

# Do you see me?

## A patient perspective

Katy Blackmore



**Katy Blackmore** - After some dark days during which Katy experienced a short course of talking therapy, she became curious enough to rethink her career path. Katy became a person-centred counsellor and she has worked in several settings including HM Prison Service, a UK Adoption charity, the homicide division of Victim Support UK, primary schools and pupil referral units.

She currently specialises in working with trauma and supporting parent/child relationships both privately and within a school and early years setting. Alongside this, Katy is developing a social enterprise project [www.embracingempathy.co.uk](http://www.embracingempathy.co.uk) aiming to support cultures of empathy within our healthcare systems.

**A**s I write to you, the medical professionals, I wonder, what is the most important message to hear from my own patient story. Shall I speak about my presentation as a toddler, the subsequent diagnostic and reparative journey and the vast array of procedures I have undergone? Or perhaps you should hear about my experience of chronic pain and the many ways I have sought to manage this on a day-to-day basis? And would it not be productive to enlighten you about my experience of being at the sharp end of a power imbalance inevitably manifested from professionals assuming the expert position? But... no, I want to talk about **Shame**.

Aged 18 months my parents realised that I was not walking the way my brother had, I was referred to the local orthopaedic surgeon and



diagnosed with bilateral CDH which set me on a course of corrective surgery that had mixed results. My left hip surgery was successful, but my right hip refused to respond. At age seven, my parents were told that there was little chance that I would walk again. However, a timely referral to GOSH gave me new hope. A successful Colonna procedure enabled me to walk for a short time. Puberty brought uneven leg growth, requiring two lengthening surgeries over four years. But by age 18, I could again walk unaided, and I enjoyed nearly three years at university before I was struck by a car just ahead of my finals. This led to more surgery at RNOH, including a titanium nail in my tibia that I still have today.

After some dark days post-finals, I realised that I had been harbouring childhood medical trauma and began my own therapeutic journey to understand and heal these wounds from childhood that were impacting on my adult life. I discovered latent 'Toxic Shame' at the root of my life story, informing every decision, instilling every feeling that I faced in the moment. I had never experienced my body as my own, having been repeatedly exposed to strangers in the most undignified ways. I watched my family in pain as they were exposed to my pain: all of this made me feel wrong inside. To feel right, I was as 'good' as I could be, cried as little as possible, was courageous and brave in the face of each new procedure, and did my best to take care of others around me to feel validated. My cup always had to be half-full in a world that felt empty and unsafe. All my efforts failed to take away the 'wrongness' within. The trouble with compliance and painted on smiles is, of course, that my shame was banished into the

depths of my soul only to leak out in other ways... perfectionism, a reliance on alcohol, an inability to hold boundaries or say no to people, feeling I had no voice and crippling anxiety, I could go on...

So, what is *Shame*? The Oxford English dictionary definition is **'a painful feeling of humiliation or distress caused by the consciousness of wrong or foolish behaviour'**. We need to acknowledge this feeling to set our moral compass, stick within the boundaries of what is right and behave appropriately towards self and others. Now whilst I wasn't 'wrong' to have been born with a disability, constant intimate exposure to painful, dehumanising procedures, knowing that loved ones were suffering at my expense led to an internalised sense of shame and feeling that my whole being was in fact wrong. This is when healthy shame becomes toxic. John Bradshaw stated that *"shame as a healthy human emotion can be transformed into shame as a state of being... [which] is to believe that one's being is flawed, that one is defective as a human being. [Shame] becomes toxic and dehumanising"*<sup>1</sup>.

Throughout my childhood, I suffered trauma from countless physical procedures alongside the additional complex layer of trauma associated with my compromised feelings of worth. Long-term such high psychological distress levels in individuals with trauma exposure are associated with elevated inflammatory markers. Various studies over recent decades have explored the link between childhood trauma and inflammation, which can lead to chronic diseases, for example cardiovascular issues and psychiatric conditions such as depression. Research findings from a study on childhood trauma and adult inflammation concluded that there was *"strong evidence that childhood traumatic events significantly impact on the inflammatory immune system, with trajectories reaching into adulthood, thus offering a potential molecular pathway by which early trauma confers vulnerability to developing psychiatric and physical disorders later in life"*<sup>2</sup>. Perhaps, no wonder that tonsillitis and other illnesses were ever-present throughout my childhood. This is important for all healthcare professionals to hold in mind when interacting with patients in an ever-stretched healthcare system.

Whilst much of this impact was unavoidable, there have also been many distressing interactions with healthcare staff which, whilst unintended could have been avoided. Professionals entering the room who did not acknowledge me, nurses standing over me, dressing my wounds whilst talking to

each other about my body parts, receptionists who worked only to script, and consultants who talked over me and worked hard to avoid eye contact when addressing me. Every time I was faced with a substandard interaction my complex trauma was compounded, my self-worth was further diminished, and I was silenced again.

Only when I was 20 years old did I meet a consultant who treated me with a level of compassion and empathy that helped me feel truly seen as a person and not a set of medical records. They would look directly into my eyes, wait patiently to hear my thoughts, and had a natural capacity to empathise with my experiences. Alongside this, an ever-supportive network of family and friends, pockets of gold standard healthcare provision and my determination to recover from my trauma has helped me find my voice and place myself in a position of strength that can be used to help both myself and others.

It has led me to a personal project that focuses research on how to create a culture of empathy within our healthcare systems to support **both** professionals and service users in their positions, bolstering staff within highly pressurised environments and reducing the impact of internalised shame in their patients. Brene Brown sees empathy as **"the natural antidote to shame [ ] If we can share our story with someone who responds with empathy and understanding, shame cannot survive."**

Empathy is defined as *"the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another"*.

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Developing empathy is crucial for establishing relationships and behaving compassionately towards others.

Experiencing empathy with a medical professional whom I knew was held in high esteem helped me to consider myself, for the first time, through a more compassionate lens. I reached out to a couple of therapists in my twenties, but it was only in my early thirties as a young mother and a practicing counsellor myself that I really began my own discovery of self and journey towards the self-compassion necessary to heal from my toxic shame. Gentle encouragement from my clinical supervisor led me into the therapy room not as the 'good'

therapist or the 'good' wife and mother, but as me. I started to feel for myself, to acknowledge my losses and appreciate my struggle to endure painful situations. I found I was able to access many needs within me that had laid dormant, and for the first time in my life I could find ways to meet these needs with intention and care. I realised I had been denying so much of my pain that it was impossible for me to know when I needed to take care of myself in even the most basic of ways like sitting down to rest a while or remembering to eat. So powerful is the neuroscience of our >>

emotions that it was about a year or more after my therapist had suggested a daily ritual of putting lotion on my body, that I realised I had routinely covered only the top half of my body, neglecting my legs! My poor legs, I had denied them for decades, and yet they had survived so much, done so much for me, only for me to disown and disconnect from them completely. Today I can acknowledge and be proud of my body and its battle scars, my body tells my story, and my voice, now unsilenced, protects and advocates for me and others who I care about.

NHS England states that “Compassion is how care is given through relationships based on empathy, respect and dignity. It can also be described as intelligent kindness and is central to how people perceive their care.” For me this concept underpins quality of care within all systems, in fact it should be at the heart of all human interactions. However, turning concept into widespread practice is not easy, and twelve years on there is still an ongoing need to improve consistency in the quality of interactions between healthcare professionals and service users. Systems are shaped by people who have feelings, and who need to know how to care for themselves and each other. We all have a lived experience, a narrative that forms and shapes our intentions and actions, much of which we do on autopilot.

It is easy to become comfortable with our environments and routines, humans thrive on routine, but this does not always produce best practice.

Years ago, I attended A&E with a severe facial cellulitis. After a misdiagnosis by the duty consultant, a junior doctor listened to my opinion then strategically waited for a staff changeover, which led to a second opinion garnering swift appropriate treatment. This caring individual looked me in the eyes with concern and listened to me. They were committed to hearing me and challenged their own system of practice to do so, which made all the difference to the outcome. Perhaps this highlights a need to challenge internal hierarchies that at times foster a culture of fear in communications up the chain.

I understand the bigger picture of an extremely pressurised service with more demand than supply and staff who are also feeling underappreciated and ‘unseen’. I will not be another voice complaining about a provision that heals and that has enabled me to walk without aid. I wish to give back to a system of people who service humanity at its most vulnerable; to help that system heal. Compassion and empathy must start within; you and the work that you do within the healthcare profession is invaluable, and to take

good care of others you must take good care of yourselves first. Years of personal therapy has taught me that this is no small task, and at times I do forget to practice what I preach. Nonetheless, I am committed to starting each new day holding on to the promise I have made to me to view myself and others through a compassionate lens.

It is this that I would like you to take home today; with each new day consider what you need, to be the best version of yourself, for both you and those around you. When you go into work tomorrow, take the time to ask at least one of your colleagues how they are, and really listen to their answer. When you see your first patient instead of looking through the lens of the procedure you are planning, look into their eyes and imagine being in their shoes; what would you hope for from your doctor if it was you? Lead with your humanity. There will never be enough hours in the day to complete all our ‘to-do’ lists, there will always be deadlines and hierarchy and system pressures. But we cannot escape our humanness and at our core this must be honoured, not only for ourselves but for all those around us. In a world that teaches us daily to disconnect, we must fight back with commitment to a human connection, to feeling for ourselves and for others so that we allow our needs to be met within our imperfect systems. In your interactions, you have the power to limit your patient’s trauma, and to create a better quality of everyday life for yourselves and others around you. I see you; I see the heavy weight of responsibility carried when others look to you to fix them, the stress and burnout of a system under pressure, and the never-ending, often thankless, list of tasks to be done. And I see the individuals you serve; I see their fear at the unknown and feel their pain as they navigate the trauma of illness and suffering. Our humanity connects us; we are all one and in order not only to exist but to thrive we must remember this.

*“When humanness is lost the radical difference between the bodies in the pit and people walking on the street is lost.”*

**Edward Bond, Playwright**

*‘Love and work are the cornerstones of our humanness.’*

**Sigmund Freud ■**

### I've Got This

‘Dear Little me,

I've got this. You rest now, you've earned it.

You've done so well, you have survived the poking and prodding,

Enduring the subtle cruelty of a system that cannot see.

You are still here,

Amazing You!’

‘Dear Little me,

I see you are still frozen in your fear,

No voice to tell of the horrors in the There and Then nor the Here and Now.

Silent compliance is your saviour.

And yet it holds you back, sweet one.’

‘Dear Little me,

Life has taught us the value of fight...

Don't you see? You are not frozen in fear anymore, unable to run or push back.

Together we have a voice now.’

‘Dear Little me,

I will take the reins today.

I love you little one,

And I've got this.’

**By Katy Blackmore**

### References

1. Bradshaw, John. (2015). *Healing the Shame that Binds You*. Health Communications, Inc., Deerfield Beach, FL 33442.
2. Baumeister D, Akhtar R, Ciufolini S, et al. Childhood trauma and adulthood inflammation: a meta-analysis of peripheral C-reactive protein, interleukin-6 and tumour necrosis factor- $\alpha$ . *Mol Psychiatry*. 2016;21(5):642-9.