



CASE STUDY

WORDS OF WISDOM

Born with a unilateral cleft lip and palate was a difficult start for Ciaran Kearney, says **Joy Orpen**, but this outgoing teen has put years of surgery and angst well and truly behind him

Ciaran Kearney is one of those high-octane, entertaining teenagers who always amuses. From the very moment his tall, lanky frame slides into the room, you need to be alert to keep up with the ideas tumbling from his razor-sharp mind. Of one thing you can be certain — when Ciaran's around there will be laughter and there will be chatter.

Yet communicating used to be so difficult for the 16-year-old that incessant tantrums were common. The outbursts were born of a terrible frustration because he could not make himself understood — the reason for that was a birth defect, which made speech difficult and affected his hearing.

Ciaran, one of four boys, was born in Drogheda, Co Louth, in 1997. The first thing his mother Elaine noticed was his startling blue eyes. The next thing was a gash on his upper lip. "I was shocked. I recognised it as a harelip but I didn't know anything about them," she says.

Before long they learned that Ciaran had been born with a unilateral cleft (meaning fissure or split) lip and palate and, though the situation was complicated, his difficulties could be resolved over time. Shortly afterwards, he was assessed by the "cleft team" at the St Francis Clinic in Children's University Hospital, **Temple Street**, Dublin.

In the early stages, there were practical problems to overcome. Because the baby had a gap the size of Elaine's little finger running from his upper lip, through the gum, along the roof of his

mouth to the back of his throat, he had problems feeding. "When he brought up wind, the milk would go down his nose," says Elaine. So he drank from a special bottle and while that worked well, they still had to keep a close eye on him.

Eight weeks later, his lip was repaired. Elaine recalls: "I was surprised how well he looked after the op."

Three months later, Ciaran's palate was also repaired, but unfortunately he contracted a virus and a small opening later developed in his palate.

When Ciaran began talking it became clear his speech was badly affected. He was taken to a speech therapist who surprised Elaine by putting more emphasis on teaching Ciaran sign language than on improving his verbal language skills.

Looking back, she now realises that the therapist recognised her son's urgent need to communicate. "His speech was very unclear," she says. "He just couldn't form the words. He had two older brothers chatting away, getting their needs met, but he couldn't even make himself understood. So he'd get very frustrated and angry."

Elaine explains that Ciaran's younger brother, Aaron, was also born with a cleft of the soft palate. However, his condition was much less pronounced and he only needed one operation. Nonetheless she was kept very busy ferrying two toddlers up and down to Dublin by bus.

She says while staff at **Temple Street** Hospital were absolutely brilliant, trying to access therapy for Ciaran was a

nightmare. "Having speech therapy was a slow process; quite often there would be very long breaks between sessions," she says.

She also admits that Ciaran wasn't the most co-operative child. "He was bright, he loved the stimulation of school and he liked being with other people. He was a very sociable child full of chatter. The problem was, no one knew what he was talking about — his head would be 100 times ahead of his speech," she says.

So when Ciaran was four, he had a tonsillectomy and a pharyngoplasty — palate surgery to improve speech — to tighten up the muscles at the back of his throat.

When he was six, he began attending the orthodontist at St James's Hospital under the care of a multi-disciplinary team, specifically designed to deal with children with cleft lips and palates.

Elaine says his teeth were badly misplaced because of the cleft palate. "One of his teeth was growing sideways," she explains.

Over the years Ciaran has had baby teeth and a few permanent teeth removed, as well as having a brace fitted.

In 2008 he had an alveolar bone graft — a small piece of bone from his hip was used to bridge the gap in his gum. This was followed by another repair to his palate.

He also needed five sets of grommets over the years, as the Eustachian tubes, which stretch from the middle ear to the vicinity of the nose and soft palate, were damaged. This has caused some loss of hearing; but so far Ciaran has managed without a hearing aid.

These days he attends the orthodontic clinic at St James's Hospital every six weeks and continues to wear a brace; his parents are delighted with the outcome.

"I remember once asking myself 'how will they ever get these teeth right?' and look at them now — they're almost perfect," Elaine says.

Ciaran remarks: "I still need the brace to straighten my teeth and I will have to have a tooth implanted to fill a gap in my upper gum."

While he has struggled over the years, he is able to keep things in perspective. "You take it as it comes," he says. "I hated getting braces — but what could I do? And sure, there have been times when I wondered, 'Why me?' But what's the point of that? That's not going to help."

Eamonn McKiernan, consultant orthodontist at St James's Hospital, says their goal in treating Ciaran is to give him the best "bite" possible, coupled with a pleasing aesthetic outcome.

He says the first phase of Ciaran's treatment involved preparing the jaw for a bone graft, while the second dealt with his misaligned teeth. He says Ciaran still requires a tooth implant, which will be done when his facial growth is complete at around 19 years of age.

Elaine and her husband Martin both agree that the Cleft Lip and Palate Association of Ireland was an invaluable source of support for them over the years. Ciaran loved the family days but not for obvious reasons.

"It wasn't about being with other kids with cleft palates, because that never really affected me — it was about having fun with other children," he says.

However, he does admit the whole experience has shaped who he is. "If you've been through a lot, you can deal with more. Everyone goes through problems — we all have to deal with stuff at some point," he says. "My speech still isn't perfect but most people can understand me, so that's grand."

This young lad can now look forward with confidence to making a great success of his bright future. **I**



*Cleft Lip and Palate Association of Ireland, tel: (087) 131-9803, or see www.cleft.ie
Children's University Hospital Temple Street, see www.cuh.ie*

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