



A PATIENT EXPERIENCE

A story of patience



INTRODUCTION: Hi I'm Shaun, and this is my mum, Gretta. We're here to tell you about our personal journey with the ICU. First, I'm going to tell you a little bit about me before I had my accident.



I was 19 years old, studying applied physics in the University of Limerick and working part time as a waiter and bar man in Aherlow house hotel in Tipperary. I enjoyed playing Rugby in my spare time along with martial arts and chess. I was a founder member of the chess team in my school, and thought a lot of my fellow students how to play.

My only memory of that day was when I initially woke up in hospital. I tried to move but was unable to. My head was quite fuzzy and I was disorientated about where I was. My parents were at my bedside and explained what had happened: I was driving home from work, when my car was involved in a collision with an ambulance. I had no memory of what happened since before the accident, but my mam and dad reassured me that everything would be ok. I'll let my mam fill you in on her recollection of that period in time before I continue.





We were just a normal family, but to us, we were the perfect family, enjoying our busy lives and forever making plans for the future. The evening of the 27th July, 2013, was about to test our love, strength, and determination. My husband and I were sitting at home waiting for Shaun to finish work. There were lots of presents on the table for him- my daughter, Chloe had just returned from Disneyland with the majorettes that afternoon and had brought him home a giant mug for his coffee, my mam, dad and sister had also returned from visiting my brother in Australia and had brought home rayban sunglasses he requested along with other bits and pieces. The Garda car pulled up outside and I immediately knew that something was wrong with Shaun. They told us we needed to get to the hospital as quickly as possible but couldn't tell us any more. The journey in was a blur, I can remember telling my husband to drive faster as I needed to know he was still alive and calling my mum to go to the house to mind our two younger kids as I left them with the garda who called to the house. When we got to South Tipperary general hospital, I went in while my husband parked the car. I remember being in a crowded waiting room and being called in to a room beside rescus. I worked in this hospital as a midwife so I knew this was not good. After what felt like an eternity, a lovely nurse and doctor came and spoke to us



they told us to prepare for the worst, that Shaun had broken his neck in the worst possible way and his injury was incompatible with life, but they would do their best to stabilize him while we gathered family and made a decision about organ donation. They moved him to the ICU and I spent the whole night by his bedside pleading with him silently to wake up.



The following morning at around 7 am, my sister and niece had just arrived from Dublin, and as they walked in the ICU door, nothing short of a miracle had occurred. Shaun popped his eyes open and worded the words 'well mam, hi Anne, hi Kellie' through his lips. He was awake and very aware. This was the first turning point for us. We knew everyone in the ICU was rooting for Shaun to survive and the discussion began to have him transferred to the only dedicated spinal injuries unit in Ireland in the Mater hospital, Dublin.



The Staff in STGH were absolutely fantastic, they were sensitive, understanding and caring, at the most difficult time in my familys life, when our perfect family bubble had burst. It was the little things they did along with the big things: allowing visitors to spend some time with him, allowing us to eat as a family at his bedside, all the little things we had taken so much for granted before, that we might never get to do again. All the time, Shaun was so well looked after, as he drifted in and out of consciousness. At one point he asked us what happened. We told him not to worry, that we would 'fix this' which we really believed at this point, but we would have said it either way to keep him calm. Finally, the Monday afternoon, two days later, it was decided that Shaun was worth taking the chance on transferring to Dublin. We were told to say goodbye before he left as the odds were stacked against him arriving to Dublin alive.



But against the odds, and with the amazing care he continued to receive, Shaun arrived to the ICU in Dublin to await a full medical review and plan of action. Surgery was performed on the Tuesday afternoon, to stabilize the fractures on his C1 and C2 vertebrae. Again, a daunting wait, not knowing whether Shaun would survive, would end with slight relief. Shaun had yet again beaten the odds. Two days later a tracheostomy insertion was performed, and we were told to take each day as it comes, but after all Shaun had been through, we were more and more hopeful as the days went by. And Shaun never let us down. Four weeks after his admission to the ICU with the help of the amazing, professional, caring staff, Shaun was finally ready to move to HDU. Although this might be hard to understand, for us this was like a gift from heaven. And things would only get better and better.



A couple of weeks later, we were waiting outside the HDU when a nurse came out and asked us had we heard Shaun Speak. She told us Shauns trachy cuff had deflated overnight and they could hear him calling for a nurse. She brought us in and deflated his cuff for a couple of minutes while he spoke to us while monitoring his saturations. I think I shed my first tears of joy that day. Initially we were told that he would never speak, eat or drink again, but here he was speaking with ease. What else would our miracle achieve.



Weeks went by, numerous angels in the form of Consultants, registrars, SHO's, nurses, HCA,s, physios, Speech and language therapists, occupational therapists, and all the other diligent staff in the Mater, made our new home environment welcoming, family orientated and comfortable. Shaun's next move was to the Spinal unit where he would spend almost a year. I'll pass you on to shaun now to continue our story.....



In a lot of ways, the spinal unit was great, from getting me back eating and drinking to organising the eye gaze and chair it gave me the tools to back to my life. It was like a new home, but it wasn't, from my family having to drive two hours to see me to not being able continue college it was grand at first but as days turned to weeks, weeks to months things became more difficult.



Hospital isn't a place to call home no matter how good everyone there is, especially when you know it's not the final step on the journey home. I remember being told that I wouldn't get any movement back and that was disheartening be not half as bad as being kept waiting for months on end to go to rehab in a different country tearing my family apart.



It continued like that for months after everything was organised and took endless research and emails on my family's part to get me to rehab. It was difficult even to get a medical card without more trouble than it really should have been. I had help from people in and outside the hospital but there was no clear channel to get anything. we felt lost and stuck in limbo. When we got the news I was finally being sent to rehab It was great - it would be three months and home, but it wasn't meant to be.



I was taught a lot in rehab but well after I finished the programme, I was still there, not an end in sight, my mam came over with me and stayed in a hotel but it was difficult with the rest of our family in a different country. They put a full home care package template together for easy implementation when I was back in the country. I spent nine months in Stoke Mandeville waiting to be accepted back to Ireland and required fighting on my family's part and even getting politicians and spinal injuries Ireland involved to get back to the mater.



I returned to the mater feeling excited I would be home soon but that didn't happen. It took weeks of meetings and arguments before we were told we would be discharged back to the hospital in Clonmel, but in the weeks of trying to come to an agreement that I would be given a home care package, the care plan from England was lost. I spent 300 days in ICU waiting for another one to be organised and implemented.



Nevertheless I 've made it back where I wanted to be and I'm home now with a great home care team and I'm back enjoying studying full time in UL and even got to develop some games and websites even got to meet the Munster team. I'm grateful to have gotten back home and I want to thank everyone who helped get me there. I'll let mam tell you a bit more.



I hope by giving this talk it will show not only the difficulties we faced coming home but what can be done when there's a clear path and allow others not only to survive but thrive and achieve their dreams (maybe just a bit faster).



Thanks Shaun.

As Shaun said, getting him home was the biggest battle we ever fought! Long term residential care in a nursing home was mentioned, but we never entertained that as an option- Shaun did not survive against all odds to live out his days in a nursing home as far as we were concerned, and I vowed to bring him home where he belonged no matter what the consequence. As a family, we wrote letter after letter, email after email, and eventually contacted Spinal Injuries Ireland. The CEO of Spinal Injuries Ireland and I lobbied every politician in Tipperary together, and eventually, along with the help of the teams in the Mater, NRH and STGH, we secured funding for Shauns home care package. Home Instead was chosen to be Shauns home care agency and training commenced for Shaun to come home.



Training of the personnel who would look after Shaun not only when he came home but also on his transfer to STGH ICU was a vital component of his success story.

The spinal injuries unit in the Mater and STGH ICU facilitated a full training program in Shaun's very specialized care. In turn, STGH ICU facilitated the training of Shaun's home care team, to make them competent in Shaun's day to day holistic cares, along with fast identification of infection/sepsis. STGH ICU also put an action plan in place if the need for an admission arises. He is sent straight to AMU for full triage assessment and plan of care to be implemented. If IV antibiotics are required, the community intervention team come to the house to administer. Overnight admissions have been avoided or at least minimized as a result, and we often joke that Shaun is like the president when he goes there with all the staff popping in to say hi!!!



We were very lucky to have learned so much from the UK that we could transfer to here. We kept lines of communication open with regular MDT meetings, which we still attend with Shauns home care agency. We set goals that were in some minds unachievable but to us were the only option. We challenged every obstacle by not giving up but trying to find at least a solution, if not a compromise, and while we dream of a future where Spinal cord injuries will be curable, we also live our lives to the fullest, we don't sit and wait, we live for now!

Shaun is now attending university as a full time student, enjoying hot whiskeys when he's out for his Fillet steak dinners and probably has a better social life than me. This wouldn't have been achieved if not for the fantastic holistic care Shaun received in both ICUs.



We are very lucky to be where we are today. We have many people to thank for that. Our amazingly supportive family and friends, all the medical and other personnel we had the privilege of meeting in the HSE, The Mater, STGH and NRH, who all continue to deliver an exceptionally high level of care and who we now also refer to as family, our fantastic home care team, and all the staff at home instead, we will be forever grateful to each and every one of you.



My family's dream for the future is to see a clear pathway of care for people with spinal injuries that will guide the Multi disciplinary team of health care professionals along with the HSE, procurement managers and all stakeholders on best practice regarding discharge home from the earliest possible stage in ICU, which is their fundamental right. We hope that when making decisions regarding people's lives that professionals will stop and think 'how would I feel if this were my child, or mother, or ME, because it could, some day, be any of us.

We finally hope that the support networks for people with Spinal Injuries and their families will continue to grow and develop and that the world will see people like Shaun, not as disabled, but alternatively enabled.



Thank you for your time.