

INTERVIEW WITH ORLA HENNELLY

Zara's wish come true

BALBRIGGAN MUM, ORLA HENNELLY TALKS TO KEN PHELAN ABOUT HOW MAKE-A-WISH IRELAND HELPED MAKE A DREAM COME TRUE FOR HER DAUGHTER, ZARA

WITH Make-a-Wish Ireland celebrating special Irish mums during 'Wish Week' from March 8 - March 14, The Fingal Independent speaks to one incredible Balbriggan mum who has raised her dependent daughter in the face of adversity and helped make her wish come true.

Orla Hennelly was pregnant with daughter Zara in 2008 when a routine scan showed something was wrong with her pregnancy. Zara was found to have severe problems in utero, and when born, suffered a range of conditions which would leave her fully dependent on her parents.

Here, Orla speaks of the events leading up to Zara's birth, and how she has miraculously survived to become a bubbly 12-year-old girl.

'She had a stroke in utero, so when I was pregnant between a 20 and 30 week scan they noticed on the scan that she was after having

quite a substantial bleed, she was about 30 weeks when we found out. So obviously until she was born they couldn't tell how bad things would be, she was born then about four weeks early, that was in May 2008, and they did MRI and CT scans and that, then she was born and we realised that she'd had a stroke and her brain hadn't recovered from it. There was never any reason as to why it happened, there was no way of finding out what

caused it and so her diagnosis I suppose is she has severe global developmental delay.

'Zara is spastic quadriplegic, she's no use of her arms or her legs; she has epilepsy, she's visually impaired and then obviously in most recent years she had a lot more complex medical needs, like she's tube fed and she has grown scoliosis and a dislocated hip and stuff like that. So she suffers very badly with nerve pain, mainly around her feeding and her stomach and stuff like that, so that's kind of what she suffers with.'

Looking back, Orla says she doesn't know how she coped in those early days, the only comfort

being at the time that she had found out there was a problem with Zara before she was born, so that she was in some way prepared for the worst.

When Zara was born, Orla says, doctors were telling her mum it was 'one day at a time', so that she and husband Val didn't know if Zara would even survive. Despite a poor prognosis, however, Zoe very much survived and is now a happy 12-year-old girl.

Orla explains it was tough for the whole family living with Zara's condition, but thankfully, she received incredible support from outside the home:

'She had great schooling I suppose, she started quite young, it was called St Joseph's School for the Blind at the time, but it's now called Child Vision. She was there until she was three, like preschool I suppose and she was looked after

by amazing people – physios, OTs and all her therapies under the one school, then she moved to St Michael's House in Baldoyle and she's been there since. It's the same there, in that everything is linked in with the school, so the schooling end of things she's had a wonderful few years of schooling and therapies.

'Obviously over the years she's had her different illnesses, like she was initially tube-fed into her stomach but that kind of stopped working after about two years, so two years of constantly vomiting and her tummy bleeding and she was in and out of hospital and just trying to get that under control. So she ended up having to have her feeding tube bypassing her tummy because her tummy kind of stopped working, so all her pain is kind of related to all those kind of areas.

'She wasn't in hospital a lot, I must say, touch wood, but the first kind of year of her life she was in and out for a couple of weeks at a time, and that was always to do with her seizures, her epilepsy and trying to keep it under control. It's still not under control but it's down to two or three seizures a day so it doesn't have a huge impact on her life, she kind of just gets on with things after her seizure.'

Make-A-Wish Ireland - which grants the wishes of children with life-threatening medical conditions - last year granted Zara a very special wish, providing her with her own sensory garden at the back of her parents' house. As Orla

explains, the addition of the sensory garden has made a huge difference to Zara, and especially during lockdown, when she was unable to venture outside.

'Louise was our wish granter in Make-A-Wish, and she said let's put our heads together and try and come up with something that would give Zara some happiness and some joy, and we thought because we'd be in lockdown with COVID, we came up with the idea of a sensory garden. The fences were painted colourfully, the flowers, the plant pots, everything is very colourful. There are scented plants, like there's

lavender and there's a lemon tree and a lot of wind chimes and a water feature and lights and it's great because obviously with lockdown when we're in Level 5, we can't bring her anywhere.

'We just have to keep her as safe as possible and she had to reduce her schooling hours because she was getting a lot of discomfort and pain, so we reduced her hours to just three days a week and it's just brilliant that, rather her being in the house even on a cold day she can still sit out under the canopy with the water feature and the lights and everything.'

Orla says Zara managed to cope with lockdown remarkably well, thanks in part to the sensory garden but also due to the time she spent with her mum. Orla too somehow managed to cope with lockdown, despite caring for a dependent child around the clock.

'She coped really well, her physical and intellectual disability is really really severe so she wouldn't even understand COVID or lockdown. Obviously she recognises that she's indoors, but there was never any kind of regression or anything like that. We did our best to try and keep her active with what she likes doing in school, like the painting, the arts and crafts and the music and the foot massages and stuff, so she's coped really really well, and then obviously the garden is there since last August and that's helped hugely because it's somewhere to bring her when you can't bring her outside for walks and that, because it was just too dangerous. So she really coped very well, I must say.

'I would think of myself as a strong person, myself and my husband. I gave up work when Zara was two to look after her because just with the sheer volume of appointments, physiotherapy, occupational therapy and that, and just her general health. Lockdown though was a bit of a struggle. I have an 18-year-old who's doing her Leaving Cert and a six-year-old that's in senior infants. They all have they're own different types of interaction and you're trying to keep a six-year-old busy, Zara along with all her health problems and then you're trying to get them studying and stuff so it wasn't great but I suppose I try to think of the positive in everything. The way I look

at it is that you may never get a chance to be at home with all your children for longer than a week or two, if you were a full-time worker taking holidays. The fact that they all had that time off together, and my husband was off a little bit too so I just thought that was great, you kind of just have to look for the positive in it or else you wouldn't be able to manage it.'

Orla says that thankfully, Zara continues to receive respite from the Laura Lynn Foundation, and is able to avail of the full range

of services there. As for Zara's health, her stomach problem as well as other issues 'can't be fixed', so that for her family it's a case of 'trying to manage symptoms from day-to-day rather looking for a solution.'

At the moment, Orla adds, Zara can manage her feeds, but as time goes by her feeding will deteriorate. Because of her range of problems, her condition is classified as 'life-limiting.' For Orla and Val, though, it has been nothing short of a miracle that Zara has reached her twelfth birthday. For now, her family continue to attend to her every need, and give her all the love she deserves in the hope that she will see many more. Zara may be confined indoors, like the rest of us, but she can thank Make-A-Wish Ireland for providing a little escapism in her own special little garden, and making a magical wish come true.



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Zara with her sister, Willow in the sensory garden.



Zara with her parents, Val and Orla in the sensory garden.