

## Star's Story: Our Star Shines On

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*This story of a daughter has been told anonymously by her mother.*

Eight years ago I wrote the story of 'Our Star' who was then seven years old.

As a result of medical mismanagement she had severe Cerebral Palsy but was even then a shining star. I encouraged parents to ask questions of doctors if they had concerns and to always ask about procedures they didn't understand.

Above all, I wanted parents to believe in their children. Eight years on, what has changed?

Our Star is now 15.

Tomorrow night she boards a plane bound for Barcelona to attend a conference for people with complex communication needs.

She regularly presents to speech pathology students at university about her experiences using AAC (augmentative and alternative communication) and has talked to occupational therapy students about the joys and pitfalls of being hoisted in and out of a wheelchair. She has presented a paper at a national conference, and in two weeks will assist at a workshop about dancing with a physical disability.

She attends a special school (a decision she was involved in making—the final choice was hers), uses her eyes to access a PODD (pragmatic organisation dynamic display) communication book and her communication device and plans to get into advocacy for non-verbal people when she is older.

Our Star is part of the Queensland Youth Parliament this year. She has won an international award with two other teens about using communication devices.

She has skied, sailed, surfed, played wheelchair soccer and attended Girl Guides. She has travelled to four states in Australia and to seven countries around the world.

The journey has not always been easy. Our Star has had hospitalisations for serious illness. She has had to work hard to communicate using her eyes, to learn to drive a power wheelchair, and to remain healthy enough to do all the things she enjoys.

As a family we have made sacrifices, but we all sacrifice for our children; it is part of being a parent. We have had to adjust, modify dreams and reset goals.

We have had to stand up and say "we believe our daughter can do this" and then we have stood by her as she achieved her goals and dreams.

The journey is not yet over.

Our Star plans to attend TAFE and university. To do this she will have to get a Year 12 certificate—not easy when you have decided to attend a special school, but still achievable if you are committed to your goal and you have people around you who believe in you and will stand by you.

Our Star will have to write her papers and essays for university with her eyes. She will have to communicate with peers, fellow students and lecturers. She will have to organise her life so that she is not over-tired, can manage her work load and still has time to enjoy life.

She will have to learn to overcome obstacles that are placed by people who never consider the needs of people who use wheelchairs or are non-verbal.

Will she be able to do it? We believe so, and we will stand by her and watch her achieve the goals she has set herself. If she wants our help we will give it.

Our Star has learnt to believe in herself. She is determined and strong willed. She has become a self-advocate—she has had to.

A wise man once said: “Success is not a place at which one arrives but rather the spirit with which one undertakes and continues the journey.”

I have learnt many things in the last 15 years, and I know I will learn more as I watch Our Star continue to shine, but perhaps the most important is this: Believe in your child, have a dream for them, be their advocate and teach them to advocate for themselves.

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