

Real change – without exception

Ralph Waldo Emerson once wrote that “What lies before us and what lies behind us are tiny matters compared to what lies within us.” As a nineteenth century American poet, he would never know the significance of those words to one family, my family, who have witnessed the true power of that something that lies within.

What lies within my brother, a man less than two years my senior who is already a veteran of the care system, is a determination beyond any other I have seen. His is a determination to smile, a determination to achieve and a determination to trust in the absence of reason. Ben has proven without question that Emerson was right.

I was born the sister of a boy with learning disabilities and stand here today with that responsibility on my shoulders. My responsibility to my brother - both the boy that once was and the man that now is. The responsibility has been a constant throughout my life and now, twenty years on, I realise how big that responsibility truly is.

Fourteen years ago, when Ben walked in to his first residential school, the journey before him was one aimed to nurture him from the challenging young boy that he was into a man with skills, aspirations and potential. It would be a smooth road, one that would see Ben learn, grow and achieve. At that point, we would not have considered the reality that followed as even the slimmest of possibilities.

Ben entered that first residential school as the result of input from a vast team of professionals working behind the scenes. His first

night away from the family home and of his long journey through the care system came with the, albeit painful, blessings of his family. The significance of the professionals entrusted with Ben's care was to increase over time. They would be the people to see Ben move when a failure to cope with his behaviour resulted in exclusion from schools. They would be the ones to decide where he would live next. Perhaps most pivotal though was the decision, when Ben's mental health deteriorated at eighteen, to move him to Winterbourne View.

Winterbourne View is a name with a legacy, it now symbolises not just one of the greatest failings of the modern care system to date but one of the most cruel elements of human nature: our ability to seek and exploit vulnerability. The events of Winterbourne prove that no matter how far we think we have come: the journey to the equal, just and rightful treatment of people learning disabilities is not one that has come to an end. For me, though, it represents the darkest of times for Ben, our relationship and our family.

For twenty years I have known my brother. Through seven schools and three adult care facilities I have battled to maintain a relationship with him. Understanding him has at times been a struggle yet though our time together was often sparse, I have fought to be his sister. For that I was rewarded with a relationship unlike any other I have ever known- it was a relationship that thrived in love, trust and determination. It is a relationship that was almost lost to Winterbourne View.

When I think of the days that Ben spent in Winterbourne View, I often wonder where I was. Where was I when Ben received the carpet burn on his head that first raised my suspicions? What was I thinking when I believed it would be wrong to suspect

professionals of failing in their duty of care so dramatically that they may actively seek to abuse my brother? Where was I when Ben's jaw was broken and tooth lost as he was 'punched or kicked' by a member of staff who remains unpunished?

Was I being the teenager that Ben deserved to be?

Ben's journey through the darkness did not end when he was discharged from Winterbourne View. Instead, the move to his new 'home', seemed to push the light at the end of the tunnel ever further into the distance.

Instincts that had seen me silently question the goings on behind the doors at Winterbourne View quickly resurfaced- this time drawing me and my family into a battle to protect my brother. It was a long- fought battle and one that saw my family begin to crumble under the strain. At seventeen years old I sat in meetings with my brothers abusers and willed for the turmoil to end and for Ben to be safe.

It took a year. For someone to listen. For someone to care. For someone to prove that we were right.

Today my brother seems like a haunted man: his eyes like doorways to a troubled past, his mind a tangle of memories and his life a puzzle- once torn apart- that is slowly, patiently and lovingly being rebuilt by those who care about him. We feared that the group of people who care about Ben would never be joined by carers that also do. Bens current carers, however, a group tasked with the challenge of finding hope in a lost young man are doing so with the utmost care and affection. The care and affection that Ben has always deserved. When our broken family lost its trust in the world, these were the people that

proved that good people do exist, that good places do exist.

What lies before us and what lies behind us are tiny matters compared to what lies within us. This is true of the care system as much as it is true of every person living and working within it. What lies behind the care system is a web of misery dating back hundreds of years and extending, sadly, to this day. This is a system born from institutions, designed to facilitate community care and support for those who, in the past, had been segregated, degraded and ill-treated. It is a system that has failed many times and, for many, continues to fail to this day. But it is also a system with the tools, the support and the capacity to build a positive future for all.

I can only hope that what lies ahead is different.

That Ben's pain and the suffering of all those whose experiences have been similar is learnt from.

That no parent, no sibling, no family member has to stand by and watch, as we have, as their loved one is torn apart in the system designed to care.

We can only hope that our voices begin to matter.

I have been the silence. I have been the person too scared, too young, too naïve to believe that my voice matters. I have been the person who lost their voice in the turmoil of circumstance. I have been the person whose guilt crippled my every word, my every emotion, my every hope.

I have been that person. And I have been this person.

The wound in the care system is exposed- every day the media seek stories of further mistreatment in care facilities around the country and all too often their thirst is quenched. There are more people suffering as I speak and they will continue to suffer until real change is seen.

Our society should have moved on from such archaic treatment of people with learning disabilities, from looking down on those who may lag behind. We have proven ourselves to be a society that cares when abuse is exposed, one that calls for change, that has a voice.

This should be the legacy- not Winterbourne View, nor the next place or the many places that have, and continue to fail in their duty of care. But a society that speaks for its most vulnerable members, sought change when their pain occurred and made a difference to their lives when their voices were silenced. It is a legacy that cannot and will not happen without substantial change at the core of the system and, as I speak today, what lies before my brother and the many other who call the care system home, remains undecided.

I can only hope that the legacy they deserve is achieved.