given a huge amount of control over how I live and how I spend my days. I am not told how I have to do things or when I have to do them. It's a lot like being a grown-up – which I am – I'm 20 in a few days' time.

I chose how my flat was decorated. I chose the colour of the paint and the curtains. I chose which room I have as my yoga room and I went out and bought the plates and crockery for the kitchen.

I am also allowed to have pets – this is the best thing about my new life. I find animals so calming, I have days when I get anxious and stroking my pet guinea pigs, Rosie and Ely, or cuddling my lop-eared rabbit, Thumper, relaxes me almost instantly. I also have a couple of pet fish.

The most important things in my new life are my staff. They are **AWESOME!**

First off - they all understand **MY autism**. They found out loads about me from my dad and my mum, so they knew all the things I like to do and the things that make me struggle- not just the things I do when I'm stressed. The staff also all know about my Demand Avoidance and how by reducing the pressures I'm put under I become a much happier person.

Everyone understands that I don't cope well being stuck indoors – I don't ever watch telly but always have to be doing something from the moment I wake to the moment I go to bed. I'm at my most relaxed and happy when I'm busy, but because I also like to keep doing different things, I'm quite exhausting!

My staff do loads of things that help me. They let me try new things such as dying my hair or having my ears pierced – twice! I needed my hand held and I cried even though small children were having theirs done without problems. They also help me to do loads of things that I enjoy – from fishing to sledging and from water fights to shopping for clothes, they are there to support me.

I love doing drama and role-play. It is something I do when I get anxious because it gives me total control – I decide what we are going to act out. It can be dramas about aliens, animals or cartoon characters like the Teenage Mutant Ninja Turtles. It helps me unwind when I can give people scripts or certain lines, or when I tell them to say things or move in certain ways. It's ultimate power over other people in a non-controlling way. Sounds weird doesn't it, but remember my brain isn't wired like yours. When I'm feeling that I'm getting too many instructions or demands it helps me to do drama because I am then in charge and it addresses the balance. It's therefore important that the learning disability nurses working with me are ones that are happy to dress up in costumes, wear wigs and face paint, and are ok with running around like giant turtles.

All of this takes special people..

When I have staff around me who I can see want to help me by joining in, then it makes it easier for me to do the stuff they need me to do. Things like taking medication, having routine medical or dental check-ups, meeting strangers, going to new places, catching up on education and all the other things I missed out on when in hospital. They all become easier for me with people who know how I interpret the world.





I'm trying loads of new things – I really like cooking but I need a bit of extra help using the cooker or cutting things up with a knife because I get scared easily. The nursing team all know this and either support me or do things for me to stop me getting overloaded. They do all this because they understand how I see the world. I'm not lazy or just want things the easy way – I genuinely find simple things like stirring hot saucepans really scary.

I still have bad days where I say unkind things or act aggressively when I'm anxious, but instead of locking me away the nursing team support me to calm myself down then they look at what happened with a view to doing things differently the next time. Everything is learning for them and for me. I'm learning who I am and what I can do. I had been shut away for so long I forgot what an amazing person I am. I also realised how mentally strong I am. I know I can cope with anything life throws at me.

In the 12 months or so I have been out of the secure hospitals I have changed massively. I can control my emotions more easily because the team have helped me identify my feelings. I am much more accepting that not everything can be done the second I want it doing.

I'm happier now than I have ever been and I'm looking forward to the next stage in my life. I want my own house where my family can come and stay with me. I want a dog, a camper van to go on holiday in and I would love to go to college then get a job working with animals. I want to live an amazing life in the way I want to live.

I know I can achieve all of this. The nursing team who help me all believe I can do it too. **Nothing is going to stop me – I'm in control of my life, but I'm also supported by amazing people who have promised to get me there.**





**No one is too disabled,
or too affected by
mental health difficulties,
to lead an ordinary life**

Changing Our Lives

Tel: 0300 302 0770

Email: ask@changingourlives.org

Web: www.changingourlives.org

Twitter: [@positive_lives](https://twitter.com/positive_lives)

Registered Charity Number: 1093883