



“After he died, the little plastic ID band that was around his tiny wrist should have been slipped onto mine. There was nothing more that could have been done for him, but there was plenty that needed to be done for me. I needed an infusion of truth and compassion. And the nurses and doctors who took care of him, they needed it too.”

Leilani Schweitzer

When we lost our children, Joshua in 2008, and Jasmine in 2011, we needed truth and compassion. We needed care to be given to us that kept our suffering to a minimum and gave us hope of ‘recovering’ as best we could from tragedy.

The trust the public have in healthcare is fiduciary trust. A belief that staff and the organisation are motivated and intend to act in the patient’s best interest at all times, and never take advantage of their vulnerability

Sidney Dekker says that when there has been an incident of harm, we must ask, “Who is hurt?”, “What do they need?”, and “Whose obligation is it to meet that need?”

We wanted to be recognised as people who had been hurt, with needs that needed to be met. We believed that the system would act in the best interests of our children and ourselves, because that is the trust we all place in our healthcare system at all times.

Instead we were not treated as people in pain who needed urgent care. There was no transparency or openness, our core need, without which even beginning the process of grieving became difficult, yet alone the hope of healing and reconciliation. There appeared to be little concern or respect for our children and ourselves, or the devastating impact of lack of truth or compassion on our physical and mental health, our relationships, and many other aspects of our lives. We had to ‘work’ for information we needed and deserved to know. The healthcare system did not act in our best interests. There was no placing of a plastic ID band on our wrist.

We experienced betrayal of our fiduciary trust. Our child was the patient, they had died, and it seemed that now they, and we, were owed nothing. Not even a full and truthful explanation and apology. Worse, the organisations where these things happened acted in ways to serve their own interests above ours. We were managed as a source of risk, rather than cared for as harmed people. Sadly, our experiences are not unusual.



In the aftermath of harm, focus is on protecting future patients by learning and preventing a repeat. The safety of those harmed this time is frequently neglected. Those harmed by healthcare will say 'we don't want this to happen to anyone else' Again, this puts the focus on protecting the future patient. Harmed patients and families want to protect future patients, of course they do, but they also want to be protected themselves, to receive the care they need to recover, and not to be caused any further preventable harm by the healthcare systems treatment of them.

Good engagement with harmed patients and families will come from a deep understanding that its purpose is not just to provide information or gather insight, it is delivery of a core care need for their safety, to help them recover.

In the aftermath of our loss, we needed healthcare to fully acknowledge and thoroughly understand our experience of what had happened to our children and the impact it had on us. We needed answers to all of the questions that we had, that were important to us, and we needed those regardless of whether anyone else felt our question relevant or important. We needed staff to be supported to give us honest accounts of their actions and their reflections. We needed a collaborative approach to reach a truthful and evidence-based explanation of events. We needed help and support to understand what all the processes were that were happening and how to engage with them. We needed the system to learn and to see meaningful change, but we also needed the system to help us heal, recover, and restore our trust. Meaningful engagement coming from a place of care could have provided that. Instead we experienced a healthcare system that had little interest in our needs, that made our healing and recovery impossible, and caused us further preventable harm.

To promote the urgent need for the system to support the healing and recovery of harmed patients, we have founded the **Harmed Patients Alliance**. Working with a wide range of experts, we will increase understanding of what harmed people need to be helped to cope and recover, and will work collaboratively towards a future where they get it.

Joanne Hughes
James Titcombe
Harmed Patients Alliance

To find out more about the Patient Safety Virtual Congress
visit virtual.patientsafetycongress.co.uk and register [here](#).

Alternatively contact Ryan Bessent

E: ryan.bessent@wilmingtonhealthcare.com T: +44(0)20 7608 9045