Supporting a loved one at the end of life is a challenging, emotional and sacred act of love. But how do you cope when the end of life happens at the beginning of life – when the person you are losing is your beautiful, infant child?

In early 2012, **Brian and Sharon Thompson**, found themselves in this very dark place. They were told their only and beautiful daughter, Victoria, was going to die. But they also began to realise they would have to fight to secure the best end-of-life care for her.

Uniquely, unlike most families who fight to have their loved one die at home, the Thompsons had to battle at every turn to ensure Victoria could die away from home. As they explain, this was exactly what Victoria needed.

Gorgeous Victoria Thompson had an important message to pass on, right from the day she arrived into this world, on September 27th 2011. Sharon describes the day she was born:

"I looked into her deep, dark eyes. She looked back with intent – as if she had a message she needed to give me before life and people interrupted us. Those eyes were so wise. I knew she was a special soul. I told her so out loud."

A traumatic birth and first night, were signs of what was to come for much of Victoria's short life. However, Brian and Sharon took a healthy baby home. Victoria developed like any baby would. Contented, she slept well, giggled and guzzled her bottle.

Family, friends and strangers were smitten with her bursting personality. Brian, Sharon and Victoria were a family woven tightly together by the golden thread of love that a special, new baby brings.

After a few months, things slowly began to change for Victoria. There were sudden moments of distress, screaming and constant crying. It was clear that something was wrong as Victoria flatly refused to take her bottle and the crying got worse.

Victoria was finally admitted to hospital but Brian and Sharon found that they still had to fight for their baby. They had to confront the professionals. They had to ask hard questions, to demand answers, to get them to really examine what was happening with their daughter as a person, not just as a patient.

As would be the case through the family's entire end-of-life journey, it was the nurses who became their allies and encouraged them to make demands for Victoria. Sharon described the nurses they encountered as 'earthly warrior angels'.

After a difficult time of force-feeding, Victoria was transferred to Crumlin Children's Hospital. There things were much the same for Victoria – but extensive tests were done.

"We met a brilliant Neurology team. We knew right away they'd do their best for Victoria. Again, the nurses were amazing. We were still in hell. We didn't know what was wrong. It was particularly hard for Brian as he was travelling up to north Donegal and back. His elderly mother needed care."

Weeks passed and the news they never wanted to hear came – the news that Victoria, in her own gentle and wise way, had begun to prepare them for. Contained in the diagnosis and prognosis were some unbearable realities:

Victoria had an incurable, untreatable rare condition which left her in constant and severe pain.

"Victoria's nerve endings were un-insulated. They were raw. She also had horrendous symptoms. Terrible things no child should endure. We can only think about that at times. Our first question was 'how do you fix it?' Then you're told– it can't be fixed."

Talking to Sharon it's clear that a well of emotion is always just below the surface. Every so often, the raw memories of little Victoria's struggle and a mother's primal love, conspire to allow tears to flow. It feels like a natural and powerful part of how Victoria wants her story to be told.

But alongside all the tears, there were moments of great joy. One such joyous moment was when LauraLynn, Ireland's only Children's Hospice, came into their lives. LauraLynn allowed the Thompsons to deliver on a sacred promise to Victoria – to give her the best life she could possibly have. It also allowed them to give her the best end-of-life.

The possibility of bringing Victoria to LauraLynn came out of yet another crisis on their journey.

"It seemed to us that once it became clear that Victoria wasn't going to be cured, the system was programmed to get her out of hospital and back to home. Whether that was the best thing for her or not, seemed irrelevant. Most parents given a choice would want their child to die in the comfort of home, among the people who love them. But if that's not a viable option for the child, what happens?"

Brian and Sharon felt deeply that dying at home wasn't the best or right thing for Victoria. Despite wonderful family support, Victoria needed precision pain control, complicated medication and 24/7 care. They didn't have the knowledge or the expertise to do that. They knew they didn't have the safety valve of much needed external, specialist services.

"It's quite incredible how strong the subtle pressure is. It's as if the unspoken mantra is - 'good parents cope'. Brian and I would have coped with any kind of challenge once we knew our daughter was safe and comfortable. However, the message I was getting from Victoria was 'dying at home isn't the best thing for me – I need somewhere special'. So we had to fight for her again."

That 'somewhere special' turned out to be LauraLynn, the Children's Hospice.

"We were back in crisis. We had reluctantly agreed to bring Victoria back to a hospital closer to home. It was a disaster. Victoria was in even more distress. We were at our wits end. Friends had found LauraLynn online. I rang in a wave of a panic. I explained that the hospitals wished for our baby to go home to die. We couldn't take Victoria home. I asked if they could help us."

The answer couldn't have been more clear, generous and reassuring.

'LauraLynn was made for children like Victoria. We're here for as long as she needs us.'

After an assessment of Victoria's care needs, the Thompsons *'moved in for the next three months'*. Victoria was only 6 months old. The safety and beauty of LauraLynn for them was wonderful. The physical environment was modern, spacious, calm and bright. Sharon and Brian speak emotionally about the quality and empathy of the people and the care.

"Every professional has time to talk to you, to sit with you. Everyone is willing to do whatever it takes. It was hard to fathom why it's the only children's hospice. We were allowed to be Victoria's parents. We could relax a little knowing her needs were being met. Victoria was home."

It was like as if LauraLynn and Victoria had been created for each other. In a strange act of magical synchronicity, LauraLynn and Victoria shared the same birthday. If Victoria had lived a little longer, they would have celebrated their first birthday together.

Through the activities and care in LauraLynn, Victoria's family made memories, until it was her time to leave them:

"Victoria, even at the end doing things her way, waited for the day of her nine-month birthday to die. Nine months inside, nine months in the outside world. She was fading slowly through the night. When she felt we were as ready as we could be, she moved on peacefully, knowing we were with her.'

"LauraLynn enabled us to give Victoria everything she needed. I think children's palliative care needs strong voices. It's so important. Parents should be able to give children the best, especially children at the end of life. A society should look after its dying children."

Now that Victoria is gone, Sharon is philosophical about the future:

"Despite our grief and missing her always, Victoria gives us a sense of peace and purpose when there is none. Also a sense of love and joy we didn't know was there. We are so besotted with her and her strength.

Her patience and resolve were huge. Her presence was intoxicating. Finding a role now is a strange thing. We want to go forward."

Brian and Sharon have certainly moved forward. Along with some incredible friends, family members and strangers, they've raised over €210,000 for LauraLynn in Victoria's memory.

Victoria's magical messages have spread far and wide. They have inspired, soothed, caused tears and laughter. The money raised will help families receive the extraordinary consolation and positive benefits of specialised, quality palliative care.

And right this minute, Victoria seems to be sending an important message through the words on this page. The message that she couldn't have achieved all of this without her extraordinary parents, and her special friends who still love and fight for her every day.