

“SHADOW CHILDREN” - SIBLINGS OF A CRITICALLY ILL CHILD

Caring for Siblings with a life limiting condition – Terry Ring, Founder of Cliona’s Foundation

Serious illness in a child engulfs families and changes brothers and sisters, too. Caring for a seriously ill child takes a tremendous toll on the whole family and healthy siblings are no exception. Cliona’s Foundation has supported non-medical expenses for 400 families with a sick child in 29 counties across Ireland.



CASE STUDY NO.1: THE WATERS, CASTLEBAR, CO. MAYO

Maria Waters, from Castlebar, Mayo is the mother of 3; Rhianna (9), Oisín (4) and Shannon (8 months). When Shannon was born in June 2016 she was immediately transferred to Our Lady’s Hospital in Crumlin where she was diagnosed with a rare and complex heart condition that requires ongoing monitoring treatment and major surgery. Speaking on the issue Maria said:

- **“Siblings of critically ill children are hugely impacted.**
- **We’ve just got home for the first time since Shannon was born 8 months ago.**
- **With Rhianna, me being away from home has definitely affected her school work, up until now she’s never had problems with school work, her behaviour and personality completely changed she became quite cheeky but since we’ve been home she’s been as good as gold like a different person.**
- **With Oisín he became really upset missing us. He was hysterical and always wanted Mommy. He has been so upset with major crying fits in playschool. He was lashing out a lot in playschool and we had parents complaining about him because he’s even left a few other boys in bruises. I’m so worried he will get branded as a bully and the teachers all know that that’s not him.”**

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- **“When Shannon was only 8 weeks old she went into cardiac arrest. My son Oisín was actually there at the time. But none of us could get in to see Shannon because of what was happening”.**
- **“I started crying and Oisín he looked up at me and said “Mommy don’t cry Shannon is going to be okay”.**
- **“I couldn’t believe it I had missed his fourth birthday the week before with being in hospital with Shannon and here he was a four year old comforting me!”**
- **“Rhianna was never there before anything happened but we would always tell her”.**
- **“I think for Rhianna understanding the condition makes her less worried. But then it’s hard to tell how Rhianna really feels I think she blocks out a lot of it”.**



Cliona’s Foundation has supported non-medical expenses for 400 families of a child with a life limiting condition in 30 counties across Ireland.

HOW DO YOU COMPENSATE?

- **“Now that we are all at home again myself or my partner will try bring them somewhere fun at the weekend. It’s hard to get the time to all do things together but we have applied for nurses so hopefully we can get granted to have them for five hours in the week and this can then be our time for fun with Rhianna and Oisín”.**

“Cliona’s Foundation are fantastic, I didn’t hear of them before all of this. Because my partner was self-employed he was off work for 7 weeks. The bills were piling in and with two other young kids at Christmas just around the corner, things didn’t look as bleak. I applied to Cliona’s Foundation and literally 2 weeks later I got a cheque in the post. It was honestly like winning the lottery”.



CASE STUDY NUMBER 2: THE GARDINERS, KILKENNY

Caroline Gardiner, from Kilkenny is the mother of Rachel (9), Jack (7) Charlie (6) and Dylan (5). When Dylan was born at 27 weeks and just 750g odds were not in his favour. He has a complex medical history which resulted in him spending from 20/01/2012 to 04/03/2014 between Holles Street and Crumlin hospital.

Speaking on the issue Caroline said:

- ***“To me my eldest daughter Rachel is the most effected since Dylan was born. It was her first year at school and there was lots of things I feel she missed out on and it even comes back on her now, after school activities where unheard off because I wasn't there, we didn't have friends over to play so I think the knock on effect on her was probably more dramatic than it was for the boys. She missed out on Irish Dancing and swimming classes with her peers and by the time she was able to start these classes she was behind from her peers and I think in return it affected her confidence and even now her confidence is very low”.***
- ***“The boys were very young that it didn't affect them as much Jack was 2 years and 5 months and Charlie was only 14 months himself. They grew up with it whereas Rachel was the eldest. They know the hole in Dylan's neck needs to be fixed and that when it we can all go swimming together. I've even promised them a holiday because they've been on one before”.***
- ***“None of the kids would be overly confident, for us we were delighted to have our son Dylan home with all the family but all the nurses coming in to the house and I'm not sure what effect that had on the kids”.***
- ***“Weekdays I would drive up and back to Holles Street/Crumlin in Dublin. Sat/Sun John Joe went up or when all possible we all went up”.***

COPING WITH A CRITICALLY ILL SIBLING

- ***“For the boys they have each other but also because they were so young it really has been the norm for them. Obviously when they are sick they want me to be there. In the summer when it's a lovely day I'd love to take them to beach or somewhere and we can't go with Dylan”.***
- ***“Because Dylan can't speak he can often express himself through other ways and sometimes he bites the boys but they never retaliate like I know they would if someone else did that”.***
- ***“They tell him they love him every day”.***
- ***“They know he can't do everything and they understand that”.***
- ***“When me and Dylan go to pick them up from school the kids will be showing him off to everyone!”***
- ***“One time Charlie had one of his friends in the car with him and he started explaining to his friend how Dylan needs a tube to breathe as if this was the norm”.***

HOW DO YOU COMPENSATE?

- ***“At the minute we don't have nurses so I dont get to spend time with just Rachel, Jack and Charlie. We never do anything the 6 of us. And I feel sorry for them because when you bring Dylan it is all about Dylan. My husband goes to soccer with the boys at the weekend and I do bring Rachel to athletics”.***
- ***“We had nursing support hours initially but they greatly reduced, when Dylan got decanulated in November 2015 we lost all our nursing hours. Whilst the HSE afford 5 hours home help the nurse is not able to feed Dylan and cannot be left on her own with him.***
- ***“It's not that we don't want to bring Dylan with us everywhere we go but just to be able to relay to them that they are just as important to us as Dylan and life is not always centred around him.”***

“All our savings and more had diminished due to long term hospital admissions and distance from home to Dublin so we are not in a position financially to fund au pairs or any outside help. Cliona's Foundation has greatly supported us. We were not expecting anything like the donation they gave us and have gladly used it for respite hours”.