

Caoimhe's Story

The term 'life-limiting' is a shocking one – infused with sadness, worry and heartbreak. But most families who have children with a 'life-limiting' condition turn that diagnosis on its head. And if ever a couple embodied the inherent contradiction between what the words mean – and how a family copes – it's the Murphys.



Twelve and a half years ago, **Siobhan and Martin Murphy** heard the phrase used along with the words 'Jouberts Syndrome'. They were receiving news of their infant daughter **Caoimhe's** diagnosis. What followed was a rollercoaster journey of heartbreak, worry and round-the-clock care. But for Caoimhe, her condition was anything but life-limiting. Watching her play, listen, observe and communicate, 'life unlimited' seems far more apt. That's all because of the love and care of her parents, her

siblings, relations, friends and professionals.

How to define 12 year-old Caoimhe Murphy? Only one person can. She does it herself. After a couple of hours in her company you get the impression that, in many important ways, Caoimhe controls life, despite life's sometimes cruel efforts to control her. Her priorities fly in the face of any stereotype of disability.

A bright, sit-in, model racing car lies unused in the middle of the living room – it seems she's much too sophisticated for toys like this. Her passions revolve around much more mature interests. Computers, going places, music, dancing, meeting people. And of course clothes and fashion.

But the most important magnetic force in her life are her marvelous parents. Martin and Siobhan, her brother Gavin and sister Emma, and of course her wonderful aunt Elaine, hilariously known as 'Mum Number 1', because of her very special relationship with, and loving commitment to, Caoimhe.

There's no doubt that the symptoms and impacts of Caoimhe's life-limiting illness affect her profoundly. She has a heavy and unfair burden to bear. But her remarkable family ensures that these don't define her. 'Jouberts Syndrome' is a very rare condition – and comes with a host of associated complications. Caoimhe is dependent on her parents Siobhan and Martin for all her needs. She is unable to walk, she has no speech, and has problems hearing.

But Caoimhe, in her lust for life, has found ways to thrive. She can move around in her walker. She has developed her own intriguing language through sounds and signals. She is a busy and bubbly girl.

Like many other parents in this situation, Martin and Siobhan had to quickly come to terms with so much in a very short time. Caoimhe's complex condition. An onslaught of fears and worries. Her life



and death battle to survive as a baby. The medical jargon and the various versions of her prognosis. Siobhan recollects:

“They came and said she had Joubert’s syndrome. We hadn’t a clue what it was. We got on the internet and it was the worst thing ever. It was heart breaking for us. Her particular syndrome is such a rarity that even the professionals here had to learn about it. And that’s something we’ve come to know

and accept. Everyone is learning at the same time. Ourselves, the paediatricians, the nurses, the home care.

For Martin their life is measured in milestones:

“They said we’ll be lucky if she survives three years. So could you imagine then what it was like when she first went to school? – fantastic. Now she’s into secondary. Her First Communion, could you imagine her Confirmation? Could you imagine when her sister got married and I was taking her into the cathedral in her white dress?”

But Martin remembers many dark days:

“It was touch and go in the beginning. Every time she was being fed she turned blue. I’d never seen her eyes open. So she was in neonatal and then she was transferred to Daisy Hill Hospital and then the Royal Victoria Hospital. We knew it was very serious. They had to put the camera down. She ended up being ventilated and in intensive care. She had heart problems too. But they couldn’t get her off the machine.”

Each time they tried, it failed and was making things worse. So the last time they tried it, it was going to be the final attempt and Caoimhe started breathing oxygen. The next 24 hours were scary. Siobhan believes her bravery pulled her through. The family’s traumatic journey has left scars but it has also brought thoughtful insight and optimism:

“Were not the same people we were”. Martin’s description is not a casual one – he means it in quite a profound way. This simple phrase captures heartfuls of drama, emotion and history over 12 years.

“Things were just perfect for us, two kids, education, opportunity, a business. But because of Caoimhe, our eyes have been opened. To people, to circumstances, to stories, to care facilities – and most of all to the goodness, the generosity and the bravery that you encounter.” Siobhan agrees:

“We’ve done things and coped in a way I never thought was possible. We’ve met the most amazing people – other supportive and generous parents of children with life-limiting illnesses. Great consultants and nurses and medical staff.”

Martin’s attitude to professionals has changed hugely too:

“I used to be frustrated with the doctors and nurses but now I’ve learned what they do and how they care. We are all like one big happy family.”



There's a natural anger that develops – a sense of terrible unfairness that any parent would feel on hearing their child won't live as long as most others. And there's also a frustration of wanting to do more, to cut through the jargon and demand the system be better. Martin describes a cathartic moment:

"I really felt extreme angry about it all. You just don't know what you're doing. Two days before her heart operation I drove down to see the cardiologist. I was furious with everybody and everything. I was shouting in the car. I had really lost it. Then, suddenly, a serenity came over me, like okay Martin, do you want to micromanage everything? Let them get on with it, and we'll do our bit. The whole thing lifted. In retrospect, it seems like someone or something was looking after me."

Siobhan talks about another milestone, another piece of learning for the family:

"I was approached by the palliative nurse asking us how would we would feel about the hospice [Horizon House]? For me hospice was a place to die. But then they took us down to see the building." Martin takes up the story:

"It was a bleak rainy day. But once we got to Horizon House, we got a tour of the whole place, really started to take it all in, all beautiful and colourful – and what I really liked about it was this isn't a place to die, it's Horizon House. There was a walled garden. A pool with water running down it. A place for families to stay. Everyone was friendly and professional. And we came out with a different attitude – with hope – and we never looked back. Our heroes now are people in there, unbelievable people, staff and the families and children."

So what of the future? Martin and Siobhan are comfortable with the question: *"It's taking each day as it comes. Valuing life. And appreciating that Horizon House is one of the most significant reasons as to why Caoimhe is twelve. She loves it there. She gets so excited when we go there."*

Siobhan adds: *"It's good for everyone. It's just four or five times a year but it makes such a difference. The fact that I can sleep soundly tells you how much confidence we have in them."* Martin agrees:

"With Caoimhe's prognosis, we never thought we would be here today. Every day is a bonus now."

Watching Caoimhe interact with her loving parents, she is happy in the present and she has so much to look forward to. Martin has a parting shot filled with pride and generosity:

"12 years and there's been enough tears to fill a swimming pool. But I'll tell you something – whatever it is that has Caoimhe here today, I'd love to bottle it and give it to everyone."