In 2001 in Limerick, a remarkable little baby, **Sean Holland**, announced himself proudly to the world. Brimming with joy and love, Sean's devoted parents **Pearl and John** along with Sean's 3-year-old adoring sister, **Niamh**, had no idea then that this gorgeous, new-born infant was about to single-handedly chart their family's life's journey. Six months later, Sean was diagnosed with life-limiting Lissencephaly and a spectrum of other very serious conditions. He was given two years to live.

For the family, it was a time of heartbreak, confusion and desperate worry. But, somehow, they found an extraordinary strength. They soon began to set their own standards and to negotiate a frustrating and difficult pathway through the healthcare system by turning to the only assets they had – self reliance, belief in Sean, the love of family, friends and neighbours and by following a simple formula: doing what they thought was best for their wonderful son.

Meeting them in person, it's clear they've worked hundreds of minor miracles. And so has Sean himself. Twelve years later, he is still living out his very full life, his winning personality proudly breaking through his severe physical and neurological disabilities. Everyday he continues to define himself: a fanatical Munster supporter; a serial visitor to Disneyland; his Gaelic Footballing sister's biggest fan; and so much more.

Sean's story begins long before Sean was born with the first meeting of his parents in Christmas 1989 in Buddy's Bar in Limerick city. John remembers it well:

"In she walked. That lovely big mad head of curly red hair and that big mad smile and I went Jesus Christ, she got me. It was definitely love at first sight."

Laughing at John's memory of the meeting, Pearl describes the initial spark for her as more 'slow burn' but it's obvious the attraction was there from the start. Soon they were a strong couple. Marriage in 1996. Their beautiful daughter Niamh arrived in 1998. Then Sean was born in 2001. Pearl says there were no warning signs during her pregnancy:
"He was a bit small when he was born but he was perfect. As time went by it was clear that he wasn't developing like he should".

The day the consultant diagnosed Sean with, initially, Microcephaly and then subsequently, Lissencephaly, everything changed. The Holland family began to experience vastly different standards and cultures of palliative care – the good, the awful and the loving. They were bombarded with scientific and medical jargon at times when they were very vulnerable. John describes the traumatic time around Sean's diagnosis.
"I was in college in Dublin training to become a paramedic. I was travelling up and down so Pearl was on her own coping with so much. I was struggling too, trying to study and stay in touch with all the changing information on Sean's condition. It was a horrible, horrible time."

They met the most caring and understanding professionals but they also had a number of shockingly insensitive and professionally incompetent encounters. Pearl and John are very emotional when they describe one such encounter that happened early on their journey:
"Because the information is flooding at you, my sister had advised me to write down my questions before meeting the consultant. I was in the beginning of my list – very important issues about our son's care and life expectancy – when Pearl understandably got very upset. I stopped for a minute to comfort her. When I went to get him to continue, he had just disappeared, no apology or explanation. He had just told us that 'Sean was going to die. Get on with our lives. Leave Sean in hospital' and then he leaves us hanging with that insensitive news."

On another occasion the consultant pointed at Pearl and told her *'it was all her fault'* by way of explaining the X-chromosomal link to her side of the family. The effect of that incredibly inappropriate information delivery devastated and infuriated Pearl and John.

The Hollands have experienced the best and the worst of care at every milestone – from diagnosis, prognosis, to information overload, to having to become de-facto medical experts, to hospital care, home care, respite and planning for the future. They're certainly very articulate and passionate in describing their own common-sense definition of quality palliative care and the simple principles that must be at its heart:

"It's actually a partnership between the family and the experts – not a one-way thing. You need people who are prepared to listen and give you time. You need a really great GP, which we're so lucky to have. We're not looking for heroes who get everything right – that's not possible – we just want competent professionals and the system to have Sean's best interest at heart. And a bit of human empathy and sensitivity."

For Pearl and John, Sean's care regime is relentless – 24/7 every day, every night. He has multiple problems like scoliosis, constant severe congestion of his lungs, he needs Botox injections into his muscles to relax them; his hip clicks in and out of place; he has seizures; he's had strokes, chest infections and pneumonia. And the wondrous thing about this family is that in the very next sentence they can talk with natural ease about the fun they have together. The joy they get from a simple smile. The craic they can still knock out of life. Blissful images of the family dancing in the living room with Sean laughing in their arms.

After just a couple of hours in their company it's clear that Pearl and John are the best champions Sean could wish for. But families that have children with life-shortening conditions inherit many serious financial, domestic and family challenges. Time becomes a precious commodity. Because of the uncompromising care schedule, siblings often have to cope with less parent time than other children. But John and Pearl are so proud of their 16 year-old daughter Niamh.

"She's experienced things we wish she didn't have to. But for her, that's just part of life. I don't know any other teenager that has to look in that mirror and face the fact that her little brother, as sure as night follows day, will die much sooner than he should."

Pearl can't hold back the tears as she continues:
"One day she was in the car with me when Sean stopped breathing. She saw me banging on his back in panic trying to bring him back to us. She saw a woman giving him CPR on the side of the road. She saw him turn blue and ashen. She is an absolutely super, super girl, daughter and sister. And on top of that, she's a fantastic and skilled carer for Sean too."

Other parents with children facing a shortened life often ask them for advice. John has words of enlightened but humble wisdom:
"I tell them it's just a learning thing. Anything you do out of love won't be wrong. There's no manual on it – but all I can say is everything we did was for the right reason. So I'd say to families today – just go with your gut, and your knowledge of your child. But equally if you don't like your consultant, get rid of him or her and move on to better things because there are fantastic professionals out there.

As the interview finishes I'm reminded of something John said in the very beginning of our chat:
"When your child is first diagnosed, you bury your dreams and later you need to imagine new dreams. Because every man has a dream about his son – that he'll play hurling for Limerick, rugby for Munster. That he or she will be a doctor, a musician, whatever you want your child to be. So you have to go – that's not going to happen, so now I have to form a new dream. I have to bury that old dream."

The Hollands have done just that. They've turned a nightmare into a new dream for Sean. And it's almost as if Sean has had a dream for them too – because as John attests:
"We have a brilliant child who has given us so much, who has made us what we are."

Wonderful dreams and challenging realities. These are the narratives that move and inspire everyone who meets this remarkable family.