Having to come to terms with the unfolding nightmare that their daughter Emma's life was going to be a very short one, **Carol and Fergie Heffernan** experienced the devastating lows no parent should have to face. But they also felt the empowering and enriching support of the opposite – sensitive and helpful palliative care and heart-felt emotional support. Two ordinary – but very extraordinary – parents, share the moving story of their wonderful daughter Emma's sixteen very full weeks of living.

"Emma's going off to the moon". This was the ingenious way three and a half year-old Billy immediately explained his sister's passing. His dad Fergie had just broken it to him that Emma was 'going'. Fergie knew he had to find the right words to help his son understand. But Billy found his own words. So now every night Billy waves at the moon and tells Emma he loves her.

The infectious love and natural support between Carol and Fergie comes across so strongly. Their ease in each other's company. The intimate glances: shorthand for encouragement and mutual support. It's clear Fergie is a great husband and father. But when they first met, it was Carol who made the running. Just a week after their first meeting, she texted him: *"Are you interested or what?"* Fergie didn't take much convincing. They were a popular couple. A few years down the road and along came their pride and joy Billy.

They faced the normal struggles that young couples face but for the Heffernan's newly formed family, life was positive. Then they got the wonderful news that they were to have another child, a girl this time.

Carol had no idea of the trauma and heartbreak they were about to go through.

"My pregnancy was fine. There were no alarm bells. Emma was quite small when she was born on Monday July 1st. I didn't see anything out of the ordinary but Fergie did notice that her cry was very weak."

The Paediatrician said she had concerns that Emma wasn't sucking properly, that her breathing was irregular and she wasn't crying normally. Emma was taken into special care and monitored. It became clear she was having small seizures. Carol remembers her panic:

"I couldn't stop crying. All I could say was 'Please tell me she's not going to die'. I had gone from complete happiness to emotional hell in a couple of days".

But the thought that Emma might not survive wasn't really in Fergie's and Carol's minds. They were sure the doctors would find the problem and fix it. After tests and monitoring the decision was quickly made to transfer Emma to a specialist hospital 80 miles away. Fergie remembers the moment when their new reality became clear:

"The shock of how serious things were hit us when the ambulance overtook our car as we drove to the hospital. We thought we'd be taking her home. But there she was, on her own in an ambulance with a doctor and nurse."

When they arrived, their first sight of Emma, was another disturbing moment. She was in an incubator attached to tubes, leads and machines. A series of very difficult and invasive tests and investigations followed. A transfer to another specialist hospital and back. Lumbar punctures. Feeding tubes. EEGs. Carol describes how they felt:

"Her poor little body was bruised from so many needles. All you want to do is protect your baby. To make sure she's happy and comfortable. You'd do anything. It broke our hearts."

On the Wednesday they were given the worst news any parent could receive. Fergie remembers hearing key phrases and language they weren't used to:

"We were told things weren't good. They said they didn't know exactly what was wrong but it was 'certainly life limiting'. 'Not compatible with life'. 'Short life expectancy'. Phrases like that. It was like this bomb was dropped with no emotion and then we were left to cope."

Emma was transferred to Temple Street and things were much better there.

"Everywhere we went the nurses were amazing. They were picking up the pieces. Giving great care. Giving us emotional support."

Emma was having desaturations. The level of oxygen in her blood would drop right down to critical levels. Fergie explains that babies are born with three key abilities – to cry, to suck and to breathe and Emma's brain was struggling with all three functions. They brought Emma back to their local hospital. But after a couple of weeks of having to be with her 24/7 in a hospital environment, they were at breaking point.

"Fergie was at home painting Emma's room. I called him and said I can't take any more. Come over and collect us. We need to be together – the four of us. We need to be at home."

Caring for Emma at home was an enormously demanding medical and physical challenge. But these extraordinary parents never thought twice about it. It was an act of simple and unconditional love. It required round the clock care and attention to detail. They had to bring home an oxygen monitor, a feeding pump system, an apnea monitor, a vast range of different medications. Fergie describes the experience:

"There was never an hour when she didn't need something. I'd have to insert her feeding tube through her nose and down into her stomach. We'd have to watch the oxygen levels. She'd stop breathing regularly. She was having seizures. We were taking turns minding her. You couldn't risk falling asleep."

And all the while, 'normal' life had to carry on for the Heffernans as well. Billy needed them more than ever. And the myriad of everyday pressures of life continued to build.

'The bank doesn't care how sick your child is – you still need to pay the mortgage."

People rallied around. Fergie's workmates all did overtime – and his boss and a customer helped – so he could keep his wage. Carol and Fergie's journey through unspeakable loss was filled with countless inspiring moments and acts of kindness like this. Their sense of awe and emotional gratitude is obvious.

A positive turning point happened the day the Jack and Jill Foundation came into their lives. After all the jargon and process of the previous weeks, they had one simple message. *'We're here to help'*. Fergie explains that they offered 16 hours of care – two full nights – for Emma at home:

"They were amazing. The nurses were so professional and so caring. Even on the nights they weren't here, if we needed anything, we'd phone and they would do anything they could for you. They'd come right over if they needed to. It was like Emma's last days were really valued. That meant so much to us."

After just 16 weeks of life little Emma decided it was time to go. She was very sick. She was tired out. She passed away peacefully in the warm embrace of her loving family – having spent her last eight weeks at home.

Looking through a beautiful book of photographs of Emma, Carol remarks:

"When we look back, it was lovely that we had this special time to take care of her. But I really believe Emma was also taking care of us – preparing us for what was to happen – making sure we were ready. Several times she had stopped breathing but she came back to us with a big gasp for life. We knew she'd given all she could. She'd struggled so much that in a way we were relieved her pain was gone, her distress was over, she was free."

The Heffernans describe Emma's funeral in images that would melt anyone's heart. Sitting in the back of the car with Emma's little casket on their lap. Fergie carrying Emma from the church to the graveyard. A dad holding his baby daughter for the last time. Another powerful act of simple love.

Today, Emma's story goes on. Fergie and Carol don't want to forget, they want to remember. That's their way of dealing with their pain and celebrating the full person and personality that Emma was. They also have thoughtful, insightful and passionate views on the end-of-life journey for children and families.

Despite, at times along the way, receiving the most amazing care and understanding, they are constructively critical of a broken and sometimes insensitive system.

There were dark days when they were given personal and upsetting news in impersonal and public places. Other dismal moments when a little empathy would have helped them better understand the life-changing meaning of the medical jargon that was being impatiently communicated.

Cold occasions when maybe Emma was dealt with more as a 'case' that can't be helped when she should have been looked after as a vibrant and beautiful person with vital life still to live.

But they also had wonderful experiences of what a 'fit-for-purpose, end-of-life service can offer. They didn't know what palliative care was until they began to feel its benefit. Near the end, for them, good palliative care wasn't about just pain control and medical care. It wasn't about the individual bits. It was about how it all combines. The medical. The emotional. The spiritual. The family's own role. The care and sensitivity of professionals. The community. The person.

The best parts of Emma's last weeks helped Carol and Fergie prepare. It allowed them make good decisions for Emma. It helped them say the important things to Emma they needed to say. It helped them say their goodbyes.

It helped Emma die well.

To this day it helps her big brother Billy – he looks up at the moon with a smile, he sings to her and says 'Emma I love you'.